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A systematic literature review of observable symptoms

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ABSTRACT

Proceedings of the 6th IASSIDD Europe Congress: Value Diversity

PRESIDENTIAL ADDRESS

Value Diversity

Prof. Dr. Alice Schippers
University of Humanistic Studies, Utrecht, The Netherlands

In light of current worldwide developments, the conference theme "Value Diversity" explicitly refers to the changes we need to see.

The Covid-19 pandemic is a disruptive force, a crisis that at the same time accelerates and reveals the effects of exclusionary (neoliberal) societal structures. Recently, the Black Lives Matter (BLM) movement is further disrupting the status quo by fiercely protesting the racism that has been at the root of many injustices around the colonized world for so long. The pandemic, BLM and disability rights all intersect at various crucial points, including police violence, exclusion from important healthcare practices and resources, and the overall violation of human rights.

In order to tackle such issues at their core, it has to be recognized that we need to Value Diversity. There is value to humankind in finally embracing what has been undervalued in the past: to value diversity means to move forward on the path towards social inclusion for people with disabilities, and towards equality for all. This matter needs to be seriously considered through scientific study and information sharing, through debate on how social structures exclude people with intellectual and developmental disabilities from participating in society.

We need to value diversity in political and media representation to include perspectives and input and output from all walks of life.

We need to value diversity in healthcare policies to create specialised treatments and fair prioritisation, and to raise awareness of the reciprocity of relationships between people with disabilities and their families/caregivers, who rely on each other's proximity for their well-being.

We need to value diversity in designing a "New Normal" in which nobody will be left behind, and in which the rights and privileges of one group will not impede those of another.

KEYNOTE DEBATES

Keynote debate: "New Eugenics"
Track: Ethics, Politics and Diversity

Keynote speaker: Prof. Fiona Kumari Campbell, University of Dundee
Co-speaker: Dr. Fabrizio Fea, Vice President of EASPD
Co-speaker: Lesley Verbeek, Research Master student, University of Groningen
Debate leader: Prof. Hans Reinders, Vrije Universiteit Amsterdam

In the Special Interest Research Group for Ethics' publication "The quiet progress of the New Eugenics," following IASSIDD's 16th World Congress in Glasgow in 2019, its authors (Prof. Dr. Hans Reinders, Prof. Dr. Tim Stainton and Prof. Dr. Trevor R. Parmenter) "consider recent developments in terminating human life affected by intellectual and developmental disability." These developments include "ending the lives of severely disabled prematurely born infants, terminating pregnancies after positive outcomes of genetic screening and testing, and ending the lives of persons with intellectual and developmental disabilities by means of euthanasia." The justification for these practices is rooted in ideas about a strong correlation between intellectual and developmental disabilities and a poor quality of life, which, as the authors argue, ignores "alternative views, most of all the views of persons and families directly implicated who do not consider living with intellectual and developmental disabilities identical with a life full of suffering."

Some readers expressed concerns about using a term as abhorrent as *eugenics* to describe these developments. It is indeed a concept that is widely rejected as anachronistic, as Prof. Dr. Hans Reinders recognizes. To completely reject this direct comparison, however, would be to also reject the unresolved and deeply rooted undercurrents of ableism that are at the core of both "old" eugenics and certain present-day philosophies and practices in science, healthcare and beyond.

Comparing "old" and "new" eugenics, as is done in this debate from several different perspectives, can help to navigate the impact of ableism on people's lived experience. It opens up space for the examination of whether it is truly too far-fetched to argue that eugenics never disappeared, but rather took on a new form.

"The quiet progress of the New Eugenics" can be accessed here: https://onlinelibrary.wiley.com/doi/abs/10.1111/jppi.12298.

Keynote debate: "COVID-19"
Track: Health, Behaviour and Disability Conditions

Keynote speaker: Luk Zelderloo, Secretary General, EASPD
Keynote speaker: Christine Linehan, University College Dublin; chair, IASSIDD Comparative Policy and Practice SIRG
Debate leader: Boris van der Ham, chair, Vereniging Gehandicaptenzorg Nederland (VGN)

During the IASSIDD conference in Glasgow, a Memorandum of Understanding (MoU) was signed between IASSIDD and the European Association of Service providers for Persons with Disabilities (EASPD) on August 8th 2019. EASPD promotes equal opportunities for people with disabilities through effective and high-quality service systems, and works towards ensuring the full implementation of the UN Convention on the Rights of Persons with Disabilities, thereby representing over 17,000 organisations. The MoU is an important agreement expressing the willingness to collaborate and to improve the understanding of intellectual disabilities and help create a more inclusive, fulfilling, and accepting society.

The COVID-19 pandemic has the effect of accelerating and revealing exclusionary practices in society, and we are witnessing widespread failures to accommodate to the needs of people with disabilities. At the same time, healthcare workers and organisations who have to work harder than ever before to help vulnerable groups, are met by many with expressions of support and calls for action to reform healthcare. IASSIDD and EASPD's aim for this debate is to bring together professionals who can share their views on the impact of COVID-19 on people with disabilities and their relatives and caregivers, and on the crucial role that service providers can play, and who can provide an insight into how we should move forward.

Keynote debate: “Why care about the end of life?”
Track: Ethics, Politics and Diversity

Keynote speaker: Prof. Dr. Stuart Todd, University of South Wales
Co-speaker: Dr. Michael Echteld, Avans University of Applied Sciences; Stichting Prisma
Debate leader: Prof. Dr. Carlo Leget, University of Humanistic Studies in Utrecht; Health Council of the Netherlands

As people we have always cared about the end of life. In the past we cared because the fate of the dead was important. We may care less about this now than before, but we do care, and probably worry about how we will die. Yet in relation to some groups of people, we are less inclined to think about this topic.

One of those groups includes people with intellectual disabilities and those who survive them. However, the coronavirus has, to an extent, changed this. Death, dying and people with intellectual disabilities are now more talked about than ever before. It is, perhaps, the last act of inclusion, to draw people into conversations about death, to draw death into conversations about intellectual disability—to talk about what it means to die with an intellectual disability, or to experience the death of a person with an intellectual disability.

These are conversations that are becoming possible, but they still retain challenges and taboos. These are conversations of importance to everyone connected to intellectual disabilities, whether as an individual, a relative, a professional, a researcher or a policy maker. What do we do about death? What should we do about death in intellectual disabilities? Of course we should stop premature death - that is where we have most of the conversations. However, death will happen, too soon, maybe too late, but happen it will. And when it happens, it has some meaning for us all. Bringing death into conversations about our work and why we do the work we do is the final act of inclusion in the modern world.

Keynote debate: “Mental Health”
Track: The Course of Life/IDD Across the Lifespan

Keynote speaker: Prof. Peter E. Langdon, Centre for Educational Development, Appraisal & Research, University of Warwick; Coventry and Warwickshire Partnership NHS Trust
Co-speaker: Prof. Carlo Schuengel, Vrije Universiteit Amsterdam; co-director, Amsterdam Public Health Research Institute; leader, Academic Collaborative Center of ‘s Heeren Loo
Co-speaker: Dr. Biza Stenfert Kroese, University of Birmingham; chair, CanDo
Co-speaker: Prof. Stijn Vandevelde, Ghent University
Debate leader: Prof. Andrew Jahoda, University of Glasgow

“Talking” psychological therapies with people who have intellectual disabilities: do we need more focus upon social inclusion?

This debate and discussion will focus on talking psychological therapies with people with intellectual disabilities. We will consider whether adapting psychological therapies for use with people who have intellectual disabilities should include an increased focus on social issues. This includes a range of issues such as poverty, stigma, bullying, labelling, and broadly, all forms of social exclusion throughout our shared society. Whether therapists consider this effectively within the therapeutic process will be discussed and debated.

The likely benefits of an increased focus on methods to promote social inclusion within psychological therapies for people with intellectual disabilities will be considered.

Keynote debate: “Between choice and judgement: Parents with intellectual disabilities”
Track: Quality of Life and Support: Individuals, Families, Communities

Keynote speakers: two parents with an intellectual disability (tba)
Co-speaker: Dr. Preethy Sarah Samuel, Wayne State University
Co-speaker: Dr. Marjorie Aunos, chair, IASSIDD Parenting and Parents with Intellectual and Developmental Disabilities SIRG
Co-speaker: Dr. Marja Hodes, ASVZ (Algemene Stichting Voor Zorg- en dienstverlening)
Debate leader: Prof. Dr. Geert van Hove, Ghent University

Even if the choice of becoming a parent is a fundamental right as outlined in the United Nations' Convention on the Rights of Persons with Disabilities (2006), parenthood can still be a challenging role for many people with intellectual disabilities. The challenges come from the fact that parents with intellectual disabilities face more health problems and are more likely to live in deprived neighbourhoods, have low incomes and report low levels of social support.

In addition, not only is it difficult for them to get access to proper support, they are also more often confronted by child protection services, resulting in a high rate of out of home placements. Furthermore, their choice to become a parent is regularly questioned and they are faced with persistent stigma about the quality of their parental functioning. Irrelevant of research outcomes, the majority of society is still convinced that parents with intellectual disabilities should not be parents at all.

In this debate we highlight the stories of parents with an intellectual disability. Together with these parents, we will talk about the challenges they were facing when they chose parenthood and how they dealt with these challenges. We will bring in the perspective of looking at parenthood from the ableism lens, where the "perfect" parent is one of abled body and mind. We will broaden the discussion to parenthood with disability in general, as we will listen to the narrative of a researcher/mother who became disabled (paraplegia, wheelchair user) when her son was almost two years old. Finally, we will look at parenthood from a family quality of life perspective, as we will share with the audience some take-away messages.

ROUNDTABLES

A right to learn! Adult learning programs for people with IDD

Sharon Kerr[1], Mary-Ann O'Donovan[2], Vimallan Manokara[3]
[1]*Centre for Disability Studies, University of Sydney, Sydney, Australia;* [2]*Centre for Disability Studies, Sydney, Australia;* [3]*MINDS Institute of Intellectual and Developmental Disabilities, Singapore, Singapore*

Description: Article 24 of the UN CRPD states the rights of people with a disability to lifelong learning directed to the full development of their human potential and to enable them to participate effectively in society. This roundtable will present two adult learning programs for people with intellectual and developmental disability, firstly a lifelong learning program with a customised curriculum currently being developed and trialled by MINDS Singapore presented by Vimallan Manokara. Secondly, the "uni 2 beyond" program providing participants with an intellectual and developmental disability to participate as "audit students" alongside the general student body in courses offered by the University of Sydney in Australia, presented by Sharon Kerr. Both presentations will inform discussion surrounding the challenges of initiating adult learning programs in 2021. During this roundtable, Mary-Ann O'Donovan will facilitate discussion and invite questions from the audience on these two adult learning programs, and lend her expertise as a global specialist in this field.

Contribution: It is anticipated that this roundtable will generate discussion regarding the rights of people with intellectual and developmental disabilities to access education and the opportunities that it affords throughout their lifespan. Further, new ideas formed and international collaborations will be fostered for the promotion of learning programs for people with intellectual and developmental disability globally.

What do "development" and "progress" look like in children and adults with profound intellectual and multiple disability?

Juliet Goldbart[1]
[1]*Manchester Metropolitan University, Manchester, UK*

Description: The limited research on cognitive development and educational progression in children with profound intellectual and multiple disabilities suggests that they make little educational progress after the middle school years. If we truly value people with profound intellectual and multiple disabilities, is educational progress important? Development comprises more than cognition and educational progress. Physical development may continue in line with chronological age and interpersonal relationships may expand and deepen over time. How should we support families and educate children with very complex needs? We propose four speakers who will consider contrasting aspects of this topic: Education, Physical development and health, Interpersonal issues, A parent's perspective.

Contribution: We expect participants to discuss whether "progress" is a meaningful concept in profound intellectual and multiple disabilities, and whether an over-emphasis on progress could result in a lack of consideration of interpersonal and emotional issues. Outcomes could include suggestions regarding the education of children and young people with profound intellectual and multiple disabilities, how this might change over their life course, how interpersonal and community engagement can be supported.

Curricula for students with intellectual disabilities: international perspectives

Tobias Buchner[1], Rhonda Faragher[2], Karrie Shogren[3], Kenneth Poon[4], Judith McKenzie[5]
[1]*University of Education Upper Austria, Linz, Austria;* [2]*University of Queensland, Brisbane, Australia;* [3]*University of Kansas, Lawrence, Kansas, USA;* [4]*National Institute of Education, Singapore, Singapore;* [5]*University of Cape Town, Cape Town, South Africa*

Description: Curricula define learning goals across grades, and the intended content and process goals of different subjects. They are therefore of key relevance for instruction and learning in schools. Over the course of the last 40 years, most countries around the globe developed specific curricula for students with intellectual disabilities, in order to help professionals in schools adapt to the learning needs of this population. In the last decade, some countries, e.g. Australia, moved away from such an approach and developed one curriculum for all students, so that students with intellectual disabilities are supposed to be taught and assessed with reference to that curriculum with support. However, relatively little is known about the developments in the area of curriculum and inclusive education of students with intellectual disabilities from an international comparative perspective. In order to fill this gap, participants of the roundtable will compare curricula in relation to students with intellectual disabilities from five countries (Australia, Austria, Singapore, South Africa and USA).

Contribution: The expert group will focus on different aspects, such as inclusiveness (one curriculum for all vs. special curricula), assessment (of students with intellectual disabilities against the general curriculum) and the nature of reasonable adjustments for various subjects.

Autism and employment: Strategies and alternatives

Mitzi Waltz[1], Simon Bury[2], Hilary Fertig[3], Agnieszka Siedler[4], Daniel Leong[5]
[1]*Athena Institute, Vrije Universiteit Amsterdam, Amsterdam, The Netherlands;* [2]*La Trobe University, Bundoora, Australia;* [3]*Employment Autism, New Malden, UK;* [4]*Akademia Pedagogiki Specjalnej im. Marii Grzegorzewskiej, Warsaw, Poland;* [5]*ASEAN Autism Self Advocacy Network, Singapore*

Description: In Europe, the percentage of autistic adults in paid employment has actually gone down recently—and the pandemic is likely to affect this group even more adversely than the general public. This roundtable will include participants from different countries, who work with different sub-groups within the autistic community, to explore strategies for increasing employment rates, and ensuring that employment experiences are life-affirming and provide adequate income. We will also discuss potential and actual alternatives to employment for autistic adults that can provide similar social benefits (belonging, making a societal contribution) and, in some cases, financial benefits. A brief introduction from the chair, including most recent statistical data, will be followed by panelists briefly presenting the situation in their own countries/the sub-group they work with.

Contribution: Adults with autism are increasingly accessing higher levels of education, including completion of secondary school and higher vocational education or university. This investment on the part of autistic people, their families, and professionals represents high potential across the adult lifespan, but significant barriers remain. This is intended as a practical strategy-sharing session. We will generate strategies to increase the number of autistic adults in paid employment, and workable, positive alternatives to employment.

Evaluating social inclusion programs across cultures: Lessons from Special Olympics Unified Schools

Ashlyn Smith[1], Meghan Hussey[1], Michelle Yin[2]
[1]*Special Olympics International, Washington, DC, USA;* [2]*American Institutes for Research, Washington, USA*

Description: Special Olympics Unified Schools uses inclusive sport, youth leadership, and whole school advocacy to foster socially inclusive school environments for students with and without intellectual disability. Over a decade of rigorous evaluation in the United States has demonstrated positive impacts of this program for all students. However, there is a lack of global evidence, especially in developing countries where access to inclusive education for children with intellectual disability is often hampered by lack of data demonstrating its effects. The Play Unified Learn Unified project has created an opportunity to grow Unified Schools globally and create a global evaluation framework and tools to assess the implementation and impact of this program around the world. Presenters in this roundtable will describe the process and preliminary findings of creating and adapting this evaluation framework across four countries with diverse students, and different cultural contexts and education systems. The audience will be invited to share similar experiences and questions.

Contribution: This discussion will provide solutions for cross-cultural evaluations in education and ideas for future work in evaluation adaption, with the ultimate goal of addressing the lack of data that exists to combat stigma and foster social inclusion for students with intellectual disability.

Ethics is everyone's business

Ruth Northway[1], Petra Bjorne[2], Marjorie Aunos[3], Esther Bakker-van Gijssel[4]
[1]*University of South Wales, Pontypridd, UK;* [2]*Department for Disability Support, Malmo, Sweden;* [3]*Brock University, St. Catharines, Canada;* [4]*Radboud University Medical Center, Nijmegen, The Netherlands*

Description: Research, policy and practice in the field of intellectual disability present a range of ethical challenges. IASSIDD provides an important forum for discussion of ethical issues and the development of appropriate responses. However, for this potential to be realised it is important that SIRGs work together, and that there is recognition that ethical issues are relevant to the work of all SIRGs. This roundtable, coordinated by the Ethics SIRG in collaboration with the Health and Parenting SIRGs, aims to: 1) Reflect on recent collaborative work between these SIRGs, 2) Explore the potential for extending this collaborative work to additional SIRGs, 3) Begin the development of a collaborative programme of work focused on ethical issues. The roundtable will be chaired by Ruth Northway (co-chair of the Ethics SIRG) and will include presentations by Esther Bakker-van Gissel (Health SIRG), Marjorie Aunos (Parenting SIRG) and Petra Bjorne (co-chair of the Ethics SIRG). This will be followed by group discussion.

Contribution: This roundtable will contribute to the "Ethics, politics and diversity" track. Through exploration of the way(s) in which ethical issues are relevant to the work of all SIRGs, it will provide the basis for the development of a future programme of collaborative work.

Paternalist governance: Between care and disablism

Kurt Bendix-Olsen[1], Henar González[2], Grace Khawam[3]
[1]*UCL Erhvervsakademi og Professionshøjskole, Odense, Denmark;* [2]*Universitat Autònoma de Barcelona, Bellaterra, Spain;* [3]*University of Oxford Brookes, Oxford, UK*

Description: Persistent stigmatization and "othering" of individuals with intellectual disability have led to their representation as vulnerable citizens lacking autonomy and needing to be "governed from the outside." This has been reflected in policies and practices that often provide paternalistic justifications of interference and sometimes coercion in a person's life. The autonomy vs. paternalism debate remains an ethical dilemma of valid significance in different national governance contexts, and in institutional and community care settings. After providing a contextual definition of paternalism in policy and practice, the presenters will demonstrate manifested forms of paternalism in daycare, education, transition and employment through examples from Denmark, Lebanon and Spain. The presenters will argue that paternalism is a form of disablism which could further exacerbate oppression of persons with intellectual disability and may contradict the principles of care. A discussion on implications in social development policies and service provisions will be facilitated with the audience.

Contribution: Participants will be invited to engage in the debate and in a collective self-reflection of their own practices as scholars, service providers, caregivers, parents and self-advocates. Propositions of person-centered policies and social care practices which promote autonomy, diversity and active citizenship will be discussed.

Newer approaches to assessment and certification of intellectual and developmental disability: Implications for service delivery

Thomas Kishore[1], John Vijay Sagar Kommu[1], Manohar Harshnini[1]
[1]*National Institute of Mental Health and Neurosciences, Bangalore, India*

Description: Intellectual and developmental disorder (IDD), which in legal terms is known as intellectual disability, is one of the 21 disability conditions identified in India. There are several provisions in India for early identification and intervention, health, education, vocational training and employment. But fundamental to availing all services is ascertaining the condition and certifying the disability. The existing guidelines emphasize use of standardized assessment tools for ascertaining the condition, including its severity and degree of disability. However, there are specific limitations to this approach such as lack of adequate manpower, non-availability of tools that meet the diverse needs of the population, lack of updated norms, trained manpower and most importantly, limited applicability for understanding the support needs and programme planning goals. Clinical diagnosis of intellectual and developmental disability is made based on ICD criteria, but the measures used for disability assessment methods are very old. There is an increased emphasis on adaptive behaviours in identifying intellectual and developmental disability and on determining the support system rather than rigidly defining the severity levels based on intelligence quotients.

Contribution: In this regard, aims and objectives of the discussion are as follows:

1) Reviewing the existing methods of assessment and identification of IDD, 2) Identifying system-related challenges in the process of identification and certification of IDD, 3) Examining newer approaches to identification and certification of disability in IDD, 4) Strategies for optimum use of resources in identification IDD and service delivery and 5) Drawing a road map for policy-related changes for effective service delivery in IDD.

Inclusive research

Andrew Miller[1], Ruth Callander[1], Deborah Kinnear[2], Deborah James[3]
[1]*The Scottish Commission for People with Learning Disabilities, Glasgow, UK;* [2]*Scottish Learning Disability Conservatory, Glasgow, UK;* [3]*Manchester Metropolitan University, Manchester, UK*

Description: Inclusive research practices are seen as worthwhile for myriad reasons, including improved research quality, as well as the intrinsic value of including research subjects in the process. It is becoming commonplace, yet there is little agreement as to what inclusion should look like in practice. Authors will provide examples of methods of inclusive research in their work and lead a discussion. Discussants will prepare responses to the following questions: 1) What should inclusion look like for research projects involving people with learning disabilities? 2) What are the benefits? 3) What are your worries?

Contribution: Utilising different examples of inclusive research from the authors, the roundtable will provide an open forum for people with learning disabilities, researchers and interested stakeholders to discuss the benefits and drawbacks of inclusive research, good (and bad) practice, the tensions between inclusive research and academic rigour. The congress provides a unique opportunity to discuss issues associated with the inclusion of people with learning disabilities in research projects with global leaders in research.

Promoting experiential expertise in research, education, practice and policy—The next step

Gonny Ten Haaft[1], Joos Vaessen[1]
[1]*ZonMw, Den Haag, The Netherlands*

Description: Experiential expertise can contribute substantially to improve research, policy and practice in health and social care. Although the concept and use of experiential expertise is developing rapidly, it is relatively new in the field of health and social care. Knowledge about experiential expertise and how to bring it to its own is increasing, however it is still diffuse and scattered. ZonMw, the Dutch funder for research and innovation in health care, stimulates experiential expertise in various ways. ZonMw is developing a signalement about the state of affairs of experiential expertise in the Netherlands and has hired a quartermaster to further stimulate the position of experiential expertise in the field.

Contribution: In the roundtable, the results about the position and the requirements to further improve the position of experiential expertise in policy, practice, research and education will be discussed in an interactive way with experts and audience. The position of experiential experts and the role of policymakers, researchers, client advocacy organizations and funders in this will be a key theme.

Data management in disability research: Are you getting the most from your data?

Gail Birkbeck[1], Adam Nolan[2], Christine Linehan[2]
[1]*University College Cork, Cork, Ireland;* [2]*University College Dublin, Dublin, Ireland*

Description: Data management can often be deferred while researchers crank up activities related to study design and data collection. Funders, however, are increasingly requiring data management plans (DMPs) and open access to data when a study concludes. This roundtable considers the development and implementation of a DMP using a case study of a global anonymous online survey of the experiences of caregivers during the pandemic. We present an outline of this study's data management activities including data documentation, storage and access to data, analyses, delivery of findings to target audiences as well as governance issues pertinent to ethical approval and data ownership.

Contribution: Increasingly research data is being treated as having value in its own right and not just as a by-product of the research process. We aim to share our experiences and insights into the tools and systems needed to manage and share research data more effectively. We hope to encourage other disability researchers to consider the increasing data management requirements of funders and the opportunity to share disability data in open repositories. We ask why so little disability data is archived and what ethical issues may arise from open access data policies.

End-of-life decisions and End-of-life care under crisis conditions: Lessons learnt from COVID-19

Irene Tuffrey-Wijne[1], Sabine Schaeper[2], Britt-Evy Westergard[3], Marieke Groot[4]
[1]*Kingston & St George's University, London, UK;* [2]*Catholic University of Applied Sciences NRW, Cologne, Germany;* [3]*Oslo Metropolitan University, Oslo, Norway;* [4]*Radboud University, Nijmegen, The Netherlands*

Description: There have been concerns that some adults with intellectual disabilities may not get the right care and support when they approach the end of life, and when they are dying. These concerns have continued during the COVID-19 pandemic. Pressing issues have included shorter periods of dying, barriers to accessing healthcare (including intensive and end-of-life care), confusion over do-not-resuscitate orders, and the isolation both people with intellectual disabilities and carers/staff may have experienced in the last days/weeks of life. This roundtable discussion draws on the results of an international survey on end-of-life care and how COVID-19 has affected this. We will provide an overview of the results of the survey, and look in detail at data from the UK, Germany, Norway and the Netherlands.

Contribution: Discussion points will include: What concerns around end-of-life issues during the COVID-19 pandemic have been raised in your country or area of work? How have, or can, these be addressed? COVID-19 may have exposed pre-existing problems or inequalities in end-of-life care provision, but it may also have provided new opportunities or new ways of addressing the issues. What can we learn from this for post-pandemic end-of-life decision making and the provision of end-of-life care to people with intellectual disabilities?

Theorising support for parents with intellectual and developmental disabilities and their families: Care, social practices and vulnerability

Danielle Turney[1], Beth Tarleton[2], Gillian Macintyre[3]
[1] *Queen's University Belfast, Belfast, UK;* [2]*University of Bristol, Bristol, UK;* [3]*University of Strathclyde, Glasgow, UK*

Description: Our interest here is in the role of theory in informing work with parents with intellectual and developmental disabilities. Work in this area has offered numerous practice-based insights but has not always paid the same attention to theory. However, our work has highlighted the potential contribution of three different perspectives that we think have much to offer: conceptualisations of care, social practices, and vulnerability. The three speakers have all been involved in research with parents with intellectual and developmental disabilities, and have drawn on these approaches in their work. Each speaker will introduce one of the perspectives (care ethics: Turney; social practice theory: Tarleton; vulnerability: MacIntyre) and apply it to a vignette drawn from practice which will be shared with participants at the beginning. Audience members will be invited to discuss each approach in relation both to the vignette and their own country/practice context.

Contribution: The discussion will allow participants to explore the potential utility of each approach and how it might enhance understanding of effective and positive support for parents with intellectual and developmental disabilities and their families. We hope this will contribute to wider debate about how family support needs are conceptualised and how theory can support the development of best practice.

Injustice in the child welfare system: Research on parents with intellectual disability

Laura Pacheco[1], James Rice[2], Marjorie Aunos[1], David McConnell[3]
[1]*CIUSSS-ODIM, Lachine, Canada;* [2]*University of Iceland, Reykjavík, Iceland;* [3]*University of Alberta, Edmonton, Canada*

Description: Decades of international research has shown that parents with intellectual disability are over-represented within the child welfare system. They are the most vulnerable group of caregivers to have their children permanently removed from their care. Systemic and institutional barriers are at the heart of this social issue. This includes but is not limited to assumptions of incompetence, over-reliance on parental disability to justify child welfare involvement and or child apprehension, and biased and unequipped service systems. Three researchers will present findings from different research projects. The aim will be to engage the audience in a research-based discussion on the social inequities these families face in the child welfare system and how future research can respond to this institutional disableism.

Contribution: This roundtable will contribute to the state of research knowledge regarding the intersection of parents with intellectual disabilities and the child welfare system. The rich discussion and insights garnered within this roundtable with parents and parenting SIRG members will also provide a basis for a webinar within IASSIDD on this topic within the quality of life and support: Individuals, Families and Communities track.

Prenatal and postpartum health disparities in women with intellectual and developmental disabilities: Generating recommendations for action

Hilary Brown[1], Mitra Monika[2], Willi Horner-Johnson[3], David McConnell[4]
[1]University of Toronto Scarborough, Toronto, Canada; [2]Brandeis University, Waltham, Massachusetts, USA; [3]Oregon Health Sciences University, Portland, Oregon, USA; [4]University of Alberta, Edmonton, Alberta, Canada

Description: The perinatal health of women with intellectual and developmental disabilities has received minimal clinical and public health attention. This interactive roundtable examines the health of pregnant and postpartum women with intellectual and developmental disabilities and identifies research, clinical, and policy priorities to improve their outcomes. Panelists Hilary Brown, Monika Mitra, and Willi Horner-Johnson and chair David McConnell will discuss research on pregnancy and postpartum complications, as well as experiences of health care access, among women with intellectual and developmental disabilities. Available health, mental health, and other supports for this population will be identified. The audience will be engaged through a series of discussion questions and activities about possible intervention approaches and clinical practice recommendations to improve perinatal care.

Contribution: This Roundtable is a follow-up activity to a webinar on the same topic organized by the IASSIDD Parenting SIRG in Spring 2021. The expected outcomes of the roundtable will be development of a set of research, clinical, and/or policy recommendations in the form of an IASSIDD report, to improve health care for pregnant and postpartum women with intellectual and developmental disabilities. This Roundtable will contribute to the Congress theme of "value diversity" and Track 2 by improving quality of life and support for diverse populations of pregnant and postpartum women.

Using robotics in support for parents with intellectual disabilities: Ethical issues

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[1]ASVZ, Sliedrecht, The Netherlands; [2]Garage 2020, Rotterdam, The Netherlands

Description: Using robotics to support parents with intellectual disabilities in the performance of their child-rearing tasks might help them to improve family quality of life. Proper assistance for these parents is affirmed in the UN Convention on the Rights for Persons with Disabilities. However, tools to support parents can be used appropriately or inappropriately, depending on the mindset of the professionals using these tools. In this roundtable we would like to discuss ethical issues concerning the use of robotics in supporting parents.

Two issues will be pinpointed: 1) What is the best way to collect support needs from parents with intellectual disabilities in participation action research? 2) What is important to do or to leave to catch ideas of parents and not the ideas from professionals about these needs? Support tools like robotics can be used in a positive supportive or in a coercive way. What are the pitfalls to take into account? What are the ideas about ethical protocols?

Contribution: With this discussion we contribute to the discussion of a careful use of robotics in supporting parents with intellectual disabilities. We raise awareness about the pitfalls that might harm parents when ethical issues are not addressed.

Under the radar: Parents with intellectual disability in the U.S. child welfare system

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Description: There is broad understanding that parents with disability are overrepresented in the U.S. child welfare system, and this roundtable will use findings from a recent study as a springboard for discussion. That study examined the degree to which parental disability was reported in the U.S. child welfare system and uncovered that parental intellectual and developmental disability goes unreported approximately 70% of the time; however, reporting was significantly higher in jurisdictions that allow consideration of parental disability in decision-making related to termination of parental rights. This finding suggests that the continued failure to support parents with intellectual and developmental disability in the U.S. may be related to the fact that parental disability itself is often unidentified, leaving parents and families without opportunities to benefit from potentially helpful services and supports.

Contribution: The contribution of this roundtable is to build a better understanding of how reporting of parental disability in child welfare may be a first step in supporting families. Discussion will include implications for U.S.-based research, ongoing discrimination and invisibility of parents with intellectual and developmental disability within the U.S. child welfare system, legal implications of invisibility, and lessons the U.S. can learn from other countries that have developed considerable research in the area of parenting with intellectual and developmental disability.

Valuing diversity: What does this mean for parents with intellectual and developmental disability and their children?

Margaret Spencer[1], Marjorie Aunos[2]
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Description: There is greater openness and opportunities for those once denied the right to parent to become parents; coupled with the emergence and acceptance of diverse ways of being a family and parenting. This acceptance has been afforded mainly to those with status, resources and power, while those on the margins of society—such as parents with intellectual and developmental disability—continue to struggle to have the diversity they bring to parenthood recognised, respected, and supported. Disablist and ableist attitudes, policies and practices undermine justice for parents with intellectual and developmental disability and their children. Disablist assumptions about parents with intellectual and developmental disability remain entrenched and pervasive; while hegemonic ableist constructs of parenthood continue to define expectations, frame how parents with intellectual and developmental disability are assessed, treated and judged, and used to legitimise the actions taken to justify the termination of their rights. The objective of this roundtable to envisage how our research and practice can more effectively address disablism and ableism. This roundtable will be led by a panel of experienced and emerging parenting with intellectual and developmental disability researchers, parents with intellectual and developmental disability and leaders pursuing justice for other marginalised parents.

Contribution: This roundtable will make an important contribution to informing current and next generation research related to parents with intellectual and developmental disability.

Building bridges: Similarities and differences between parents with intellectual and developmental disability and physical disabilities

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Description: In the last decades, there has been substantial research on the parenting of adults living with intellectual and developmental disability. However, few parallels have been made with other disability groups, such as parents living with physical disabilities, including parents also living with cognitive impairments. This roundtable will be chaired by Gwynnyth Llewellyn (University of Sydney) and will include speakers from four different Canadian universities: Evelina Pituch (Université de Montréal), Coralie Mercerat (Université du Québec à Montréal), Lesley Tarasoff (University of Toronto Scarborough) and Lyndsey Hahn (University of Alberta). The audience will engage in a 30-minute discussion after four five-minute presentations focusing on parents with physical disabilities' needs and postpartum services.

Contribution: Drawing comparisons with other parenting research fields may reveal gaps in knowledge and new ways to move forward for parents with disabilities. This roundtable will discuss the similar and different life experiences of parents with disabilities. What issues do parents face? In making sure that no parent is left behind, should future research be all-inclusive or focus on specific parental diagnoses? This roundtable will be the first of many more international initiatives that aim to build strong bridges amongst various parenting fields.

Bridge the gap: Collaboration between parents with intellectual disability, child protection services and professionals

Marja Hodes[1], Marcia Lever[2], Yvonne Blesgraaf[3], Manouk van Voskuilen[4]
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Description: When safety becomes an issue in families headed by parents with intellectual disabilities, different fundamental rights can become in conflict. On one hand, the child has the right to grow up in a safe environment. On the other hand, parents have the right to educate their child. Two different camps can emerge: one fighting for the rights of the child and one fighting for the rights of parents. In this presentation we will argue that child's safety can only be guaranteed when there is a close cooperation between parents, child protection services and service providers. We present a good practice example with serious concerns about child's safety. We show how close collaboration between parents, child protection services and service provider end up in good enough safety for the child, using the Dutch program HoldOn, a program based on solution-focused principles. In the roundtable we discuss difficulties in collaboration, and how to overcome these difficulties.

Contribution: With this discussion we contribute in bridging the gap between child and parent rights. We show a new perspective to enhance quality of life for children and their parents in such a way that parents feel respected and children are safe and cherished.

How to foster durable inclusion of people with intellectual and developmental disability in medical research?

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Description: Shared decision making (SDM) is increasingly important in medical practice and research. Systematic involvement of people with intellectual and developmental disabilities in medical research may contribute to research and treatments that are optimally tailored to the health and lifeworld of people with intellectual and developmental disabilities. Medical research traditionally relies heavily on objective health indicators. So, how does one include peoples' expertise in medical research designs that generally do not accommodate subjective experiences? Adjustments on the epistemological level may ensure that peoples' experiential expertise is durably integrated in medical research designs. We present a concept-framework for inclusion of people with intellectual and developmental disabilities' expertise in medical research based on SDM. This framework is informed by an epistemic conceptual analysis, and our first experiences with involving people with intellectual and developmental disabilities in medical research within the HA-ID consortium (Healthy Ageing and Intellectual Disabilities) at the Erasmus Medical Center, University Medical Centre Rotterdam.

Contribution: We will share our ideas and experiences with inclusion of people with intellectual and developmental disabilities in research and invite participants to share their experiences and expertise. This will improve our framework and helps the intellectual and developmental disabilities research community to develop shared ideas and practices on how to involve people with intellectual and developmental disabilities in various forms of medical research.

Easy English and Easy Read, 2 years on

Cathy Basterfield[1], Xavier Moonen[2]

[1]*Access Easy English, Mentone East, Australia;* [2]*University of Amsterdam, Amsterdam, The Netherlands*

Description: Two years ago at the World Congress in Scotland, an inaugural roundtable met to discuss issues around the current research and development of accessible written information. Many questions were raised.

Some further research has been published since 2019. There are many more questions that need to be explored.

The COVID-19 pandemic has raised many issues for people with intellectual disability in their access to written information in a way they need it, at the time they needed it. Technical PLAIN Standards and Easy to Read Standards are being discussed and developed or ratified in other sectors that identify the need for clear and accessible written information. We need to engage in these processes, and consider how they may be of practical benefit for the research being undertaken in our sector. This may have an impact on documents being created with and for people with intellectual disability and low literacy.

Contribution: 1) To build on the international collaboration; 2) To share current policies and practise for accessible information in different countries; barriers and facilitators; 3) To share issues raised during the pandemic, and possible solutions; 4) To share knowledge on research that is currently underway, is being considered, and to propose other research questions.

Track 1: Inclusive Education and Employment

PRESENTATIONS IN A SYMPOSIUM

Being close at a distance: Learning maths

Family math: Involving parents in mathematics education of children with Down syndrome

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Background: An experimental pedagogical research regarding children with Down syndrome approaching mathematics in their home environment was designed, taking advantage of the lockdown conditions in Spain in response to the Covid-19 pandemic. We explored: a) an informal approach involving home spaces and objects, and b) the engagement of parents and siblings.

Method: A series of 14 mathematical challenges was designed on a weekly basis, regarding whole numbers (counting, cardinality, little oral problems), plane geometry (straight lines, polygons, circle) and solids (cylinders, orthohedrons). The target consisted of 16 children aged 3 to 13 whose families received the request by WhatsApp and were asked to record a short video that synthesized the child's work. The video material was analyzed in video-compilations.

Results: All the families took assiduous part in the weekly activities showing deep engagement maintaining the weekly connection, organizing the activity and producing videos, in which a joyful approach resonates.

Conclusions: This project is part of an ongoing research on the educational role of mathematics in youngsters with intellectual and developmental disabilities, that explores the need to linking informal experiences on number and form with school mathematics. Moreover, the approach by means of challenges rather than execution of tasks proved crucial in engaging both children and parents.

Students with Down syndrome using technology to learn secondary mathematics

Rhonda Faragher[1], Kim Beswick[2]

[1]*University of Queensland, St Lucia, Queensland, Australia;* [2]*The University of New South Wales, Sydney, Australia*

Background: The research investigated the way secondary students with Down syndrome used technology, such as spreadsheets and calculators to learn concepts in the secondary mathematics curriculum.

Method: Five secondary school aged students who were being taught the standard secondary mathematics curriculum, with adjustments, in regular classrooms participated over the two years of the study. Classroom observation rounds involved video recording of lessons, interviews with teachers and collection of lesson artefacts. Four observations rounds were undertaken for each participant. Data specifically related to the use of mathematics technology were analysed through a disability studies in mathematics framework.

Results: All students were expected to make use of technology to support their learning, and teachers explicitly taught them how to do so. The technology served as affordances and enablers to undertake more sophisticated mathematics than would have been possible without.

Conclusions: The use of the technological tools of mathematics is fundamental for the effective use of mathematics in life contexts. Furthermore, these tools have shown the value in making secondary mathematics accessible to learners with Down syndrome. Implications for learning mathematics at distance are proposed based on extrapolations from the analysed data.

A Zoom-window to keep in touch

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Background: The research investigates a way to keep children with intellectual disabilities engaged to the math game through online sessions with an expert, where arithmetical problems resolution is the basis of the sessions. We also intend to furnish parents with fun, useful mathematical games.

Method: Four children are participating weekly in Zoom-sessions that are being recorded, deeply analyzed, and edited into free, online short videos since March 2020. Material (to use on the computer or homemade) is e-mailed to parents before and after the sessions.

Results: The avatars keep children immersed in the experience of living mathematics, which has proven to be so useful for learning them, and soften the distance imposition. We have also experienced that children enjoy and learn much more not only when they solve, but when they propose problems, and besides, this helps us to get to know their understanding process better.

Conclusions: In distance learning we still can make children to live mathematics through an avatar, and learn how they develop a mathematical mental process. Furthermore, these sessions have shown us how to help parents that want to be involved in their childrens' math formation.

Co-production and co-creation in inclusive education

Including people with intellectual disability in online health education

Eilish Burke[1], Anna Bakker[2], Holly Dennehy[1], Sarah Bowman[1], Alyt Oppewal[2]
[1]*Trinity College, University of Dublin, Dublin, Ireland;* [2]*Erasmus MC, University Medical Center, Rotterdam, The Netherlands*

Background: The online platform "Get Wise" aims to empower people with intellectual disability with the knowledge and skills to manage their health. The platform and learning modules ("Going to the doctor" and "Bone health") were developed in co-creation with people with intellectual disability.

Methods: People with intellectual disability were recruited in Ireland and the Netherlands. Because of the COVID-19 pandemic we changed our methodology from onsite focus groups to online semi-structured interviews through Microsoft Teams. In total, 14 Irish and 6 Dutch participants participated in the interviews. Participants expressed what they wanted to learn and shared their experiences with the internet. During the development, an additional 14 Irish and 3 Dutch participants piloted the platform. They shared their opinion on the accessibility and the quality and comprehensibility of the featured information.

Results: People with intellectual disability provided valuable input for developing and improving the "Get Wise" platform and modules. Participants enjoyed participating and being involved in the development. Online interviews were a feasible method to conduct the interviews.

Conclusions: The co-creation with people with intellectual disability resulted in an accessible online platform that has been live since January 2021 and empowers people with intellectual disability to manage their health.

Get Wise about your health: Developing inclusive online education

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Background: To develop, refine and validate a health education course co-created and co-developed with individuals with intellectual disability in an accessible easy-read manner on a novel digital platform. The objective was to address and improve each individual's health and knowledge to empower the individual to become an informed consumer of health.

Method: The study adopts a qualitative approach through semi-structured interviews with individuals with intellectual disability on topics related to the course modules. Contributions were gathered from an open-ended questionnaire delivered online. Thirty-seven individuals with intellectual disability from Ireland and the Netherlands participated. Thematic analysis was used to identify major themes. Material developed was reviewed and piloted tested with individuals. Ethical approval was granted from each service provider ethics committee.

Results: Individuals informed course content and supported reasonable adjustments. Modules developed included: "Attending the doctor" and "Bone health." Participants expressed a keen interest to engage with online education and demonstrated their ability to successfully identify key concepts from their experience contributing to course development.

Conclusions: Participants were highly motivated to participate in the study and provided rich information which informed the creation and development of the Get Wise course available at https://www.getwiseid.eu/#/.

Promoting engagement during a pandemic, advancing the health and wellbeing of individuals with intellectual disabilities

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Background: To engage individuals with intellectual disability virtually to promote health and wellbeing considering the COVID-19 outbreak. The objective was to promote well-being and to empower individuals with ID to demonstrate how they were keeping healthy and staying well, and to encourage all to engage in health promotion activities.

Method: The research team developed an online campaign "Get Connected, Stay Connected" to target individuals to support them to overcome any isolation or negative impacts individuals with intellectual disability experienced throughout lockdown in Ireland. As people with intellectual disability have lower digital literacy skills and lower levels of technology usage, the research team conducted an outreach to service providers to raise awareness about the campaign and engage participants.

Results: Participants actively engaged with others online and shared innovative ways to maintain good health. Over 400 individuals engaged with the "Get Connected, Stay Connected" campaign.

Conclusions: Participants were highly motivated to engage online and demonstrated a wealth of knowledge regarding how to stay healthy and keep well. The project provided a stimulus and motivation to promote engagement. Participants shared innovative ways to maintain good health and well-being.

A novel approach to engaging people with intellectual disability as contributors in research

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Background: To engage individuals with intellectual disability in focus groups through a variety of innovative methods and establish how they could inform the conversation on how to include people with intellectual disability in healthcare research.

Method: An innovative approach to focus group involvement was developed through an adapted Charette Procedure. This involved using real-life photos to stimulate and guide discussion and ultimately brainstorm in small group sessions. To ensure an inclusive approach, digital technology was adapted in the form of QR code which enabled the author to create video communication with individuals and fully inform them prior to the focus groups, irrespective of sensory impairments or literacy capabilities.

Results: The use of digital technology enabled clear communication prior to meeting individuals and established a connection with the group. This instilled greater confidence and familiarity with the individuals. The novel approach stimulated extensive discussion and brainstorming ideas which ordinarily would have been challenging for individuals with intellectual disability, promoting partnership and inclusion.

Conclusions: Healthcare research shapes and determines the healthcare landscape; by being partners in research, people with intellectual disability are empowered to shape the healthcare agenda. How researchers communicate with people with intellectual disability contributes hugely to the success of receiving rich information.

Describing pupils with intellectual disabilities

Socio-economic inequality of pupils with intellectual disability

Anna Selmayr[1], Wolfgang Dworschak[1]
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Background: The presentation is a report on the socio-economic situation of pupils with intellectual disabilities in Bavaria, Germany.

Method: The representative replication study *Schülerschaft mit dem Förderschwerpunkt geistige Entwicklung II* (SFGE-II) collected data from 1000 pupils with ID via questionnaires for teachers and parents in 2019. The wealth of the families is identified by the Family Affluence Scale (FAS, Currie et al. 1997, 2008) and net equivalent income. The results are compared with the first SFGE study and national as well as international reports.

Results: First results show that on one hand that the pupils are heterogeneous with respect to their socio-economic status, and on the other hand that there are specific constellations, such as single parents, leading to precarious situations.

Conclusions: Through further analysis we provide tangible approaches for policy and practice on how to support the vulnerable group of children and teenagers with intellectual disabilities and their families.

Reading skills among pupils with intellectual disabilities

Christoph Ratz[1]
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Background: Detailed knowledge on the literacy skills of students with intellectual disability is vital for planning instruction, creating (inclusive) learning environments, implementing educational policies or funding models and specifying future fields of research. However, there has been little research into the prevalence and variation of their reading skills. This study repeats and compares with a similar study from 2010.

Methods: The present study assessed the reading stages of some 1000 pupils with intellectual disability, regardless of aetiology, (age 6–21) in Bavaria, one of the largest regions in Germany within a randomly chosen and representative sample. Teachers described the reading and writing stages of their students in a questionnaire following the developmental model of Frith.

Results: Results indicate that 29% do not read at all, 7% read at a logographic stage, 32% at an alphabetic and 32% at an orthographic level. Writing achievements are lower on average (exact numbers are yet to be calculated.)

Conclusions: We analyze and discuss the determinants of literacy in this sample with regards to other background variables such as socio-cultural background, IQ or language development and draw conclusions for teaching and school policies.

The need for care of the pupils with intellectual disabilities and consequences for education

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Background: The situation of people with intellectual disabilities is characterised by a high degree of social dependence. This dependency becomes clear, among other things, in the care needs that these people have. The school is an institution of education. Therefore, the question arises as how intensive the need for care of pupils is, and what impact this has on educational offers.

Method: In the empirical study SFGE, teachers are asked to assess the need for care of their pupils during a morning at school.

Results/Conclusions: The presentation presents the current empirical data on this temporal assessment of the need for care of the pupils with intellectual disabilities at special schools in Bavaria. The question is also raised as to what consequences this has for teaching and the possibilities of education.

Enhancing time processing abilities and daily time management

Conceptualization and a model of time processing ability applied in research of children with intellectual and developmental disabilities

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Background: The aim is to present conceptualization and a model of time processing ability (TPA) and daily time management (DTM) and describe TPA and DTM in children with intellectual and developmental disabilities.

Methods: Children with disabilities (n=83) aged 10 to17 (M51/F32), including children with mild intellectual disabilities (n=19), ADHD (n=28), autism (n=24) and cerebral palsy (n=12) participated. TPA was assessed using Kit for assessment of Time processing ability (KaTid) and the Time-S to capture the self-rated daily time management. The constructs measured were created based on the International Classification of Functioning (ICF). Both instruments have demonstrated acceptable psychometric properties.

Results: The results showed that children with intellectual disabilities have a low level of TPA: raw score mean 38.3 (SD11-16) compared to children with other diagnoses (raw score 44.5–46.8 (SD10.08-11.53). The mean age of children with intellectual disabilities was 15 years old, while the other children were younger (mean 13–13.5 years old.) The correlation between TPA and DTM in all diagnoses will be presented.

Conclusions: The KaTid-Youth can be used to discriminate the level of TPA and the Time-S the level of DTM in children with intellectual and developmental disabilities. The model can be useful in guiding the design of intervention to improve daily functioning.

Intervention using My Time can facilitate time processing ability in children with intellectual disabilities

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Background: The aim was to evaluate effect of a new method, "My Time" for remediation of time-processing ability (TPA) in children with intellectual disabilities aged 10-17 years (n=67) in special schools.

Method: Cluster randomized and waiting-list control group design was used. Data collection included the Kit for assessment of Time-processing ability (KaTid), the Time-Parent scale and a self-rating of autonomy to assess everyday functioning. The method was implemented over an eight-week period. Data were analysed using a linear mixed model, with fixed effects for group and baseline score, and cluster nested within school size as a random effect, was performed.

Results: The intervention group increased their TPA significantly more than the control group ($p>0.05$) with an effect size Cohen's $d = 0.53$.

Conclusions: The results show that children with intellectual disabilities aged 10 to 17 years can acquire more advanced TPA at a measurable pace given remediation in time-processing ability. Children with intellectual disabilities should be identified and offered intervention. More research is needed to investigate the effect of training on everyday functioning.

Daily time management and time processing in people with a mild to moderate intellectual disability

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Background: This research aims to identify the factors that hinder and promote time processing abilities (TPA) and daily time management skills (DTM) of people with an intellectual disability. Although problems with time management are very common in persons with intellectual disabilities, literature on this topic is scarce.

Method: A modified Delphi study with individual interviews (round 1) and group discussions (round 2 and 3) for feedback on the data from the first round. An expert panel ($N=38$) is consulted divided into three groups: people with ID, (family-professional) caregivers and technology-and-care experts. Participants comment on how to support the TPA and DTM skills of persons with intellectual disabilities.

Results: Main findings, commonalities and differences between the three groups will be discussed. The results provide insight into the hindering and promoting factors and ways to support people with intellectual disabilities to improve their TPA and DTM skills. An example will be shown of the use of technology to improve wake-sleep routines in people with a severe intellectual disability.

Conclusions: Practice shows that there are various means available from (technical) devices and caregivers to support people with intellectual disabilities with DTM. Usability is partly determined by the severity of the intellectual disability and additional diagnoses of the person.

Peer relationships

Peer influence on problem behaviors in students with intellectual disabilities

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Background: Children and adolescents with intellectual disabilities exhibit increased rates of problem behaviors compared to those without intellectual disabilities. Given the evidence of peer influence in typical development, we examined the impact of classmates' characteristics on problem behaviors of students with intellectual disabilities. We expected that higher levels of problem behaviors in special needs classrooms will influence individual development of such behaviors.

Method: A longitudinal design with measurements at the beginning and the end of a school year was applied. Staff reported on problem behaviors of 1125 students with intellectual disabilities (69% boys; age 11.30 years, $SD = 3.75$) attending 16 Swiss special needs schools.

Results: Multi-level analyses showed that higher individual scores of anxiety, problems in relating socially, and communication disturbances at T2 were predicted by higher classroom-levels of the same problem behaviors at T1, controlling for individual problem behaviors at T1 and other covariates. More within-classroom heterogeneity of students' anxiety reduced the peer effect on anxious behavior. Students' development of communication skills benefitted from attending classrooms in which there was more heterogeneity in the levels of communication problems.

Conclusions: Our results point to the importance of the classroom peer context for the social adjustment of students with intellectual disabilities.

Ingroup influence of peers on adolescents with intellectual disabilities: A minimal group experiment

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Background: Adolescents with intellectual disabilities often have difficulties to assess the hostility of unknown persons in ambiguous situations and may therefore use social cues to achieve certainty. The aim of this study was to examine to what extent adolescents with intellectual disabilities orientate themselves towards an ingroup of peers when conflicting opinions of an in- and outgroup of peers are evident at the same time.

Method: A computer-based experiment based on the minimal group paradigm was developed and conducted with adolescents with intellectual disabilities ($N=38$; $M=14.86$ years, $SD=1.35$), typically developing adolescents ($N=38$; M=14.66 years, SD=1.14), and typically developing children ($N=38$, $M=7.93$ years, $SD=.61$). *Results* When making social judgments, adolescents with intellectual disabilities showed a greater susceptibility to peer ingroup influence than typically developing adolescents ($p < .001$). No difference in openness to ingroup influence was found in comparison to typically developing children ($p = .824$).

Conclusions: In ambiguous social judgment situations, adolescents with intellectual disabilities exhibit an increased tendency to rely on cues from an unknown ingroup of peers to judge other people. Opportunities and risks associated with this tendency are discussed.

Social acceptance and rejection in special needs schools

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Background: The social status of students with intellectual disabilities in special needs schools has been little studied so far. The present study focused on the influence of individual problem behavior on acceptance and rejection of these students. Based on the person-group-similarity-model (Stormshak et al., 1999) the moderating effect of descriptive classroom norms in special needs schools was also examined.

Method: Using questionnaires, school staff at special needs schools provided information on the problem behavior and social status of 1125 students with intellectual disabilities ($M=11.97$ years, $SD=3.75$; female=31%) at the beginning (T1) and end (T2) of a school year.

Results: More individual problem behavior at the beginning of the school year predicted significantly less individual acceptance and more individual rejection at the end of the school year, under control of social status at T1. The classroom norm on problem behavior had no moderating effect on the influence of individual problem behavior on social status.

Conclusions: This finding is consistent with findings from other school contexts where problem behaviors have proven to be a risk factor for social integration in school. The results will be discussed in terms of their relevance for the support of students with intellectual disabilities.

Progress and children with profound intellectual and multiple disabilities

Parental behavior and child interactive engagement: A longitudinal study on children with profound intellectual and multiple disabilities

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Background: Knowledge on the long-term interactive interplay between children with a significant cognitive and motor developmental delay and their parents is very scarce. We aimed to characterize the (in)variability and potential mutual influence of parent's interactional style and child interactive engagement throughout early childhood.

Method: Every six months over the course of two years, 35 parent-child dyads (children aged 6 to 59 months) were video-taped during a 15-minute unstructured play situation. Video-taped observations were scored using the Child and Maternal Behavior Rating Scales.

Results: No consistent group-level trend was found. Within singular interactions, parent's responsive behavior and child interactive engagement (attention and initiation) seem to be strongly related. Initial child initiation seems to positively predict parents' achievement orientation and directive behavior two years later.

Conclusions: Parental responsiveness might be an effective interactional strategy to increase child engagement and higher levels of engagement in children possibly can facilitate parental responsiveness within a concrete interaction. The more initiative children show, the more parents might have hope for developmental benefits resulting from a directive/achievement-oriented approach. Further research is warranted, applying more differentiated and dynamically evaluated outcome measures and a longer follow-up time frame, with specific attention to inter-individual differences.

Changes in communicative behaviour in young children with profound and multiple disabilities

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Background: In children with significant cognitive and motor developmental delays, communicative development is complicated because of the interplay of several developmental domains. In assessment, they are all very likely to be assigned to the same group of low performers, showing a very restricted and idiosyncratic communicative repertoire, almost never reaching the level of intentional communication. However, changes in their communicative behaviour are expected over time. These changes will be the subject of this presentation.

Method: This study is based on the data of 23 participants (initial age between 11 and 54 months) and used a coding scheme, specifically developed for the analysis of early communicative behaviours within this target group. The outcome variables of this coding scheme are combined in three clustered scores that will be analyzed longitudinally (two years): communication proficiency, discomfort and discontentedness and differentiation in behaviour towards objects or persons.

Results/Conclusions: First the individual changes will be explored in order to find out how a change in communicative behaviour is established within this group. Next, we will look for group patterns and see whether different patterns can be identified. The preliminary results will be presented.

Assessing children with profound intellectual and multiple disabilities using Routes for Learning: What the data from one school tells us

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Background: To explore the longitudinal data collected by one school on progress of children with PIMD using Routes for learning (RfL) (WAG, 2006), an educational assessment tool for children with profound intellectual and multiple disabilities based on typical development covering communication, cognition and environmental interaction.

Method: A school has been keeping data on individual children's progress using RfL since 2006, consisting of the sequence in which the boxes were attained, the highest-numbered box achieved and the total boxes achieved at each time point. Ethical approval was obtained for access to an anonymised version of this data.

Results: The sequence in which Routemap boxes were attained by children shows good agreement with the theoretical sequence. Younger children acquired higher-numbered boxes at a significantly faster rate than older children.

Conclusions: Further investigation is needed into the factors contributing to these results. The order in which boxes were achieved may in part be determined by the teaching strategy of the school. Data on the total number of boxes achieved at each time point will be presented, but the apparently slower progress of older children may be due to teachers concentrating on generalising skills already acquired, or a larger developmental gap between later and earlier boxes.

Education, training and employment: Sharing the successes and challenges of the DCU Ability project

Career guidance, work experience and progression towards work: Lessons from the DCU Ability project

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[1]*Dublin City University, Dublin, Ireland*

Background: The aim is to provide a comprehensive explanation of the careers guidance and work experience offered during the DCU Ability project including the process of engaging employers. A further aim is to present the resources offered to learners and their supporters to ensure progress continues once the introduction to work course is finished.

Method: An explanation of the approach taken to career guidance is given including data on the number and range of work placements offered to learners. The detail of the engagement required with employers is explained and the challenges in securing meaningful work experience highlighted. Some detail is given regarding the employers and their requirements in supporting learners. The move to online is then detailed and that impact on placement and subsequent developments to ensure that learners had the tools to progress once workplaces opened again.

Results: Learners with intellectual disabilities can be supported to have a meaningful experience in the workplace. A variety of experiences allow for individual choice around work.

Conclusions: Work experience once correctly prepared and supported can lead to employment. Students can be given appropriate tools to help them seek work once they have finished a work preparation programme.

Education, training and employment: Sharing the successes and challenges of the DCU Ability project

Toff Andersen[1], Eilish King[1], Schira Reddy[1], Mary Petrie[1]
[1]*Dublin City University, Dublin, Ireland*

Background: The main aim is to explain the project, provide overall data detailing the numbers of learners supported and the type of supports offered.

Method: An analysis and evaluation of the project will be provided including: an analysis of the participant demographic information; a breakdown by numbers and description of the training approaches used and the effectiveness; metrics on work experience placements and effectiveness of approach; the project outcomes expected and effectiveness of using different training approach; overall lessons learnt and key findings will be explained.

Results: The results will provide insight on the metrics of this unique project approach and give tangible and measurable results of the impact of Covid-19 on the outcomes of the project. It also provides comparable data sets on effectiveness of the "intervention."

Conclusions: The project will demonstrate that positive outcomes can still be achieved with young adults with intellectual disabilities. It will also demonstrate that original planned data sets can still be used as comparative sets, but it is critical from a project perspective to undertake continual project evaluation to ensure that large changes to the project, due to unforeseen circumstances, can still be accommodated, explained and evaluated, adding research value.

Transition to online teaching and learning: An explanation from the DCU Ability project

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Background: The main aim is to detail a move from a campus-based course to an online environment and the supports required for success. A further aim is to explain the role of technology and the adaptations required when supporting people with intellectual disability.

Method: An analysis of the move to an online introduction to work course is presented including: the development of suitable materials; identification of supports required; the impact of technology; student and supporters' feedback gathering throughout the course.

Results: The main results are that the move to online was a success. Learners and their supporters related positive experiences. Challenges included accessing technology and ensuring support was available when needed for the learners.

Conclusions: People with intellectual disability can access online education and training. Opportunities to learn online can widen access and reduce barriers that can be created by issues such as difficulties with transport or living circumstances. More research in this area is required to provide as many choices as possible and help move people who want to work towards employment.

Outcomes from a national supported employment project

Four years of outcomes from Supported Internship/Project Search schemes

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Background: As part of "Engage to Change," a Supported Employment project finding jobs for people with intellectual disability/autism spectrum conditions in Wales, six Supported Internship schemes were delivered.

Method: Three used the DFN Project SEARCH model, and schemes offered up to three placements in a year spent with a major employer. Interns receive support from an Education Tutor and Job Coaches. In the first four years of operation, the Supported Internship schemes served 129 young people aged 16 to 25 and found 256 work placements.

Results: Before the onset of Covid-19, 58% achieved a paid job, falling to 44% as the pandemic hit. This paper describes the six schemes, their interns, and provides data on intern skill development, their work placements and the jobs found. We also summarise qualitative feedback from workers, managers, work mentors and families on the success of the schemes.
Conclusions: The paper provides insights into post-Covid-19 adaptations to the scheme and describes intern-led neurodiversity awareness-raising interventions targeted at managers to support placement finding and to develop marketable skills. The paper discusses the implications of our findings for government policy, work-based training practice and transition to employment.

Impact of COVID-19 on supported employment in Wales: Implications for Supported Employment practice

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Background: “Engage to Change” is a Supported Employment project finding jobs for people with Intellectual Disability/Autism Spectrum Conditions in Wales using the Supported Employment model, Job Coaching and a small number of Supported Internship schemes. In its fourth year of operation, the project was hit by company closures and redundancies with significant negative impacts on its clients in paid placements and jobs, particularly in the retail, hospitality and leisure sectors.
Method: The paper provides describes the impact of the pandemic so far in terms of people being paid to remain off work (furloughed) and redundancies and jobs saved in the context of impacts of the population in general, highlighting inequalities in outcome.
Results/Conclusions: The paper reports the changes in Supported Employment practice that were successful in securing people's incomes and a place within government income support schemes. Further, the paper discusses the post-pandemic changes in the nature of employment and their implications for Supported Employment practice.

Using employment research to impact on policy

Stephen Beyer[1], Elisa Vigna[1], Andrea Meek[1]
[1]*National Centre for Mental Health, Cardiff University, Cardiff, UK*

Background: “Engage to Change,” a Supported Employment project finding jobs for people with intellectual disability/autism spectrum conditions in Wales was also required to leave a legacy in terms of influencing policy. The project research and service delivery team developed an Influencing Plan to build on experience and research.
Method: This paper provides a conceptual model of how research and practice experience can influence service policy and funding.
Results: We describe how our research informed the policy advice we developed from our project and the interventions mounted under the Engage to Change Influencing Plan to inform and persuade a range of important employment and training stakeholders. We describe the successes we have had and what we have learned that might improve future actions in turning research into real world impact.
Conclusions: We argue for a greater integration of research with service delivery and for a better understanding by government of evidence-based practice.

Results of the “engage to change” project and implications for supported employment policy

Elisa Vigna[1], Stephen Beyer[1], Andrea Meek[1]
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Background: “Engage to Change” is a Supported Employment project finding jobs for people with intellectual disability/autism spectrum conditions in Wales using the Supported Employment model, job coaching and a small number of Supported Internship schemes.
Method: In the first four years of operation, the project served 610 people aged 16-25, engaged 454 employers, found 388 people paid work placements and 224 paid jobs in its first four years.
Results: 86% of jobs were sustained beyond three months. The paper provides data on skills development, job types, wages and integration outcomes. We present data on the types of Job Coaching input that delivered different levels of outcome. The relationship between client characteristics and outcome are explored. We summarise worker, employer, work mentor and family feedback on the experience of employment.
Conclusions: The paper discusses the implications of our research findings for government policy and Supported Employment practice.

WORKSHOPS

How can you use adapted ICT devices with people who have profound and multiple disabilities at home or at school?

Miranda Zwijgers[1]
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Description: For persons with profound intellectual and multiple disabilities, it can be hard to use ICT devices for school, spare time, work or play. They need a lot of support from their surroundings to get something accomplished. Or they need one or more adaptations to be able to use ICT devices. But there are so many options that it is hard to find out what is possible, which choices you have in hardware and software, and how it all work together. At Royal Dutch Visio, we have gained a lot of experience in working with ICT devices and all kinds of adaptations for persons with profound intellectual and multiple disabilities. We also developed a validated ICT skills screening, iExpress, with some international partners for this target group.

Contribution: In this workshop we would like to inform you about the kind of adaptations you can think of for persons profound intellectual and multiple disabilities. But we also want to demonstrate with short videos how these adaptations work, and what kind of (paid and free) software you can use with them.

Autism & University: e–platform for students and professors

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Description: The e-platform on autism spectrum disorder of the University of Fribourg (Switzerland) aims to support the academic career of students with autism spectrum disorder and to provide professors with key knowledges in order to work in accordance with the students' needs. Adjustments for people with specific learning disabilities are now common in universities. These adjustments should follow the same path for people on the autism spectrum, estimated at 0.6% of students across Europe (HESA, 2019). The philosophy of support is thus logically oriented towards the acceptance of neurodiversity, also in academic circles, through the concept of Universal Design for Learning.
Contribution: In this workshop, we will discuss the challenges related to supports in higher education, as well as the Swiss development and implementation of this e-platform based on the Autism&Uni European project.

Valuing diversity through the development of transferable skills for future employment

Christina Cederlof[1], Carolyn Ives[1], Matthew Stranach[1], Melissa Svendsen[1]
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Description: The current pandemic has invited educators to develop innovative ways of guiding learners, many of which will continue to be valuable long after the pandemic subsides. This video workshop will share one such innovation that enhanced a program for students with intellectual disabilities. It will demonstrate how transferable skills can be developed at home or within community to improve employment skills. For people with intellectual disabilities, access to post-secondary education and job training is limited. We will demonstrate a method of remote instruction through which students choose a set of transferable skills, develop a plan to learn and practice those skills, research issues related to those skills (employment prospects, health and safety regulations, technical and aesthetic considerations), follow through with their plans, and present their skill development in e-portfolios.
Contribution: We will show how students in the Education and Skills Training Career Education program at Thompson Rivers University (TRU) were able to develop their practical skills in areas of their choice, conduct guided research, and build e-portfolios to document their work, all while staying within their COVID-safe bubbles. We are now exploring how this method might be used post-pandemic to serve more students, including those who are geographically dispersed.

Obuntu *bulamu*, a peer to peer support intervention for disability inclusion in Uganda

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Description: The focus of this workshop is to share the *Obuntu bulamu* intervention for disability inclusion in Uganda with an international audience through a (video) presentation and discussion. The *Obuntu bulamu* intervention is based on an indigenous disability theoretical framework of belonging and mutual support and responsibilities, and was developed and tested by children (with disabilities), parents, teachers, rehabilitation workers, and academicians in Uganda. Followed by a short introduction, the *Obuntu bulamu* video will show the voices of children with disabilities and their families and community members, and explain how the Obuntu bulamu intervention works. After the video display, the presenter will engage the audience in a discussion about the importance of decolonializing disability studies and inclusive education interventions in the Global South.
Contribution: The workshop will discuss the importance of considering indigenous disability frameworks in disability studies and inclusion actions in the Global South. It aims to increase awareness about the importance of valuing cultural history and concepts and critically look at importing frameworks and actions of the Global North to further "development" of the Global South. Globalization, diversity, and politics in the implementation of inclusion interventions in a neo-colonial world will be discussed.

ORAL PRESENTATIONS

Individualized educational programs of learning skills

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Background: The design and implementation of personalized educational programs (IEPs) is carried out in the context of the educational policy "one school for all." In Greece, the individual educational plans (IEPs) are prepared by the Center for Educational and Counseling Support (CECS) in order to include students with special educational needs into the general classroom and foster their participation in the learning process, as defined by the curriculum. The purpose of this study is to examine the effectiveness of IEPs in students with learning disabilities.

Method: A qualitative research project was conducted in CECS of southern Greece and lasted one year. The sample consisted of students in primary and secondary school (N = 40) who came to CECS for re-evaluation of their learning and language skills. Informal pedagogical assessment was utilized with research tools, such as Checklists of Basic Skills, protocols of systematic empirical observation (field notes), and printed documents of students.

Results: The results show that students with learning disabilities made progress in writing and reading skills. However, it was found that more support is needed in text comprehension skills that correspond to their class curriculum.

Conclusions: In the conclusion, ways to support students with learning disabilities are recorded.

The role of spontaneous gestures as a support for spatial thinking of students with intellectual disabilities

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Background: Pupils with intellectual disabilities often struggle to verbally explain how they understand mathematical concepts, especially geometric ones. However, verbal responses are not the only way to express knowledge, gestures also intervene in the reflexive process and can even support it. This research aims to explore how gestures interact with verbal expression when pupils with intellectual disabilities explore three-dimensional objects. Three questions have been formulated after a systematic review of literature: 1) How many gestures pupils with intellectual disabilities produce when solving a 3D spatial task?; 2) What kind of gestures do they use?; and 3) What are the functions of these gestures?

Methods: Twenty students with intellectual disabilities (aged 12-18 years) were enrolled in a 3 × 2 multifactorial design research project. Controls were individually paired on mental age or on verbal skills. A 3D spatial tasks battery derived from standardized paper-and-pencil tests has been created. Participants' verbal and gestural behaviours (iconic, metaphoric and deictic gestures, actions with 3D objects) were filmed. Data are coded using EUDICO Linguistic Annotator (ELAN, v. 5.9).

Results: Analyses are currently in progress.

Conclusions: The results are expected to shed light on the role and place of gestures in the way students with intellectual disabilities deal with 3D objects.

Mental health and emotional literacy in children with special educational needs and disabilities

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Background: This study investigates the relationship between emotional literacy (EL) and mental health in children with Special Educational Needs and Disabilities (SEND) and whether EL moderates the strength of the relationship between self and teachers' reports of mental health. The utility of a self-report measure of mental health was explored, as existing screening methods rely on parent and/or teacher data.

Method: Emotional recognition tasks assessed children's emotional literacy. Children's mental health and behaviour were measured using an adapted self-report measure, Me and My School. Teachers completed the Nisonger Child Behaviour Rating Form, with correlation and moderation analyses applied to explore relationships between variables.

Results: A significant positive correlation was found between teacher and child reported scores of mental health and behaviour, suggesting criterion validity of the self-report measure. However, emotional literacy scores did not correlate with mental health, nor moderate the strength of the relationship between self-report and teacher-reported scores.

Conclusions: The ceiling effect observed for EL tasks may explain the lack of moderation effect between self and teachers' reports of mental health and behaviour. Findings have implications for how the mental health of children with SEND is screened in schools and may lead to further validation of self-report measures.

Employment barriers for people with intellectual disabilities: The case of Greece

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Background: Research consistently shows that the employment rates are particularly low among people with intellectual disabilities (Parmenter, 2011; Tøssebro & Olsen, 2020) and are discriminated against in all aspects of social participation (Groce et al., 2011; Mitra, Posarac & Vick, 2013). If employed, they are much more likely to be in sheltered work (mostly segregated), in day activity centers, or without any occupation (McGlinchey et al., 2013; Tøssebro & Olsen, 2020).

Methods: Unfortunately, the same occurs in Greece. It sounds like an oxymoron, that the Greek State enacts laws to promote the employment of people with intellectual disabilities or to develop special incentive programs in private enterprises, yet the Greek working environment is not “ready” to accommodate them. People with intellectual disabilities still face serious obstacles in employment (Dimitriadou et al., 2016; Tsalis et al. 2018).

Results: This article presents the current employment provisions for people with intellectual disabilities in the Greek context. Additionally, it illustrates the employment barriers for individuals with intellectual disabilities through the lens of disability awareness, discrimination, inequality, self-stigma, accessibility to work environment and self-advocacy.

Conclusions: Implications for policy initiatives, smoothing the path for people with intellectual disabilities to exercise their right to work in practice, are also discussed.

Sound-field-amplification and improved ease of listening in students on the autism spectrum

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Background: To determine whether use of sound field amplification (SFA) systems improves classroom listening experiences in students with autism spectrum disorder.

Method: 38 classroom, gender, and age-matched Year 3 students with and without autism, across 15 classrooms from 11 Greater Brisbane region primary schools participated in this cross-over study. Following a baseline IQ, oral language, hearing and autism-screening, repeated outcome measures were ease of listening in different classroom situations and self-advocacy (LIFE-R, Anderson, Smaldino, & Spangler, 1997), and student noise perception and discrimination (Hear/Annoy Questionnaire, adapted from Dockrell & Shield, 2004), assessing whole-of-semester SFA exposure.

Results: For LIFE-R as dependent variable, main effect of autism was significant ($p<0.001$, chi2 36.12, 1df), as was two-way interaction for SFA order-test number ($p<0.01$, chi2 8.31, 1df). Compared to baseline, performance on the LIFE-R was 7.04 points higher for test two, 95% CI(3.30, 11.55), with the second term group combined benefitting more than those exposed during first term (−8.99, 95% CI(−15.11, −2.88)).

Conclusions: SFA use can improve student overall ease of listening experience, using low-cost, non-invasive whole-of-class technology. Future research should consider prolonged exposure to an increased number of participants, as well as use of a previously validated noise perception and annoyance instrument.

A multi-perspective study on sexuality education and students with intellectual disability

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Background: This inclusive study, conducted by the team of academic researchers and a co-researcher with intellectual disability, explored sexuality and sexual identity education for students with intellectual disability in New South Wales (Australia) high schools.

Method: The researchers spoke to 11 female students with intellectual disability, 10 teachers and nine parents about their experiences with and perceptions of sexuality education. The qualitative data obtained during interviews and focus groups were analysed using inductive content analysis.

Results: Data analysis revealed that many teachers had experiences with their students with intellectual disability disclosing sexual abuse and domestic violence. Some parents and students highlighted that sexuality education does not always include other than heterosexual identities. Students suggested a variety of ways in which lessons can be made more accessible by their teachers (e.g., Easy English resources, use of videos and pictures to explain new concepts, checking for understanding).

Conclusions: This study brings several recommendations, including the need to focus on students' self-determination, agency, and rights regarding sexuality education and the importance of providing schools with accessible resources to teach sexuality education.

Negatively worded items could make things go unexpectedly: Attitudes scales (CATCH and MRAI-R)

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Background: The aim of this presentation is to discuss the effect of having negatively worded items in some scales.

Method: First, a study was completed with students from elementary schools using the Chedoke-McMaster Attitudes towards Children with Handicaps scale (Rosenbaum et al., 1986). The sample contained 415 elementary school students, (56%) girls and (44%) boys. The second study regards the Arabic version of the Mental Retardation Attitude Inventory-Revised (MRAI-R) scale (Antonak & Harth, 1994).The sample in the second study was 455 undergraduate college students (214 female, 241 male).

Results: In the first study, the results of the Rasch analysis did not support the unidimensionality of the 36-item scale. Dividing items based on whether they are negatively or positively phrased improved the scale fit. In the second study, the internal consistency of the MRAI-R scale overall was good (0.76). However, it was less than 0.7 for the four subscales. CFA results for the 36-item scale indicated that the observed data did not support the four-factors model. However, separating the scale into two scales based on the phrasing type of items (positively phrased or negatively phrased) resulted in an acceptable fit for the model.

Conclusions: Negatively phrased items had a negative impact on both scales.

Social-Emotional learning and inclusive education: Suggestions from psSMILE Erasmus+ project

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Background: There is an increasing interest in Social and Emotional Learning (SEL), that is the process through which children and adults acquire and effectively apply the knowledge, attitudes, and skills necessary to understand and manage emotions, set, and achieve positive goals, establish, and maintain positive relationships, and make responsible decisions (CASEL, 2012). Students with learning and intellectual disabilities typically face difficulties with these skills and evidence available on their learning potential (see Daley and McCarthy, 2020) underline the relevance and need for guidelines supporting their active participation in SEL activities.

Method: The presentation will first summarize evidence from recent literature and relevant international projects. The attention will then focus on the ongoing Erasmus+ PSsmile project. It is aimed at developing a training program involving primary school teachers and parents as well as all primary school students.

Results: Universal Design for Learning, and Community Based Inclusive Education methodological choices, procedures and contents have been developed.

Conclusions: The set of integrated and theoretically bound choices developed, are proposed as standards for an Inclusive Social-Emotional Learning both in skills description, activities development and learning assessment with primary school students. Examples of effective activities developed will be also discussed.

A research-based visual arts curriculum for young students with cognitive disabilities in Singapore

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Background: Visual arts in education for children with an intellectual disability remains fraught with confusion about curricular directions. This study presents the findings of a two-year engagement with a special education school in Singapore in developing a visual arts curriculum.

Method: Two young students from 7 to 12, with varying levels of intellectual disabilities and cultural backgrounds, took part. The analysis used a scale of seven dimensions: art knowledge (using art elements), art skills (use of materials), attitude towards art (e.g. curiosity), communication, creativity, critical thinking and collaboration.

Results: This study to investigated artistic engagement, pedagogical issues, and possibilities beyond the constraints of learning offered by standardized assessment. Details of the artworks and examples of engagement provided an understanding of the variance in artistic and aesthetic expression. Irrespective of expression, regular opportunities for exploration, revealed high engagement and independence with materials across all students. Students recognized the visual arts as opportunities for creative exploration, communication and accessibility to friendships.

Conclusions: Researching individual engagement provided a baseline for the development of a meaningful individualized art curriculum. The content of this curriculum allows exploration and prepares students for personal fulfilment and constructively contributes to personal development.

Life skills or academic skills for students with intellectual disabilities: Parents' perspectives in Saudi Arabia

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Background: It is important to understand family members' observations and opinions with regards to the programs offered to their children with intellectual disabilities. This study aimed to examine the outcomes of special education programs for students with intellectual disabilities from the families' perspectives.

Method: The study sample comprised 150 family members of students with intellectual disabilities. The results showed that the progress in both academic and life skills was less than expected.

Results: Satisfaction was higher in public schools in comparison with private schools. Participants with children enrolled for a longer time in special education programs expressed significantly less dissatisfaction than those with children enrolled for shorter lengths of time in such programs.

Conclusions: The findings suggest the need for more involvement of family members in their children's educational future, and for more focus to improve students' life skills. Implications and recommendations to increase the families' satisfaction in regards the special education programs will be discussed.

Social entrepreneurship training for persons with developmental disabilities

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Background: Skill training is very important to fulfil the mission of inclusion of persons with disabilities, to enable them to earn a livelihood and lead a life of dignity in society, and in turn to contribute to growing economy of the country. Entrepreneurship is an employment strategy that can lead to economic self-sufficiency for people with disabilities. The present study intends to find out the issues and challenges in the effective social entrepreneurship training for persons with developmental disabilities in special set-ups and inclusive set-ups.

Methods: The study will follow a mixed method of survey and generate the data from 30 entrepreneur training centres for persons with developmental disabilities across India. The participants will be administrator of the centre, supervisors, employers and parents of persons with developmental disabilities selected through a purposive non-probability sampling procedure.

Results: The study results will depict guidelines for professionals in the disability rehabilitation field to effectively train persons with developmental disabilities and empower them through entrepreneurial skill development.

Conclusions: The outcome of the study will contribute to strengthen and suggest a road map for imparting entrepreneurial education framework for persons with developmental disabilities.

Attitudes to parenthood in youth with intellectual disabilities: Intervention as a means for informed choices

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Background: The aim of our study was to investigate the attitudes to future parenthood in youth with intellectual disabilities before and after an intervention in special upper schools.

Methods: This is a controlled intervention study, with inclusion of new students in autumn each year for three consecutive years. Participants (n=107) were students with mild or moderate intellectual disabilities, aged 16 to 20 years old, with informed consent. Data were collected before and after the intervention. The Infant Simulator Attitude Scale (ISA) was used to measure attitudes concerning future parenthood. The intervention included a combination of 13 weekly theoretical lessons and practical care with the RCB simulator during three days. The theoretical lessons were held at school once a week using the Toolkit "Children—what does that involve?" (ASVZ). The practical care endured a three day and night caring session with the RCB simulator at home.

Results: Preliminary data shows no significant differences but some change in attitudes were discovered.

Conclusions: Possibly the instrument was not optimal for this purpose. However, the results indicate that the intervention can change attitudes and thereby give insights and help youth with ID to make informed choices about adult life and of parenthood.

Early numeracy profiles in young children with intellectual disabilities: Acluster analytic approach

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Background: This study aimed to identify the different profiles of early numeracy (EN) skills in young children with moderate intellectual disabilities.

Method: We assessed early numeracy through Utrecht Early Numeracy Test (ENT) and learning aptitude through Detroit Test (DTLA-P:3), in a sample of N=155 children diagnosed with intellectual disabilities, enrolled in special school classes, mentally aged between *5;02 (y;m) and 6;10* ($M = 5.11, SD = 0.974$).

Results: Two-step cluster analysis, identified four homogenous group of children with distinct EN profiles, C1: fluent in relational and numerical skills up to 20 (27,1%), C2: fluent relational skills and numerical skills up to 10 (27,1%), C3: fluent in relational skills and inconsistent numerical skills up to 10 (27,1%) and C4: inconsistent relational skills and numerical skills up to 10 (18,7%). Differences within clusters were also identified for word, digit and object sequences, symbolic relations, sentence imitation, picture identification, motor directions, conceptual matching and design reproduction.

Conclusions: Despite the fact that the population of young children with moderate intellectual disabilities is heterogeneous in terms of their EN skills, we can observe that conceptual knowledge of number is better established than procedural knowledge in all clusters. Results are discussed for their educational implications.

Use of response cards to increase engagement of students with intellectual disabilities in inclusive math class

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Background: Classroom teachers have the responsibility to find methods to teach all students, including students with intellectual disability, to provide meaningful access to general curriculum in the current educational climate. The purpose of the current study is to evaluate the effects of teacher implemented pre-printed response cards on participation and correct responding of four students with mild to moderate intellectual disability during group instruction in elementary inclusive math class.

Method: A single subject design was used to demonstrate a functional relationship between the use of response cards in math lessons and the dependent variable, which is participation and correct response to teacher-posed questions. Specifically, the design was an ABAB reversal design.

Results: The efficacy of response cards on participation and correct response to teacher-posed questions of four elementary students with an inclusive math class was evaluated. Results showed that response cards produced large increase in correct responding during classroom instruction compared to traditional classroom teaching.

Conclusions: This study provided evidence to support that students with intellectual disabilities can be successfully included in general education classes by providing appropriate differentiation for their active engagement and involvement in classroom activities.

Discussion and narrative through gesture and sign for teenagers with intellectual disabilities

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Background: Teenagers with intellectual disabilities need to be able to: to recall and share experiences, self-advocate to discuss and debate issues. These skills prepare them for adult life. Research shows that sign and gesture can promote discourse and narrative if opportunities are provided. The aim of this study was to explore the affordances of gesture and signing in promoting discussion and self-assertion with young people with severe verbal communication difficulties.

Method: A teacher and speech and language therapist ran a weekly 30-minute session over a six-month period with four pupils with severe intellectual disabilities whose speech was unintelligible, but who were frequent users of key word signing. These sessions were loosely structured around the idea of voting, exploring the fundamentals of democratic processes – preferences, choices, reasons, voting, ranking. Sessions were videoed, transcribed and analysed to see how the manual modality was exploited as the students developed and communicated their ideas.

Results: Analysis of apparently simple behaviours revealed complex connections, developing concepts, and inclusive discursive interactions.

Conclusions: The teaching of sign tends to focus on vocabulary acquisition. This study showed that close observation of young people's use of their communicative resources enabled their teachers to recognise their potential and capacity for debate and self expression.

Promoting school inclusion through imagined intergroup contact among elementary school children

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Background: The presentation will describe two studies to promote positive attitudes toward peers with disabilities. In the first study, we tested the role of information about peers with disabilities (cognitive intervention), independently or paired with imagined contact (behavioral intervention). In the second study, we tested the effectiveness of the combined intervention (information and imagined contact) to promote positive social interactions between students with and without disabilities.

Methods: In the first study, a pre- post-test experimental study with four conditions was designed. Participants were 142 children, with a mean age of 9.87 years. Measures of attitudes, stereotypes and feelings towards, and intentions to engage in contact with peers with disabilities were administered. In the second study, a pre-post test experimental study with 190 children (Mean age = 9.87) randomly assigned to two conditions was designed. Peer sociometric nominations and direct observations of social behaviors were used.

Results: The first study revealed that the combined intervention had stronger effects on all outcome variables. The second study found that students with disabilities in the experimental groups improved their peer sociometric status and social interactions with classmates.

Conclusions: The two studies highlighted the potential of the intervention to promote the school inclusion of students with disabilities

Experiences of autistic students in mainstream school settings

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Background: The aim was to investigate the effectiveness of inclusive education based on the educational experiences and on the conceptualisation of self for autistic students. Most of the research about the effectiveness of inclusive education for autistic students has focused on the detection of students' educational outcomes and on the attainment of parents' and professionals' views and attitudes (Goodall & MacKenzie, 2018). Only a small proportion of studies have explored the experiences of students themselves and how their experiences could influence the way that they conceptualise themselves.

Method: Semi-structured interviews were conducted with six autistic students having experience of mainstream schools in England. Interpretative Phenomenological Analysis (IPA) was used to analyse the transcripts of the recorded interviews.

Results: Three themes emerged: a) "Identity formation"; b) "Invisible needs"; and c) "How to survive in mainstream education." Students mostly shared negative experiences and used negative terms to describe themselves. However, they negotiated their identity based on the acceptance they received, or not, from the school.

Conclusions: Teachers' and peers' knowledge and empathy regarding neurodiversity, and school's flexibility to meet participants' needs seemed to contribute to feelings of belonging and empowerment, as well as to a more positive experience of schooling.

My Career Story Universal: a life designing counseling for people with disabilities during COVID-19

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Background: My Career Story Universal (MCS-U; Savickas, 2019) is comprised of a self-guided autobiographical workbook designed to simulate career construction counseling in adults with disabilities.

Method: It was developed within the Life Design approach and contained a series of questions from the Career Construction Interview to elicit a life-career story. Reflecting on the answers to the questions promotes key life-design goals of adaptability, narratability, intentionality, and action. The study involved 20 young adults with intellectual disabilities with an average age of 25. The MCS-U workbook administration was conducted online during the COVID-19 epidemic.

Results: After describing its development and use, preliminary qualitative and quantitative analysis will be presented on the MCS-U. Specifically, it will describe how adults with a disability tend to describe the significant experiences over their lifetime. Their interests, desires, and resources to challenges of the current socio-cultural context and build a life design oriented towards the future were also analyzed.

Conclusions: The MCS shows some initial promise for self-guided career intervention to increase self-reflection, tell and enact the career stories of people with disabilities. Furthermore, the results highlight consistent forms of discrimination and prejudice toward people with disabilities, lack of employee training and education, and the importance of promoting inclusive and sustainable career paths.

"People are like apples, rotten or ripe": Experiences of students with autism in special education

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Background: There currently exists a highly topical debate regarding mainstream education versus special education. Special education has been shown to offer many benefits for autistic students yet, there is a limited amount of research which enables these students to have their experiences heard and understood.

Method: The current study aimed to explore how autistic students attending special schools make sense of their experiences and how they perceive themselves within special education. Through semi-structured interviews and an Interpretative Phenomenological Analysis approach, the experiences of six boys with autism was examined to reveal how they made sense of their experiences of special education as well as how they understood themselves in special education.

Results: Findings demonstrated that the students perceived special education as a place of acceptance, understanding and belonging. They also presented their perceptions of normality and how society can negatively impact upon them. Combined, these experiences assisted them with understanding their own identities and how others understand them.

Conclusions: The implications of these findings highlight the importance of research giving autistic individuals a voice and demonstrates, for educational provisions, that the environment which surrounds them is crucial for them developing a positive sense of self.

Prospective teachers' efficacy for inclusive practices in south India

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Background: Class teachers have impacts on the success of children with special education needs (SEN). In inclusive programmes, the teacher should possess sufficient skills and knowledge and a positive attitude towards students with SEN for a successful inclusion. The present study aims at exploring the perceived teacher efficacy for inclusive practices for including students with special needs in their classrooms among the student teachers in an integrated teacher training programme in an institute in South India.

Method: The method used is descriptive survey and simple random sampling was used to select the participants. A total of 241 prospective teachers who are students of four-year or six-year integrated teacher training programmes were recruited to respond to a researcher-created survey.

Results: The study reveals that 39.42% of prospective teachers had high teacher efficacy, 34.65% had medium teacher efficacy and 25.93% has low teacher efficacy for teaching students with special needs in their general education classroom settings.

Conclusions: The study also shows that that knowledge about inclusive education is a critical component that determines the efficacy of prospective teachers for teaching in inclusive settings.

Students with Down syndrome studying secondary maths: What is learnt?

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Background: This research aimed to investigate what is learnt by whom in inclusive secondary mathematics classrooms, from the perspective of the various roles in the context: teachers, teacher assistants, the students and the researchers themselves.

Method: This qualitative case study explored five secondary mathematics classrooms including students with Down syndrome over two years. Researchers worked in partnership with teaching staff to co-plan lessons with adjustments, and then lessons were observed using video recording, collection of learning artefacts, such as student work samples, and photographs.

Results: Inclusive mathematics education often focuses on the learning, or limitations of learning, of the students with intellectual disabilities. In this analysis, the focus was broader, with each group considered in turn. We found surprising learnings for each group: teachers were highly creative, though initially many oversimplified work for students with Down syndrome, teacher aides struggled with the content of the mathematics lessons and were inclined to over support learners, students were surprisingly diligent and focussed on learning mathematics, and the researchers discovered the methodological challenges of undertaking research in mathematics classrooms.

Conclusions: Policy and practice implications for each group give promise for improved inclusive education in secondary mathematics for students with Down syndrome.

Development of positive attitudes in mainstream teaching staff towards autistic students

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Background: The aim was to investigate the impact of autism awareness training on attitudes of mainstream teaching staff. The inclusion of autistic students in mainstream has become pertinent following changes to inclusion policy, however review of practice indicates that outcomes are dependent on positive attitudes of teachers.
Method: A repeated measures design was used to evaluate the impact of an autism awareness training based on the SPELL framework. Participants (n=42) were recruited from mainstream schools in Kent and South East England. Standardised measures were used to explore whether positive attitudes increased in relation to openness towards autistic students, attitudes towards inclusion, self-efficacy, perceived knowledge, and actual knowledge.
Results: Participants had high levels of openness and positive attitudes towards inclusion. Perceived knowledge and self-efficacy both increased significantly following the training and value was placed upon having the opportunity for training which gave an insight into autistic perspectives in relation to education.
Conclusions: As a pilot study, the results provide evidence of the importance of autism awareness training both in increasing positive attitudes and the value of having the SPELL framework to inform good practice. Further research is required to demonstrate generalisation and to establish consistent measures for attitudes.

Recruiting a Research Assistant with intellectual disabilities at a UK university: A case study

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Background: To present the process of recruiting a Research Assistant with intellectual disabilities at a university.
Method: A case study method is used to present the recruitment process from the perspectives of the Research Assistant who was hired, the line manager, and the human resources representative.
Results: One challenge was the university's centralised application process, which required high-level understanding of written language and navigation of a complex online platform. Close collaboration between the HR representative and line manager allowed the flexibility to provide alternative application routes and an Easy Read job description. Potential difficulties with the traditional interview format were addressed by sending candidates interview questions in advance and consulting with a member of the panel with intellectual disabilities about the format. The panel received 28 applications and interviewed three strong candidates, awarding the role to RKG, a co-author on this paper.
Conclusions: While much research into employment for people with intellectual disabilities focuses on developing candidates' skills, it is as important to ensure equality of opportunity by adapting application processes. This case study demonstrates that when adaptations are made, individuals with intellectual disabilities can demonstrate their capabilities and teams benefit from employing individuals with relevant experience and insight.

Effect of music instruction on phonological awareness and early literacy skills

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Background: Multiple studies and systematic reviews have shown that music instruction improves phonological awareness (PA) and early literacy skills in children, although findings vary. The study evaluated the effect of varying durations of music instruction exposure, over a single academic year, on PA and early literacy of young children.
Method: 42 participants (five- to seven-year-old children) were assessed with a test battery including PA, phonics, and pitch and rhythm discrimination at the beginning and end of the academic year. Based on the exposure to music instruction, participants were assigned to either a low- or high-exposure group. Additional analyses were conducted for 17 age-matched pairs and to compare participants who only received class music to those that received additional music instruction.
Results: Between-groups comparisons showed no significant difference after a single academic year of music instruction. Within-groups comparisons identified more PA improvements in the high-exposure group. Differences could potentially be a result of the high-exposure group's greater exposure to music instruction, although changes were not sufficient to result in significant between-group differences.
Conclusions: Exposure to music instruction for no less than one academic year, is required to conclusively evaluate the effect on PA and early literacy.

Employment of people with disabilities in the public sector using the integration protocol

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Background: The Netherlands and Belgium implement programmes to lift the percentage of jobs for persons with disabilities or chronic diseases in the public sector from less than 1% to 3% or more. Our presentation is on the practice of the compilation of an integration protocol (IP) by the Flemish public administration in 2007 and the Amsterdam public administration in 2017. The objective of an IP is to introduce sustainable measures that help persons with disabilities or chronic diseases work in the best possible circumstances. It is the key instrument of the Flemish and Amsterdam public administration in the organisation of supportive employment measures: In total 600 IPs have been compiled. In 2020 updates were made.

Method: The IP is prepared by the central expert on disabilities of the responsible unit. A meeting is held with the persons with disabilities or chronic diseases, the direct superior, HR employee and the expert. They agree on the measures for work in the best possible circumstances.

Results: Experiences are that more persons with disabilities or chronic diseases keep their jobs because an IP formalises concepts of reasonable accommodations.

Conclusions: IPs are accessible and useful in a variety of situations. Organisations tailor the content and process to their needs.

Developing a training course to teach research skills to people with intellectual disabilities

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Background: This project sought to investigate the feasibility and benefits for people with intellectual disabilities to learn about the research process and to gain research skills through a university-based course.

Method: An eight-session research training course for people with intellectual disabilities was developed and piloted at a university in London. The focus was on understanding the research process and gaining practical skills in collecting, analysing and presenting research data. Training methods were experimental, with an emphasis on learning by experience in a "fun" way.

Results: Ten people with intellectual disabilities completed the course, showing great enthusiasm and commitment. During the final sessions, students developed and conducted their own research projects, choosing "Employment" as their research topic. The training methods were well received. One year later, students reported an increase in confidence and new work opportunities, including four students gaining paid positions as co-researchers. This paper was co-authored by the tutors and eight of the course graduates.

Conclusions: Inclusive research is important, but in order for people with intellectual disabilities to become skilled researchers, they need to have access to adequate training opportunities. Funding should be made available for more such courses, in order to promote meaningful involvement in research.

The impacts of school closures on pupils with intellectual disabilities during the pandemic

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Background: The aim of this study is to examine the educational reality of pupils with intellectual disabilities during the closure of schools in Bavaria in May 2020. Two aspects are of particular interest: 1) How was teaching being delivered? and 2) How did teachers evaluate the situation of their pupils at home?

Method: 391 special education teachers from 89 private schools for pupils with intellectual disabilities responded to our online survey. Some parallels to a study of the "Deutsches Schulportal" allow comparisons with teachers in regular schools. Additional questions with an open format were analysed via content analysis and revealed further insights.

Results: Teachers see gains in communication with parents and in the area of digitisation. Restrictions on social contact with peers is often seen as problematic for pupils with intellectual disabilities. Pupils' lack of communication with their teachers, which is held representatively by their parents, marks another negative effect.

Conclusions: The discussion of this very special situation as a disruptive innovation implies possible perspectives for the education and teaching of pupils with intellectual disabilities, reaching beyond the Coronavirus crisis.

Online learning and mentoring for people with intellectual disability at university during COVID-19

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Background: The aim of this research project was to explore the experiences of university students with intellectual disabilities and their peer mentors who have transitioned from face-to-face learning/mentoring to online during COVID-19. Facilitators and barriers to successful online learning/mentoring will be discussed.

Method: This study used a qualitative phenomenological design with thematic and discourse analysis. Resilience theory was used to interpret data. We used convenience sampling for interviews ($N=5$) with program coordinator, students with intellectual disabilities, and peer mentors. We also examined weekly written reports and reflections of mentors ($N=4$).

Results: Participants experienced positives and challenges. Participants developed new technology skills. However, they also reported needing additional support, and missing the face-to-face contact. The program coordinator reported initial doubts about the online mode and also identified the importance of at-home support. The experience opened opportunities for increased flexibility.

Conclusions: Online modes of learning/mentoring for people with intellectual disabilities at university during COVID-19 ensured continuation of the important form of social inclusion and education during the pandemic. The experiences reported will contribute to the limited

evidence and practice recommendations for online learning/mentoring for adults with intellectual disabilities and peer mentors at university.

Professional development opportunities in protected employment settings for people with intellectual and developmental disabilities

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Background: Employment is stated as a key factor for the inclusion of people with intellectual and developmental disabilities, and for their independency and self-sufficiency (Nord et al., 2013), but the excessive protective laws from some European countries have been reported to affect the employment conditions of those workers (WHO, 2011). The study explores the design of the protected employment systems of two regions, Catalonia and Denmark. The goal is to understand how both systems are created, and to identify which elements are acting as facilitators or barriers for the professional development of their employees.
Method: Document analysis and semi-structured interviews with government employees and disability organisation leaders were conducted to analyse both systems.
Results: Despite being developed from different political traditions, both employment systems have barriers affecting the professional development options of their employees.
Conclusions: The employment systems are designed from a medical view of disability, in which the need to classify the employee according to their needs affects their professional and personal development.

Sound field amplification and improved classroom performance in students on the autism spectrum

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Background: To determine whether use of sound field amplification (SFA) systems improves classroom performance in students with autism spectrum disorder.
Method: 38 classroom-, gender- and age-matched Year 3 students with and without autism, across 15 classrooms from 11 Greater Brisbane region primary schools participated in this cross-over study. Following a baseline IQ, oral language, hearing and autism screening, repeated outcome measures including academic abilities (KTEA-3), auditory memory (TAPS), auditory attention (ATOVA), and auditory processing (CTOPP) were used, assessing whole-of-semester SFA exposure.
Results: For TAPS as dependent variable, autism spectrum disorder, test number, and three-way interaction were significant. The main effect of autism was significant ($p<0.001$, chi2 12.29, 1df), as was test number ($p<0.01$, chi2 11.69, 2df). Compared to baseline, performance was 1.04 points higher for test two, 95% CI(0.29, 1.80), and 1.34 higher for test three, 95% CI(0.57, 2.12). Three-way interaction between ASD, order and test number was significant ($p<.0001$, chi2 14.80, 2df). Finally, a post hoc power analysis for CTOPP and TAPS outcomes revealed power greater than 0.80 for test number.
Conclusions: SFA use can improve student auditory processing and auditory memory functioning, using low-cost, non-invasive whole-of-class technology. Future research should consider prolonged exposure to an increased number of participants.

Practical proposals for inclusive mathematics

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Background: Mathematics education for children with intellectual disabilities is an issue of great concern for teachers and practitioners. Our goal is to contribute to teaching practice by overcoming the common focus on learning disabilities and the limited goal of achieving simple uses of numbers. We show, in turn, how to put into play the potential of mathematics in their development and maturation.
Method: We have designed a proposal for practical activities related mostly to geometry, achievable in a school, after-school or leisure and family environment. We have been testing these activities for six years in a mathematics workshop for children with trisomy 21 in Spain.
Results: These activities suggest a path to introduce a vision of *mathematics that includes* since it involves everyone by being presented as a succession of small challenges that will cause pleasure, surprise, and joy.
Conclusions: The proposal has proven to be effective for 1) giving confidence to teachers and parents that work with children who show a delay in language, understanding, and relationship with the environment 2) contributing to a change of perspective in didactics of mathematics, moving teachers from a vision of mathematics as only suitable for the best students to an inclusive view.

Comparison of executive functions in students with intellectual disabilities and deaf and hard-of-hearing students

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Background: Executive functions (EF) comprise a set of higher cognitive processes. They guide and regulate the interaction of attentional and memory processes and are thus understood as cognitive control functions. This includes the abilities to inhibit impulsive reactions, to flexibly change the focus of attention, to keep information mentally present in working memory, and to plan action steps. EF therefore play a central role in successful learning and problem-solving. While the importance of executive functions has been extensively researched in people without disabilities, there are still considerable research gaps in the area of people with disabilities.

Method: In the study, the EF of three groups are investigated: students with intellectual disabilities, deaf and hard-of-hearing students, and deaf and hard-of-hearing students with intellectual disabilities. The age range of the subjects is 8-10 years. Each group consist of 50 students.

Results/Conclusions: The differences between the groups allow assumptions on relative strengths and weaknesses, from which important insights for schooling can be extracted. The Behavior Rating Inventory of Executive Function (BRIEF) (Gioia, Isquith, Guy & Kenworthy) is used in a German translation (Drechsler & Steinhausen, 2013) and the Communicative Competence Indicator (Hintermair, 2012). In addition, the physical fitness of the test persons is assessed.

Communication and AAC in schools for students with intellectual disability in Sweden

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Background: The present study aims to explore communication patterns and Augmentative and Alternative Communication (AAC) practice in the Compulsory School for Students with Intellectual Disabilities (CSSID) in Sweden.

Method: Students ($n = 33$, aged 6–12) and staff members ($n = 30$) from seven CSSIDs participated. Video observations were conducted during naturally occurring group activities; circle time and leisure time in the classroom. A coding scheme was used to analyze students' and staff's communicative contributions and modes. Student communicative participation was assessed by the staff, using the Communication Supports Inventory – Children and Youth (CSI-CY).

Results: Strengths in student communication, according to staff, were receptive language and AAC, and functions of communication. The greatest restrictions were found in literacy skills. Students made fewer initiations and responses than staff members. Staff used more speech, manual signs, and pointing than the students.

Conclusions: Communication and AAC practice in the Swedish CSSID has not previously been the focus of systematic research. However, in 2010, a quality inspection revealed that students' communication needs were not met to an acceptable degree. The current study will consequently contribute to knowledge within this area and propose future research topics and interventions concerning communication within the CSSID in Sweden.

Participation for students with intellectual (and multiple) disabilities needs digital education

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Background: Digitalisation is currently one of the key topics in our society but access for persons with intellectual and multiple disabilities is still challenging. The research project focuses on the perspectives of students with intellectual (and multiple) disabilities and their teachers. Two goals are being pursued: At first insights into existing concepts, experiences, needs and requirements are to be generated on the basis of empirical data; second starting points for the development of methods and access possibilities for educational offers in this context are subsequently analyzed.

Method: In the project, different methods are used, which go along with three different samples: expert interviews with school media coordinators (N=8), qualitative online survey with teachers from 14 schools (N=215), and interviews with students with intellectual (and multiple) disabilities (N=tba).

Results: In addition to the challenges resulting from the lack of technical equipment in schools and the partially low digital competences of staff and students, there is a particular lack of concepts, methods and didactic approaches to digital education for students with intellectual (and multiple) disabilities.

Conclusions: The findings of the research project will lead to the expansion and development of digital education offerings for students with intellectual (and multiple) disabilities and thus make a significant contribution to digital participation.

Difficulties working with students who have special educational needs: From a severe disabilities perspective

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Background: A teacher has an accumulation of knowledge, skills and insight, and provides support that plays a critical role in student learning and achievement. I wanted to identify the characteristics of those who teach and care for students with special educational needs in different types of schools. I aimed to discover whether a teacher's emotional intelligence and social competence affected the difficulties they experienced working with students who had different types of special educational needs.

Method: The research comprised of teachers working with special educational needs students: 55 supporting teachers, 51 mainstream school teachers, and 52 special school teachers working with those with intellectual disabilities and autism. The data was collected using a questionnaire, the Two-dimensional Emotional Intelligence Inventory (DINEMO) and the Social Competence Questionnaire.

Results: The findings highlighted differences in social competences only in the case of working with children with moderate and severe intellectual disability, moderate and moderately severe hearing impairment, chronic illness and mental illnesses. Difficulties declared by teachers working with certain types of special educational needs students may be related to their level of emotional intelligence or social competences.

Conclusions: Teachers' characteristics were found to be strongly influenced by the nature and severity of students' special educational needs, and less by teacher-related variables.

People with intellectual disabilities at the university: An inclusive programme

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Background: The Convention on the Rights of Persons with Disabilities (UN, 2006) establishes the right of all persons with disabilities to a higher education, and the obligation to guarantee the necessary support for their formative development. We aim to describe the evaluation of an inclusive experience developed at the University of Girona in which people with intellectual disabilities (ID) learnt together with undergraduate students.

Method: The evaluation of the *Diploma in basic competences for socio-labour inclusion* was developed through data collection during the initial moments, the development and at the end, using interviews, focus groups and questionnaires, as well as systematic observations. Data was analysed through thematic content analysis.

Results: University professors increased their awareness of disability and improved their teaching skills. Students with intellectual disabilities had the opportunity to continue their academic training and to actively participate in the university community. Students without disabilities approached their future work environment in a practical, experiential and natural way.

Conclusions: Such experiences raised the inclusion level at the university and promoted the social inclusion of people with intellectual disabilities. Higher education institutions should promote and facilitate the inclusion of people with intellectual disabilities.

Effects of video prompting for students with intellectual disabilities in an employment setting

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Background: This study aimed to evaluate the effects of a video prompting (VP) on waitering skills of two high school students with intellectual disabilities.

Method: A multiple probe design across behaviors was used in the community employment setting. Greeting and guiding the customer, cleaning up the table, and taking orders were the target behaviors. During the baseline phase, the participants were asked to perform target behaviors without any assistance from the job coach or video prompts. During the intervention phase, the participants watched the video and performed them. If they made an error, they were asked to watch the video again and corrected. If they failed to correct the error, the job coach taught them to complete the skills using least-to-most prompts.

Results: Results indicated that VP was effective in teaching waitering skills in a community employment setting. Both participants maintained the skills during the four-week follow-up.

Conclusions: These findings suggest that VP can be one of the effective means to teach waitering skills in community employment settings. Considering the strong evidence of positive effects of VP, it seems that this intervention can improve secondary education outcomes for students with intellectual disabilities.

Advancing employment for adults with intellectual disability in a context of crisis and instability

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Background: The study aims to investigate the social policies, dynamics and actors that advance employment for persons with intellectual disabilities, in a context of multilayered crises, high instability and non-ratification of the Convention on the Rights of Persons with Disabilities (UN CRPD). It uses the case of Lebanon, which has witnessed in 2020 an unparalleled socio-economic crisis exacerbated by the Covid-19 pandemic, heightened political instability and a humanitarian disaster after the Beirut explosion.

Method: Methods include a comprehensive review of the literature on labor laws and disability rights in Lebanon, and key informant interviews with self-advocates, activists and policy stakeholders.

Results: Legislation in Lebanon adopts an outdated medical view of persons with intellectual disabilities, using a charity discourse not recognizing their contribution to economic development. Alternatively, non-state actors and community-based initiatives have had a significant role in pushing for the employment of persons with intellectual disabilities. Implications on social policy development and practice will be discussed.

Conclusions: In a context of crises and non-ratification of the UN CRPD, learning from community experiences helps guide advocacy towards a comprehensive disability rights policy agenda. The relevance of UN CRPD Article 27 in highly unstable contexts where disability rights are not state-protected is discussed.

Informal network members' perspectives on work participation of people with intellectual disabilities: A systematic review

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Background: Participation in employment or meaningful daytime activities is considered an important element of quality of life for

people with intellectual disabilities. Informal network members, often an essential recourse in the lives of people with intellectual disabilities, might impact the successful work participation of their relatives or friends. Therefore, this systematic review aimed to examine the perspectives of informal network members of people with intellectual disabilities on participation in employment or daytime activities by people with intellectual disabilities.

Methods: A mixed-method systematic review was conducted, using PRISMA guidelines. Four electronic databases (Embase, Medline, PsychInfo & Web of Science) were systematically searched for empirical articles published in English between 1990 and 2020.

Results: The search identified 5000 titles. Of these, 22+ articles met the inclusion criteria. The majority (n = 16) of the studies were qualitative in nature and focused on the perspectives of parents of people with intellectual disabilities.

Conclusions: Enhanced scientific knowledge about the perspectives of informal network members on the work participation of people with intellectual disabilities provides valuable information on how informal network members could contribute to successful and sustainable participation in meaningful employment and daytime activities of their relatives and friends.

University student experiences of being taught and assessed by adults with intellectual disabilities

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Background: From 2016-17, academics at an Irish university collaborated with self-advocates with intellectual disabilities to co-design, co-deliver, and co-assess a disability module for third-year undergraduate social work students. Our group also conducted inclusive research regarding different stakeholders' experiences of the initiative. In this presentation, one of the self-advocates and one of the academics aim to present and discuss university students' experiences.

Methods: The study used a qualitative research framework and an inclusive research approach, which involved academics and self-advocates working together as co-researchers. Data regarding students' experiences was collected through anonymous questionnaires and focus groups and analysed thematically.

Findings: Students experienced some initial feelings of awkwardness around disability in addition to some anxiety at the prospect of being assessed by adults with intellectual disabilities. However, these feelings were transitory, and overall, participants described overwhelmingly positive experiences. Reported benefits included increased comfort around disability and greater empathy with people with disabilities.

Conclusions: There are few, if any, reports from inclusive research on collaboration in tertiary education in the existing literature. Consequently, we feel it is significant to report that initiatives like this can work and be very popular. We also hope our findings might encourage similar initiatives in other universities.

Ambitious career goals for people with intellectual disabilities: The sky's the limit

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Background: This research aims to determine whether fulfilling employment for a young man with Down syndrome can be created by designing a social enterprise in a way that is initially concerned with personal ideals, and only secondarily considers financial viability.

Method: When transitioning to adulthood, Fionn determined that standard post-secondary disability supports in Ireland would not help him make meaningful contributions to society, and he looked for a job. A journey of inquiry, aided by his father Jonathan, taught him that potential employers saw him only as an opportunity to show charity, offering jobs with low responsibility, low wages, and little chance of advancement.

Results/Conclusions: By creating a son and father social enterprise, their action research led to multiple collaborations, grants and sponsorships. In the following six years, Fionn and Jonathan (Fionnathan Productions) have taught nature workshops to over a thousand school children, lectured at 28 universities and colleges, and created social media with hundreds of thousands of online engagements. Their work has brought them around the world, from the Amazon to Zanzibar. Additionally, they are developing a program for families and allies to assist people with intellectual disabilities to achieve their career dreams, having so far consulted with 30 families.

Has the online teaching response to Covid-19 resulted in a more inclusive higher education system?

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Background: With the onset of Covid-19, traditional approaches to teaching and assessment were challenged. Higher education institutes around the world had to respond rapidly and adapt to the virtual classroom. Anecdotal evidence suggests that the Covid-19 pandemic led to an increased need and enthusiasm among tertiary educators to mainstream inclusive practice, grounded in the principles of Universal Design for Learning (UDL). However, little is understood regarding how teaching staff were positioned to respond to, and implement UDL during this rapid shift to online learning.

Method: This Centre for Disability Studies (CDS) study builds on and provides comparative data to previous surveys conducted by the Australian Disability Clearinghouse on Education and Training (ADCET) and the National Disability Coordination Officer (NDCO) Program, which captured insights from disability practitioners and students with disability.

Results: The CDS survey circulated to Australian Universities captures the academic and teaching voice to better understand the enthusiasm or appetite for UDL and inclusive design and practice, as well as current knowledge of and confidence in its implementation.
Conclusions: The implications of a university-wide approach to UDL for students with intellectual disability and/or autism at the tertiary level will also be discussed. International comparison will be provided where applicable.

Co-creation for work inclusion for adults with intellectual and developmental disabilities: Preliminary results from focus groups interviews

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Background: The study addresses work inclusion of people with intellectual and developmental disabilities. The aims of the study were to explore the impact of competence development on attitudes towards employment possibilities for adults with intellectual and developmental disabilities among decision-makers and caregivers, and to investigate how tailored job development through the Supported Employment model gives access to ordinary jobs for people with intellectual and developmental disabilities. Overall, the study contributes to the implementation of Supported Employment for people with intellectual and developmental disabilities.
Method: The study is qualitative and action-focused, using tools and platforms for co-creation and mutual innovation and learning. A focus group interview with several decisionmakers, caregivers, managers and professionals from the Public Employment Service was conducted. The interview was recorded and transcribed.
Results: Increased understanding and awareness of the importance of employment and job development for people with intellectual and developmental disabilities.
Conclusions: Our material suggests that it is possible to strengthen the employment perspective by 1) Challenging preconceptions, 2) Making stepwise changes in procedures, and 3) Trying out and reflect on new experiences. The study will result in more people with intellectual and developmental disabilities becoming employees; this will have both individual and social impact in the long term.

POSTER PRESENTATIONS

Simulated role play to facilitate Intellectual disabilities and autism awareness training

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Background: The English National Health Service (NHS) has introduced mandatory training for all health and social care provider aimed at improving outcomes of health and social care interventions for people with intellectual disabilities, and those with autism spectrum conditions (Department of Health and Social Care, 2019a, 2019b). We report findings from a pilot study in which people with intellectual disabilities were involved in simulated learning sessions with pre-registration nursing students (n = 12).
Method: A simulated session was piloted to determine its effectiveness in introducing pre-registration nursing students to care for people with intellectual disabilities and/or autism spectrum conditions. A post-session questionnaire was administered one weeks after the session, allowing the students time to reflect on their learning. The questionnaire had two sections. The first section consisted of six questions. These questions were divided into three themes. These included questions related to the content of the session (n=2), questions related to the students understanding (n=3), and question-related on the impact on practice (n=1). The second section consisted of eight questions related to students' experiences and perceptions about people with intellectual disabilities facilitating the session.
Results: Six themes emerged: importance of using real-life scenarios to education, importance of enhanced communication skills, importance of assessment skills in assessing the needs of patients with intellectual disabilities, importance of shared decision making, linking theory to practice, and making reasonable adjustments when working with people with intellectual disabilities.
Conclusions: The involvement of people with intellectual disabilities in simulated learning provides an opportunity for developing the knowledge and skills of health and social care professionals. This will improve healthcare experiences and outcomes for people with intellectual disabilities. Health and social professional regulators, and educators need to ensure active involvement of people with intellectual disabilities in delivering learning to health and social care professionals.

How a year 7 student with autism spectrum disorder and learning disabilities developed self-advocacy skills through an educational program

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Background: This study investigated how a 7th year male student developed self-advocacy skills (SAS) via an educational program and obtained support at school.
Method: The student was diagnosed with autistic spectrum disorders and learning disabilities. He joined a self-advocacy program, which focused on self-understanding and asking for help. He took one to two monthly 60-minute laboratory session(s). The program consisted of free talk, worksheets about self-understanding, and games requiring social skills. All 15 sessions used a narrative approach and transcripts were created. The contents were analyzed by four average staff using the KJ method. The viewpoints were self-understanding,

understanding others and communication. The student's self-evaluations were also analyzed.

Results: In early sessions, he could not describe himself or others. The staff admired his strengths, encouraged talking through many interactive activities. He gradually improved self-expression and began describing his friends. Consequently, he got additional support in regular classes with his mother's help. He gained some SAS but not asking skills.

Conclusions: Students who don't perform well often blame themselves. SAS is helpful for such students. Teaching SAS is important when reasonable accommodation is arranged, and new courses of study require it. This program would also be helpful for teachers to teach SAS.

Middle school inclusion for students with intellectual disabilities: Parental perspectives and experiences

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Background: Inclusive education is the most appropriate and equitable choice for supporting the education of diverse learners. Many countries, including the province of Nova Scotia, Canada, has adopted these principles. Additionally, inclusive education is a commitment to ensuring high quality, culturally responsive and equitable education to support the well-being and achievement of every student, regardless of ability. This research project aimed to explore the middle-school experiences of students with intellectual disabilities, and more specifically, students with Down syndrome.

Method: A basic qualitative research study was conducted, which investigated parental perspectives and inclusive education experiences of students with Down syndrome within the middle school level of the public school system. Semi-structured interviews were conducted with participants and a thematic approach was employed to analyze the collected data.

Results: Results suggested students with Down syndrome were educated within both a general classroom and Learning Center environment, with limited access to grade-level curriculum, had restricted peer socialization opportunities and that limited communication between home and school existed.

Conclusions: Recommendations for future study included promoting communication with parents, ensuring self-advocacy opportunities exist, and developing peer relationship-building opportunities to foster belongingness at school.

Systematic review of graphic organizer interventions for students with autism spectrum disorders

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Background: Extensive research is actively being carried out for supporting the academic achievement of students with autism spectrum disabilities. The purpose of this review is to examine the trend of graphic organizer (GO) intervention for this population and to discuss the possibilities of using this intervention for promoting inclusive teaching for all students.

Method: In this research, a total of 30 studies of GO interventions for students with autism spectrum disorders from 2010 to 2020 were selected for the analysis of variables and quality levels. Inclusion criteria, exclusion criteria, coding variables and the quality indicators were indicated.

Results: Findings suggest that GO interventions have increased the academic achievement of the students across various subjects, instructions and ages, demonstrating an evidence-based practice. However, the interventions were not mainly conducted in the general education classroom but in the separated setting as one-to-one lessons.

Conclusions: The effective GO package components or intervention method were discussed in the perspective of Universal Design for Learning (UDL). Findings carry implications for the expansion of the research scope and inclusive teaching for all students.

Innovative vocational training using virtual reality for individuals with intellectual disability

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Background: Access to interesting and skill-based employment can be limited for individuals living with intellectual disability. Vocational training to build capacity and job skills can be time consuming, expensive and rely heavily on one-to-one training and supervision.

Method: This presentation outlines a project using virtual reality (VR) to build capacity, independence, and vocational skills to increase job readiness and vocational opportunities for people living with a disability in Australian Disability Enterprises. VR simulations have been created through collaboration between Orana an employer, neuropsychologists and IT engineers from UniSA around developing food handling and recycling skills.

Results: The project is providing learners with an opportunity to practise skills at their own pace in a safe and repeatable virtual environment in order to increase competency, work-readiness, and confidence to reduce reliance on supervisors. The VR training program will increase learners' potential to reach open employment and create pathways from their day options programs. The project is being implemented in three urban and two regional Disability Services in South Australia through a collaboration with Orana and University of South Australia.

Conclusions: This presentation will present findings and experiences to date as outcomes of this project could be on international relevance.

Parents' perspectives on pedagogical transitions and educational situations of students with mild intellectual disabilities

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Background: The goal of the Swedish educational system is to offer all students a meaningful and equal education in an inclusive classroom environment. At the same time, there are parallel school systems in Sweden, comprised of the Compulsory School for Students with Intellectual Disability (CSSID) and Compulsory School (CS). The aim of this study was to explore parents' perspectives about their children's pedagogical transitions and educational situation over time.

Method: The data constitutes of six interviews with parents of students with mild intellectual disability. All interviews were inductively analyzed using thematic analysis.

Results: Three master themes were summarised: 1) Uncertainty and worries, 2) Process and interactions, and 3) The novel situation.

Conclusions: The transition from CS to CSSID requires a readjustment for parents, and they express the need for support from professionals in these transitions. The change for the children could be to meet new knowledge requirements and for parents to find new forms of interaction between home and school. For children and parents, the ability to face change was made visible: for example, trust in teachers was affected. In order to create a functioning everyday life, actors at different levels need to collaborate.

Inclusive campus life: A framework and monitoring instrument

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Background: In the pursuit of making university campuses inclusive to people with intellectual disability, a framework and monitoring instrument was developed.

Method: A design research method was applied. Such research is driven by the desire to solve field problems, working from the perspective of the practitioners dealing with these field problems. As such, this research method is mainly solution-oriented and initially strives for pragmatic validity. The practitioners in this project consisted of lecturers and management staff at schools of social work at universities in Finland, Czech Republic, Belgium and the Netherlands.

Results: A framework and monitoring instrument that proves useful for institutions of higher education to bring about inclusion of people with mild intellectual disabilities.

Conclusions: The framework and monitoring instrument is rendered applicable for any university campus in any country, irrespective of laws and regulations. The framework and monitoring instrument transcends such concerns. If applied properly, i.e., with genuine and valued involvement of people with a mild intellectual disability, we can consider it an inclusive instrument.

An autism narrative inquiry exploring engagement and inclusion in a secondary school

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Background: This project grew out of a recognition that students with autism spectrum disorders have both disabilities and abilities. This exploratory project's intention was to construct stories highlighting how students with autism spectrum disorders were using their strengths to engage in learning. It investigated what the students and their teachers viewed as barriers and facilitators affecting inclusion.

Method: A field study was conducted in a State Secondary School. Participants included students, parents and teachers. Interviews identified the student's strengths and their favourite subject. The researcher then carried out class observations and staff interviews. An interim research report was shared so that participants could review the data generated. Interviews and field notes were transcribed and reflexively analysed to identify themes. Computer software nVivo 12 was used to assist with the thematic analysis. A cross case comparison was completed. Video recordings were analysed using interpretative phenomenological analysis.

Results: Findings showed the significance place and people had on how a student used their strengths and abilities. Evidence emerged of the importance of the teacher's relationship with the participant. When this was effectively operating it enhanced engagement and inclusion.

Conclusions: The need to change how we deliver inclusion emerged. Places and people can disable or enable a student.

Teachers' perceptions about the inclusion of students with autism in Greek general school

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Background: The practice of inclusion faces a variety of problems. Given the fact that teachers play a key role in the course of inclusive education, the present study seeks to examine the perceptions of primary and special education teachers about the inclusion of students with autism in general school, as well as the factors that affect them (position, educational experience, training in autism, experience with students with autism).

Method: The research was conducted during the school year 2018/2019. The data were collected through questionnaires, which were distributed online to kindergarten teachers. The questionnaire used in this research consists of 32 closed-ended questions. The first part of the questionnaire presented here consists of nine questions and data are collected regarding demographic variables (gender, age), the speciality of teachers, the higher level of education, years of service, their specialization in special education in general, and in autism in particular, their experience in teaching students with autism and the existence of students with a personalized curriculum in their classrooms. The sample of the research consisted of 100 Primary Education teachers, 50 general and 50 special education, who taught in public Greek schools during the 2018-2019 school year.

Results: According to the statistical analysis of the data, teachers have neutral and positive perceptions on the subject, although they have a satisfactory level of knowledge about autism.

Conclusions: Their perceptions seem to be influenced by the position of responsibility they hold, while their educational experience does not have any effect on them. However, the specialization and knowledge of teachers in autism significantly affect their perceptions.

Violence and violence protection factors in residential homes and workshops from the perspective of people with intellectual disabilities and low and no functional speech

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Background: The risk of being a victim of an act of violence is particularly high among people with disabilities (Schröttle et al., 2012; Hughes et al., 2012). National research in Germany from Schröttle et al shows that one of the many reasons why perpetrators often choose vulnerable victims is that they cannot report violent acts. Building upon that, the study aims to conduct interviews with people with intellectual disabilities and low and o functional speech considering a variety of alternative and augmentative communication and easy-read questions; and investigate violence and violence protective factors in residential homes and workshops from the perspective of people with intellectual disabilities and low or no functional speech.

Method: We applied in-depth semi-structured interviews to 20 people with intellectual disabilities and low and no functional speech. Interviews were filmed. Data were analyzed by the content analysis with a particular focus on multimodal communication.

Results/Conclusions: Recommendations include: Needs-oriented adaptions of guidelines for conducting interviews with people with intellectual disabilities and low and no functional speech; communication aids to support people with intellectual disabilities and low and no functional speech to participate in an interview; learn more about violence and protective factors in residential homes.

Comparing the minimum celeration line and the beat your personal best goal-setting approaches during the mathematical practice of autistic students

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Background: This study compared two-goal setting approaches found in the precision teaching literature, namely the minimum celeration line and the personal best approach.

Method: An adapted alternating treatments design with a control condition was embedded in a concurrent multiple baseline across participants design during the mathematical practice of three male autistic students, aged 8 to 9. Each approach was randomly allocated to either the multiplication/division (x÷) table of 18 or 19, while no approach was allocated to the x÷14 table that acted as a control. Instruction utilized number families and consisted of (a) untimed practice, (b) frequency-building, (c) performance criteria, (d) graphing and (e) a token economy. Upon practice completion, an assessment of maintenance, endurance, stability, and application (MESA) was conducted.

Results: Participants improved with both conditions and maintained their performance well, while improvements with the control condition were weak. The personal best approach was highlighted as slightly more effective in terms of average performance and more efficient in terms of timings needed to achieve criterion. No differences were identified in terms of learning rate (i.e., celeration) or performance on the MESA.

Conclusions: More research is warranted to identify which goal-setting procedure is more appropriate for students in special education.

Providing students with intellectual disabilities a base for informed choice about future parenthood: Teachers' experiences

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Background: The study aimed to explore the experiences of teachers when implementing an intervention and providing students with intellectual disabilities a base for informed decisions about future parenthood at special upper secondary schools.

Method: Four focus groups interviews were conducted 2019–2020 with 16 teachers and school staff involved in the intervention at eight special schools. The intervention consisted of giving 13 lessons using the Toolkit “Children - what does it involve?” and the Real-Care-Baby (RCB). Students in groups (2–10 students) participated voluntary in the intervention.

Results: Preliminary results show that the organisational aspects, such as supportive principal and colleagues were a prerequisite to make time and space for the intervention at schools. Participants extended their teaching role in which a sense of social responsibility, dealing with ethical dilemmas and creating a deeper relationship with the students were important. The intervention was also influenced by the parents' attitudes towards parenting.

Conclusions: The intervention builds a bridge between theory and practice through using adapted didactic tools. The organisation of education requires a lot of planning and cooperation. The teachers and school staff give knowledge and support to youth with intellectual disabilities to make informed choices of adult life and of parenthood.

Online learning & COVID-19: Exploring experiences of Canadian adolescents with Down syndrome

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Background: COVID-19 has impacted the education delivery of students across the globe. Many students, especially those with intellectual disabilities, such as Down syndrome have experienced additional barriers. The pandemic has forced many schools to close temporarily and offer online platforms for education delivery.
Method: This qualitative study aimed to explore the online learning experiences of adolescents with DS who participated in a 16-week introductory online learning project. Participants included middle or high school students, with a diagnosis of Down syndrome who lived in an Atlantic Canadian province.
Results: Initial evidence collected revealed that students with Down syndrome received limited online learning opportunities or support from the public school system during COVID-19 and had received very little or no transition planning for changes in education program delivery. Additionally, it was noted that participants in the study gained independence and confidence for operating technology, demonstrated enhanced communication skills and displayed increased social skill development.
Conclusions: Although situated in Canada, the implications from this study may be readily applied to organizations engaged in online learning initiatives for students with Down syndrome across the globe.

The relation to writing of two students with autism spectrum disorder

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Background: To improve writing teaching practices for students with autism spectrum disorder in an inclusive education setting, it is instructive to examine writing difficulties from a strength-based perspective by augmenting their voice on writing. To do so, this study explores the relation to writing of teenagers with autism spectrum disorder.
Method: Writing activities of two 14-year-old students with autism spectrum disorder in inclusive settings and out of school were collected through ethnographic interviews (four per participant) and filmed observations in classes and home 12 hours and 45 minutes per participant) over six months. Qualitative analyses were performed and the data from both sources were cross-referenced.
Results: This study found a diversity of writing skills, shedding a different light on what might be considered writing difficulties for teenagers with autism spectrum disorder. It also identified what motivated the participants to engage positively in writing activities in a variety of contexts.
Conclusions: The findings underline the richness of information that we can collect by listening to the voices of students, highlighting levers of action to support student engagement in writing activities. Results also point to bridges that might be built between writing in various contexts and the importance of social interaction through writing.

A systematic review of music education studies and disability: Results, omissions and opportunities

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Background: Music training is touted as capable of delivering many benefits to learners. These benefits should be available to students with intellectual and developmental disabilities. However, a systematic review of the literature suggests that they are not.
Method: A systematic quantitative literature review searched music and education journals for original research that had investigated music education and intellectual and developmental disabilities. Studies that had described music's use and function in inclusive classrooms since 2000 were analysed.
Results: In music-education research, surprisingly few studies explore ordinary groups of children in inclusive classrooms. The results revealed that while children with intellectual and developmental disabilities are most likely present in regular classrooms, disability is rarely considered. When it is, it is almost always as a disability-specific study that fails to reveal insights into inclusive educational practices.
Conclusions: This systematic literature review has identified significant gaps in music education research which, in turn, impact the inclusion of students who have intellectual and developmental disabilities in mainstream music classes. Implications for both the inclusive music education of students with intellectual and developmental disabilities, and for reconceptualising future research, are considered.

Track 1b Aging/End of Life

PRESENTATIONS IN A SYMPOSIUM

Dementia in people with severe/profound intellectual disabilities

Dementia symptoms in persons with severe/profound intellectual disability: Expertise of practice

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Background: In people with severe or profound intellectual disabilities, it is difficult to diagnose dementia. As timely identification and diagnosis of dementia allows for a timely response to changing client wishes and needs, this study aims to examine symptoms, and diagnosis of dementia in practice.

Method: Family members and professionals were invited to fill out a survey about symptoms and diagnosis of dementia in people with severe or profound intellectual disabilities. Results of the survey were further explored within semi-structured interviews with professionals having experience with signaling and diagnosing dementia in these people. Symptoms found in the survey and transcripts of the interviews were qualitatively analyzed, using thematic analyses based on a developed symptom-matrix.

Results: The survey was filled out completely by 14 family members and 90 professionals with different backgrounds. Results showed that behavioral changes were recognized more frequently than cognitive decline. Compared to those without dementia, epilepsy and motor decline were more present in case of dementia. Fifteen interviews (until saturation) with professionals provided an in-depth view into the symptoms, and how to identify them, again stressing behavioral alterations and to a lesser extent cognitive symptoms.

Conclusions: Comprehensive results about specific symptoms will be presented during the congress.

Focus group research into relevance, symptoms and training needs

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Background: In people with severe or profound intellectual and multiple disabilities, it is difficult to differentiate dementia from their pre-existent baseline level of functioning. Moreover, studies on observable dementia symptoms are scarce. Therefore, this study examined the 1) relevance of dementia diagnosis in severe or profound intellectual disabilities, 2) observable symptoms and 3) training/information needs.

Method: Four explorative focus group sessions were held with 12 to 13 participants each (care professionals and family members) who had experience with people with severe or profound intellectual and multiple disabilities (≥40 years) and decline/dementia. Using thematic analysis, categories and (sub)themes were identified in the transcripts. To answer research question 2, symptoms mentioned were categorized using a symptom matrix.

Results: Thematic analysis showed that participants wanted to know about the diagnosis of dementia for a better understanding and to be able to make informed choices (question 1). Using a symptom matrix, cognitive and behavioral changes were shown to be the most prominent (question 2). Participants also indicated that they needed enhanced training, more knowledge development and translation, and supportive organizational choices/policies (question 3).

Conclusions: Timely identification and diagnosis of dementia allows for a timely response to changing client wishes and needs. This requires a better understanding of the symptoms.

A systematic literature review of observable symptoms

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Background: Life expectancy of people with severe or profound intellectual disability increases, which contributes to the risk of developing dementia. However, early detection and diagnosing dementia is complex, because of their low-level baseline functioning. Therefore, the aim is to identify observable dementia symptoms in adults with severe or profound intellectual disability in available literature.

Method: A systematic literature search, in line with PRISMA guidelines, was conducted in PubMed, PsycINFO and Web of Science using a combination of search terms for severe or profound intellectual disability, dementia/aging and aged population.

Results: In total, fifteen studies met inclusion criteria. Cognitive, behavioral and psychological symptoms (BPSD) and a decline in the ability to perform activities of daily living as well as neurological and physical changes were found. This presentation gives an overview of reported symptoms of (possible) dementia-related symptoms in severe or profound intellectual disability.

Conclusions: Despite growing attention for dementia in people with intellectual disabilities in literature, only very few studies have studied dementia symptoms in severe or profound intellectual disability. Given the complexity of signaling and diagnosing dementia in SPID, dedicated studies are required to unravel the natural history of dementia in severe or profound intellectual disability, specifically focusing on observable symptoms for caregivers of (early) dementia in this population.

Older adults with intellectual and developmental disorders

Evaluating dementia capability of service systems for people with intellectual and developmental disorders and dementia

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Background: People with an intellectual or developmental disability (IDD) experience complex age-related issues, including dementia-related disorders, at higher rates and earlier ages than the general population. Increased support needs of this subpopulation can strain caregivers and existing community supports. Patterns of resource awareness and utilization and unmet needs are not well understood for this subpopulation. A collaboration of the Massachusetts Council on Aging (MCOA), the Massachusetts Department of Developmental Services (DDS), and the Center for Developmental Disability Evaluation and Research (CDDER) at University of Massachusetts Medical School conducted a needs assessment with caregivers of people with intellectual and developmental disabilities to assess awareness and utilization of community-based resources, and unmet needs including for caregiver supports.

Method: Home visits, including an environmental assessment, and interviews with caregivers of 95 adults with dementia-related diagnoses were conducted. Interviews asked about changes in the adult's condition since diagnosis including a needs assessment about the dementia-related knowledge and training, care confidence levels, perceived barriers and/or concerns to care provision and resource use.

Results: About half of the caregivers reported significant changes in the person's skills, function and memory since diagnosis, as well as worsening of the person's gait, continence and swallowing. 78% of caregivers reported feeling confident providing care currently and 68% were confident about providing future care. 100% of the respondents found outreach provided by a Nurse Practitioner helpful. Caregiver concerns included lack of suitable day programming, future planning resources, and caregiver burnout/stress. Most caregivers were currently aware of some local resources but with scattered use. Environmental assessments indicated most homes, while accessible, warranted additional lighting and clutter removal. Caregivers requested additional training in addressing the behavioral and mental health needs.

Conclusions: Findings suggest a need for increased collaboration across the intellectual and developmental disability and Aging human services systems, and additional training and resource navigation guides for caregivers.

Retirement, inclusive social participation and mobility

Roger Stancliffe[1]

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Background: Retirement by people with intellectual and developmental disabilities has received limited research and policy attention. This paper will examine selected research on retirement from paid employment by reporting the findings of two separate retirement-related studies.

Method: Study 1 from Australia involved a controlled intervention to support 29 older adults with intellectual and developmental disabilities to transition to retirement by joining a mainstream community group one day per week. Study 2 is cross sectional and used 2016-17 National Core Indicators data from 39 US states.

Results: At 6-month post-test, Study 1 intervention participants experienced more inclusive community participation, made new friends and experienced more social support. There was some evidence that the intervention had protective effects on depression for individuals experiencing multiple adverse life events. In Study 2, older age groups had much lower prevalence of independent mobility, indicating age-related mobility impairment. For each age group, community employment participants were the most mobile, averaging over 90% who were independently mobile, with limited age- related decline in independent mobility. This finding suggests that individuals employed in the community who developed mobility impairment often retired.

Conclusions: Socially inclusive participation in mainstream community groups in retirement is feasible and beneficial. Further research on community employment and mobility limitations is needed to identify specific causes of effects on employment, and effective accommodations and supports. More broadly, research is needed regarding the health conditions that may lead to retirement by people with intellectual and developmental disabilities, and what can be done to prevent or manage those conditions to enable continued employment for those who want it. Further, the effects for people with intellectual and developmental disabilities of different trajectories of retirement also need examination.

What do National Core Indicators tell us about older adults with intellectual and developmental disabilities?

Valerie Bradley[1]

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Background: This presentation will draw from U.S. data collected by the In-Person Survey (IPS) as part of National Core Indicators on the outcomes and characteristics of individuals in the sample who are over 55 years of age.

Method: The data was collected during the 2017-2018 interview cycle. The proportion of individuals receiving services who are moving through late middle age and into their later years has grown over the past several years. National Core Indicators data show that the proportion of people over age 55 grew from 21.6% in 2007-2008 to 25.1% in 2017-2018. This emerging sub-group—like Baby Boomers in the general population—places new demands on public systems including health supports, community engagement, housing, and transportation. This analysis was intended to provide more information to policy makers, providers, and public managers regarding the needs of these older participants.

Results: To illuminate the needs, characteristics and outcomes of older adults receiving services, the 2017–2018 (IPS) data set was analyzed. In that cycle, 35 states and the District of Columbia collected the interview data. The total random sample included 25,562 cases of

which approximately 25% were individuals over 55 years of age. Some of the findings indicated that the older cohort was less likely to be in excellent health, was less likely to be on the autism spectrum, more likely to have limited mobility, has more transportation challenges, is more likely to live in a group setting and less likely to have friends among other findings.

Conclusions: The NCI data suggest that older individuals with intellectual and developmental disabilities will require assessments, planning approaches and supports tailored to their changing needs taking into account their health challenges, quality of life, wellness, and community involvement. Continuing to serve these older individuals in a one size fits all system will compromise their well-being.

Health-related quality of life (HRQoL) among adults with intellectual and developmental disability: Three-year follow up

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Background: In the general population, associated factors for health-related quality of life (HRQoL) have been studied extensively. However, little is known about HRQoL in adults with intellectual and developmental disabilities, as they are at a higher risk of developing chronic health conditions and result in poor health as they age, and often earlier than for the general population.

Method: This study investigated whether health status and HRQoL change over time and the associated factors for health status and HRQOL. It included 1,618 adults with intellectual and developmental disabilities across the US for whom data was completed by family members or primary caregivers over a period of three years. This included 515 adults age 40–50 and 141 aged 60 years and above. The independent variables are demographic (age, gender, diagnoses, residential status), obesity, mobility limitation, number of chronic conditions, diagnosis of anxiety/depression/epilepsy or seizure disorder, and health risk behaviors. The primary outcome measure in the present study is HRQoL (health status, physically health and mentally health days, days of activity without functional limitations, and social participation).

Results: GEE models were used to ascertain the impact of the independent factors over time. There was no change in health status and HRQoL over the three-year period. Non-smoking status, better oral hygiene, and non-sedentary are associated with better health status and HRQoL after adjusting for mobility limitation and comorbidity status. Older age was associated with poorer health outcomes, more mentally healthy days, and decreased social participation.

Conclusions: The findings suggest that increasing physical activity and improving oral hygiene behavior may improve HRQoL of adults with intellectual and developmental disabilities. As adults with intellectual and developmental disabilities age, there is an increasing need to involve them in health promotion and social activities.

ORAL PRESENTATIONS

Staff in residential services and their readiness to supporting grieving service users

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Background: As part of a larger project, the readiness of staff to supporting grieving users with intellectual disabilities in social residential services was explored. Within the project we explored their skills, abilities, knowledge, experience, personal/social capability and motivation, opinions and attitudes and, last but not least, we described the profile of workers (work experience, age, education, sex) and profile of the residential services (number of staff, internal regulations relating to death and mourning, education of employees) involved.

Method: Semi-structured questionnaire for workers conducted in all regions of Czech Republic (n=220). The data were evaluated using SPSS.

Results: Educational attainment significantly influences the opinion and attitude of workers in social residential services. Length of practice, work experience or age are far from such influence. Internal documents within the services relating to death and grieving significantly shape the perception of the workers.

Conclusions: This project brings insight into the area of grieving in people with intellectual disabilities, and more specifically into the work in social residential services. The outcomes of this project can be used in practice.

End of life care when there is a diagnosis of COVID-19

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Background: The research aim was to understand how person-centered end of life care was provided during the COVID-19 pandemic.

Method: Semi-structured and in-depth interviews conducted as part of a longitudinal study on the ageing of people with intellectual disabilities (IDS-TILDA) identified several individuals who died with and without COVID-19 during the COVID-19 pandemic in Ireland. Data was collected from the caregivers (staff and family) of these individuals, and was compared to understand differences in care received and grief experienced. Data was also compared with additional data gathered on the deaths of individuals outside of the COVID-19 period.

Results: There were differences in the level of in-person support received by the person with ID and by their caregiver, regardless of

COVID-19 status as compared to deaths outside of the pandemic period. Hospitalizations presented a particular challenge. Also, there were additional issues in terms of unsupported and unresolved grief.

Conclusions: Based on the experience of the COVID-19 pandemic, there is a need for greater attention to advanced directives for people with intellectual disabilities and to how grief is to be managed when access to the dying person is restricted.

Implementing palliative care innovations for people with intellectual disability

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Background: Sustainable improvement of palliative care for people with intellectual disability requires involvement of various stakeholders and integration into an organization's strategic policy. The current three-year participatory action research study aims to improve palliative care in organizations providing care for people with intellectual disability.

Method: Nine implementation projects in eleven care organizations for people with intellectual disability were included in this study. Action research groups including an opinion leader, an implementation expert, medical professionals, social workers, people with intellectual disability or representatives, and managers, were formed in each organization. In 2020, the eleven organizations conducted a self-evaluation of their palliative care policies and practices and a questionnaire on the perceived competencies of professionals. Based on the results, two innovations from a toolbox including six pre-selected palliative care innovations are chosen to implement within the organization. Innovations are implemented following a cyclical approach (Plan, Do, Study, Act) to improve palliative care within the organization.

Results: Results provide insight into the current palliative care policies and practices in organizations for people with intellectual disability and the implementation of the innovations.

Conclusions: This unique participatory action research study shows how sustainable improvement of palliative care can be achieved in organizations providing care for people with intellectual disability.

Don't forget about me: Dementia in rare genetic neurodevelopmental disorders, a systematic review

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Background: The lifespan of individuals with genetic intellectual disability (ID) has increased greatly in the last decades. This has exposed predispositions to health issues in this population such as early aging. Early onset cognitive and adaptive decline in functioning is often seen clinically. This may be caused by dementia, which has been studied rather extensively in Down Syndrome but barely in other genetic neurodevelopmental disorders. The aim of this systematic review was to increase understanding on associations between genetic ID syndromes and dementia.

Methods: A search was conducted in several databases. Search terms were related to dementia and genetic neurodevelopmental disorders, the latter including generic search terms for neurodevelopmental disorders as well as a list of rare genetic syndromes from the National Institute of Health. As studies on dementia were expected to be scarce, broader search terms on cognitive and adaptive decline were also included.

Results: Information was recorded on occurrence, diagnosis and clinical manifestations of dementia in genetic neurodevelopmental disorders. Validity of diagnostic methods, strengths and limitations of the studies were reported. Qualitative and descriptive analyses have been performed.

Conclusions: Findings are discussed, providing recommendation to improve dementia diagnosis and care for adults and elderly with neurodevelopmental disorders.

Palliative and end-of-life care, people with intellectual and developmental disorders and COVID-19 (PEPIC-19): An international survey

Naomi Dhollander[1], Irene Tuffrey-Wijne[2], Huda Abu-Saad Huijer[3], Michael Echteld[4], Rachel Forrester-Jones[5], Carmen Karbasi[6], Philip McCallion[7], Mary McCarron[8], Sabine Schaeper[9], Stuart Todd[10], Madeleen Uitdehaag[11], Stuart Wark[12], Britt-Evy Westergard[13]

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Background: To gain insight into the provision, quality and challenges of palliative and end-of-life care to people with intellectual and developmental disabilities at the end of life in countries across the world, both before and during the Covid-19 pandemic.

Method: An international anonymous online survey (available in English, Dutch, German, Norwegian and Spanish), developed and piloted by a team of 15 researchers from 10 countries. It consists of 13 closed and four open questions, with free text boxes to provide examples. Responses are invited from any health/social care professionals. The survey is supported by the European Association of

Palliative Care (EAPC) and builds on the 13 norms for good practice in their 2015 White Paper on intellectual and developmental disabilities.
Results: The survey was open from October 2020 to February 2021. Results are expected from 500+ respondents in 16+ countries worldwide. Data analysis will focus on what respondents consider to be the barriers and enablers in providing palliative and end-of-life care; how the Covid-19 pandemic has affected this; specific examples that illustrate both barriers and enablers; and national contexts and differences.
Conclusions: The results will be available at the congress, and provide important pointers for developing policy, practice and research priorities.

IN-DIALOGUE: Consensus on a conversation aid for shared decision making in the palliative phase

Hanna Noorlandt[1], Ida Korfage[1], Irene Tuffrey-Wijne[2], Dederieke Festen[1], Cis Vrijmoeth[3], Agnes van der Heide[1], Michael Echteld[4]
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Background: People with intellectual disabilities need to be involved in making decisions about their treatment and care. Little is known about how to involve people with intellectual and developmental disabilities in making decisions about treatment and care in the palliative phase. We therefore developed a shared decision making (SDM) conversation aid to better involve people with intellectual and developmental disabilities in making decisions in the palliative phase. We evaluated its relevance and feasibility in an expert consensus procedure.
Method: In a Delphi consensus process, an expert panel of 11 people with intellectual disabilities, 14 relatives and 65 healthcare professionals completed online questionnaires about the relevance and feasibility of a draft conversation aid.
Results: After amending the aid to the expert panel's feedback, relevance ratings were 67-97% (M=90%) and feasibility ratings 66 -86% (M=77%). The final In-Dialogue aid consists of four themes: who are you, illness/end of life, making decisions, and evaluating the decision. In-Dialogue comes in a box with a pad which resembles a board game, 13 conversation cards, 50 supporting illustrations, a workbook and an accompanying manual. Promising results have emerged from the first conversations.
Conclusions: The consensus-based conversation aid is considered sufficiently relevant and feasible to be implemented in practice.

Dying in the Covid era: UK study of adults with intellectual disabilities in social care 2020-21

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Background: The aim of the research was to explore patterns of dying and identify mortality rates among people with intellectual disabilities living in supported living or residential care facilities, and to compare findings with data collected in 2013-14 for an earlier study of a similar population.
Methods: Retrospective, cross-sectional, study of deaths in a defined population of adults with intellectual disabilities, ordinarily resident, at the time of their death, in supported living or residential care settings, using regional managers as informants. The methodology is adapted from that used in a previous study (Todd et al., 2020) For all deaths identified, data will be collected on age, gender, place of usual care and of death, and cause of death.
Results: Preliminary results will be presented on the recruitment strategy, number of providers, number of living people they supported, and the number and nature of deaths reported to date.
Conclusions: This is the first UK study to calculate, using a defined population, the mortality rate, the number of excess deaths and the proportion of these attributed to Covid in people with intellectual disabilities.

Individual cognitive stimulation therapy for individuals with intellectual disability and dementia

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Background: To examine the feasibility and acceptability of manualised individual Cognitive Stimulation Therapy (iCST) delivered by carers to adults with intellectual disability and dementia.
Method: Dyads (carer and individual with dementia) were randomised to iCST (40 sessions over 20 weeks) or a waiting list control group. Recruitment and retention of participants, intervention adherence, fidelity and acceptability were assessed. Outcome measures of cognition, adaptive functioning, quality of life and carer outcomes were collected at baseline, midpoint (11 weeks) and at 21 weeks. Carers were interviewed about their experience of iCST.
Results: Forty dyads were recruited from 12 sites in England. There was good retention with only 1 dyad dropping out and over 85% completed both assessments. Adherence to the correct session structure was poor; 70% completed at least 20 sessions but there was a high level of satisfaction with iCST. Quality of life was higher in the iCST group at 21 weeks (adjusted mean difference: 3.11; 95% CI: 0.64 to 5.58). There were no differences in the other outcome measures.
Conclusions: The intervention was feasible and acceptable and may improve quality of life. A full-scale trial is possible but improved training for carers is needed to improve fidelity.

Pepic-19: Palliative care for people with intellectual and developmental disabilities and Covid-19, comparing the Netherlands and Belgium

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Background: To gain insight into the challenges in meeting international consensus norms for palliative and end-of-life (EOL) care provision to people with intellectual and developmental disabilities in The Netherlands and Belgium, both before and during the Covid-19 pandemic.

Method: This study is part of an international survey. It builds on the 2015 White Paper from the European Association of Palliative Care (EAPC) taskforce on intellectual and developmental disabilities, which established 13 norms for good practice. We asked professionals in health or social care services, academics, researchers and educators with an interest in EOL care of people with intellectual and developmental disabilities to fill out an anonymous on-line survey. The survey has questions with Likert-scale and free text options. We distributed the survey link by e-mail, using our networks, and social media in December 2020. We will use descriptive statistics and statistics to test differences between countries and respondent subgroups. Free text will be analysed using Thematic Framework Analysis.

Results: The survey will be open until the end of March 2021. We will share the results with caregivers and policy makers involved with palliative care for people with intellectual and developmental disabilities.

Conclusions: Results will be available at congress, and focus on developing policy, practice and research priorities in both countries.

Don't let them fall: Falls prevention in people with visual and intellectual disabilities

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Background: To develop a training program for people with a visual and intellectual disability to prevent them from falling. Falls can lead to fractures, disability, and even death. The incidence of falls is high in people with intellectual disabilities and in people with visual impairments. Therefore, falls prevention in people with visual and intellectual disabilities is of great importance.

Method: The training program was based on the obstacle course of the Nijmegen Falls Prevention Program. The obstacle course has successfully been used in people with intellectual disabilities. For people with no or limited sight adjustments needed to be made to safely used the obstacle course in people with visual and intellectual disabilities. After adjusting the obstacle course, a Multiple Baseline Single-Case Experimental study was conducted. Six adults with visual and intellectual disabilities followed 10 sessions with the obstacle course. The main outcome measure was number of falls in the four months before and after training.

Results: The adjustments made to the obstacle course and first results of the study will be presented.

Conclusions: This is a first step in providing a fall prevention intervention specially developed for people with visual and intellectual disabilities.

POSTER PRESENTATIONS

Study toward the quantitative understanding of the intellectually disabled diagnosed as dementia

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Background: The purpose of this study was to clarify the status of dementia of persons with intellectual disabilities who are admitted to facilities, and to compare the prevalence of dementia between people with Down's syndrome and those who do not have Down syndrome.

Method: The survey was conducted at all facilities for people with intellectual disabilities in Japan in 2010 and 2016 by questionnaire. Caregivers were asked the number of persons with intellectual disabilities who were diagnosed as having dementia by a doctor, or who were not diagnosed but seem to be suffering from dementia.

Results/Conclusions: The 2010 survey found that 0.7% of users had a diagnosis and 1.8% had suspected dementia. On the other hand, 2016 survey showed that 1.6% had a diagnosis and 4.4% had suspected dementia. The proportion of people diagnosed with dementia and those suspected of having dementia increased. Furthermore, a comparison of the status of diagnosis of Down syndrome and non-Down syndrome in the 2016 survey suggested that the proportion of people diagnosed with dementia was significantly higher in people with Down syndrome than non-Down syndrome people.

Creating an end-of-life-sensitive organizational culture in residential services for people with intellectual and developmental disabilities

Sabine Schaeper[1], Barbara Schroer[1], Antonia Thimm[1], Clara Levin[1], Judith Sellmeyer[1]

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Background: Disability services increasingly face challenges in end-of-life care for residents. A study in three German regions explored the conditions of care in different residential settings. The study aims at deepening the analysis of predicting factors for a high quality of care.

Method: The first part of the study (online-survey and interviews with frontline-staff and managers) revealed a wide range of capacity for and attitudes towards palliative care for people with intellectual disabilities. Instruments to assess the impact of organizational culture on palliative care outcomes are a desideratum up to now. The second part of the study integrates a literature review, a quantitative study on aspects of organizational culture in group homes, and qualitative case studies.

Results: The impact of socio-historical and organizational factors is significant. Strategies to cope with increasing mortality rates can be assigned to four types of care. Specific recommendations for each of these types can encourage service providers to improve the quality of end-of-life care.

Conclusions: To ensure a participatory and person-centered culture of palliative care, sensitivity for the impact of organizational culture and professional attitudes is needed. Disability services have to develop professional capacity and organizational reflexivity.

Addressing isolation and quality of life during COVID-19

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Background: The aim was to understand how isolation among people with intellectual disabilities during lockdown may be reduced and quality of life maintained.

Method: Use of documentary and video analysis of events at Stewarts Care, a services provider in Ireland as well as interviews with people with intellectual disabilities and of staff and families to understand what interventions contributed most to reducing isolation and maintaining or increasing quality of life during the December-January COVID-19 lockdown period.

Results: Data supported that a combination of involvement in planning and participating in virtual activities, seasonal visual displays and an emphasis on maintaining communications were all helpful. Seasonal virtual displays and holiday-related activities were particularly noted.

Conclusions: There were important lessons learned, including that maintaining desired and enjoyed activities and expanding use of technology all contributed to reducing isolation and maintaining or increasing quality of life.

Risk of mortality during an emergency department visit among US autistic adults

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Background: We examined the risk of mortality during emergency department (ED) visits among autistic adults compared to the general population using the 2016–2017 National Emergency Department Sample.

Method: We modeled logistic regressions to compare risk of mortality between autistic adults (n=47,142) and age-matched sex-matched controls non-autistic adults (n=471,420) in a 1:10 ratio.

Results: We found that autistic adults had a higher risk of mortality during ED visits than their non-autistic peers (RR=2.54, 95% CI:2.19-2.94, p<0.001). This risk remained high even after adjustment for age, sex, income, epilepsy and psychiatric comorbidities, hospital teaching and urban status, hospital region, and year of ED visit (RR=1.77, 95%CI:1.28-2.11, p<0.001). The results from the interaction of sex and autism status suggest that autistic women have almost two times higher risk for mortality during ED visits (RR=1.89, 95% CI:1.37-2.6, p<0.001) than autistic men. The results from the stratified analysis also showed that autistic women had almost four times higher risk (RR=3.97, 95%CI:3.04-5.17, p<0.001) for mortality during ED visits compared to non-autistic women; this difference persisted even after adjusting for socioeconomic, clinical, and hospital characteristics (RR=2.34, 95%CI:1.71-3.20, p<0.001).

Conclusions: Our findings confirmed a higher risk of mortality during ED visits among autistic adults than peers from the general population.

Preparing for surprise: Implications of less expected dying in people with intellectual disabilities

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Background: To identify tools, research, and service strategies better to support people with intellectual disabilities whose deaths are likely to be relatively unexpected. To identify possible indicators of good end of life care in these circumstances.

Method: Reflective review to develop theoretical framework of less expected deaths and relevant clinical, service improvement, training and research tools. Results from relevant studies, enquiries, and service improvement reports will be used, from both Intellectual Disability and Older Adult areas.

Results: The deaths of adults with intellectual disabilities tend be sudden, or not to have been anticipated for longer than a few days by those caring for them. Predominant causes of death differ from the general population. This demands better anticipation, recognition of deteriorating health, and identification of frailty to prevent deaths amenable to healthcare, and to prepare for inevitable dying. Strategies are needed that allow people with intellectual disabilities, their families, and services to accommodate deaths that could not have been anticipated.

Conclusions: Existing tools that identify frailty, clinical deterioration, active dying or the need for palliative care have seldom been tested with people with intellectual disabilities. All deaths cannot be predicted. Possible research, service, and training implications will be discussed.

Concept of death: Perspectives of adults with intellectual disabilities

Manisha Kishore[1]
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Background: Death and loss within the family are often neither explained, nor processed with a person with intellectual disabilities. In an attempt to shield them from the grief situation, caregivers might avoid discussions around the topic.
Method: International literature highlights that death education and processing of grief are imperative for every individual who might be at risk of a potential loss due to chronic illness of a family member, or has faced a recent bereavement. Five individuals with intellectual disability, who had lost a family member within the past 24 months, were selected for this exploratory study. Semi-structured individual interviews were conducted to examine their understanding of the basic five death concepts of causality, irreversibility, non-functionality, universality and inevitability.
Result: The responses are thematically analysed to gain deeper insight into the perspectives, beliefs, attitudes and thoughts of participants pertaining to concepts of death, loss and bereavement.
Conclusions: This research would be extended in future to encompass caregivers' perceptions to develop as framework for effective grief processing for people with intellectual disabilities. Practical implications, limitations and future improvements will be discussed.

Palliative and end of life care

Kerry Anderson[1]
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Background: Poster will present the joint working across generic palliative and end of life care services, which incorporates best practice pathway for people with a learning disability.
Method: Development of framework for palliative and end of life care as developed by NHS Grampian MCN, has been inclusive of the needs of people with a learning disability, and as such a pathway specific for individuals needs has been created to ensure a person centred and holistic approach to care.
Results: There has been positive engagement across both acute and learning disability services.
Conclusions: The poster will showcase best practice and holistic approach to palliative care. Including guidance developed to support carers and families during the COVID-19 pandemic.

End-of-life care for people with intellectual and developmental disabilities during the COVID-19 pandemic: A systematic literature review

Anna Roemer[1]
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Background: The international systematic literature review was conducted from June to November 2020. It focused on infection and morbidity rates among people with intellectual and developmental disabilities with COVID-19 and their situation under the conditions of the global pandemic, especially with regard to their passing away.
Method: Search terms were defined and searched for in ten scientific databases over a period of five months. Research reports, journals, university publications, press releases, legal commentaries, contributions from scientific networks and statistics were included. The texts were reviewed and sorted according to relevance, summarized and analyzed.
Results: Only two surveys were published during the research period. Seven studies were announced or are currently in the survey or evaluation phase. First findings indicate a greater vulnerability of persons with intellectual and developmental disabilities depending on individual factors like comorbidities and social factors like exclusion from health care provision or isolation in residential care homes. Health care systems need to be more inclusive, staff has to build specific capacities, and crisis management has to become inclusive.
Conclusions: The systematic literature review needs to be continued to enable an international comparison of the special situation of people with intellectual and developmental disabilities at the end of life during global or local crises.

Social frailty among older adults with an intellectual disability

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Background: This study aimed to measure social frailty among older adults with an ID and analyse its capacity to predict adverse outcomes in this population.
Method: The primary data source was the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA). Ethical approval was granted by the Trinity College Dublin Faculty of Health Sciences Research Ethics Committee. A Social Frailty Index (SFI) was constructed using items which influence and describe an individual's social circumstance. Variable analysis was undertaken to probe the relationship between SFI scores and adverse health outcomes.
Results: Social frailty was associated with adverse health outcomes over time among older adults with an intellectual disability. The higher the SFI score, the greater the risk for adverse outcomes, independent of the type of deficits included.
Conclusions: This is the first study to investigate social frailty among older adults with an intellectual disability and further research is warranted. The capacity to measure social frailty in this population may have significant implications for policy and practice development. A holistic and preventative approach to social frailty should include upstream interventions that address social health disparities.

Track 1c Early Intervention/Transition

ORAL PRESENTATIONS

Impact of county factors and state policy on geographic access to BCBAs among children with autism spectrum disorders

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Background: To examine the relationship between geographic access to Board Certified Behavior Analysts (BCBAs) among children with autism spectrum disorder and county sociodemographic factors and state policy in the U.S.

Method: We integrated data from the U.S. Department of Education's Civil Rights Data Collection, Behavior Analyst Certification Board's certificant registry, and U.S. Census. The sample included counties and county equivalents (e.g., parishes) in 49 states and Washington D.C. ($N=3{,}040$). Using GIS software, we assigned BCBAs to counties based on their residence, allocated children via school districts to counties, and generated per-capita children with autism spectrum disorder/BCBA ratios. We distributed counties into five categories based on ratios: no BCBAs (reference), ≥31, 21–30, 11–20, >0–10. We used a generalized logit model for analyses.

Results: Highly affluent and urban counties had highest access. Odds ratio estimates for affluence ranged from 2.26 to 5.26. County-level poverty was positively associated with access, yet this relationship was moderated by urbanicity. Race-ethnicity and healthcare insurance coverage were negatively related to access.

Conclusions: Targeting non-urban and less affluent counties for provider recruitment and maintenance could most improve access to BCBAs. In addition to strategies specific to BCBAs, traditional strategies used for enhancing access to other healthcare providers could be useful.

Developing a statewide needs assessment of Asian American parents of children with developmental disabilities

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Background: The Asian American Needs Survey aims to understand how Asian American (AA) parents of children with developmental disabilities navigate community services and healthcare; barriers and facilitators of service use and early diagnosis; and other factors that may impact this population. We will present information about survey development, translation, and data collection processes.

Methods: We assembled a national advisory group comprised of disabilities researchers, including professionals from diverse Asian ethnic groups. We developed a comprehensive survey in English. The survey includes questions on the diagnostic process, services, parents' beliefs about developmental disabilities, coping processes. The advisory group and two AA parents raising children with developmental disabilities reviewed the survey and provided detailed feedback. We then professionally translated the final survey into four languages commonly spoken in Maryland: Korean, Japanese, Mandarin and Vietnamese.

Results: We collected data using online and in-person methods. Participants are eligible to complete the survey if they 1) live in Maryland; 2) identify as Asian or AA; 3) and are a parent or other primary caregiver of a child younger than 18 with a developmental disability. We distribute recruitment flyers and other study information through general parent support groups, autism and developmental disability organizations, developmental disabilities service providers, advocates, and developmental disabilities-related events. We also reach out to AA-specific organizations, or those with large numbers of AA members (e.g., churches and language schools), to identify AA parents of children with developmental disabilities who are potentially not involved in general organizations or groups. In collaboration with AA-specific organizations, we also host events that provide education to parents who have children with developmental disabilities.

Conclusions: The AA Needs Survey will make a significant contribution to an emerging national effort to elicit the voices of AA families raising children with developmental disabilities. Results will inform providers and policymakers on the needs of these communities.

Awareness of symmetry, order, and stability in children with Down syndrome

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Background: The framework of this communication is a research line developed in Spain proposing an approach to the teaching of mathematics that helps children with intellectual disabilities enjoy the benefits of this discipline by introducing geometry since early childhood. Specifically, our goal is to design a tool to explore the existence of naive conceptions about symmetry in children from preschool in an inclusive environment.

Method: Research sessions are designed for children to show their conceptions about symmetry while working freely on drawings and building block constructions. Implementation is carried out with two groups: 20 children from a standard school (ages 4 to 5) and three children with Down syndrome and the same age range. Children's productions are analyzed using a qualitative methodology based on *participant observation*.

Results: Children with Down syndrome recognize simple patterns of symmetry in the environment—axial symmetry of human body and shapes of nature, not noticing significant differences with children in the other group. They tend to reproduce these patterns in their productions, often seeking the beauty, order and stability associated with symmetry.

Conclusions: An observation guide has been developed in order to help teachers detect actions that show children's awareness of the existence of symmetry.

Preparation

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Background: Youth with intellectual disabilities who have been removed from birth families due to abuse or neglect and placed in residential child care must transition from these facilities as they age out of children's services. Whilst there is a range of research on leaving care and disabled youth transitions to adulthood, the experience of youth with intellectual disabilities ageing out of residential child care has been largely ignored, particularly in the Global South. This paper addresses this gap by sharing PhD findings on preparing youth with intellectual disabilities for leaving residential child care in South Africa.
Methods: Semi-structured, participatory interviews were conducted with eight youths with intellectual disabilities leaving residential child care and their caregivers. Data were analyzed using thematic analysis.
Results: Leaving care significantly impacted on the security and belonging of participants who needed a participatory, transparent approach to transitional planning. There was also a lack of attention to the specialized support needs of this group to prepare them for their post-care lives.
Conclusions: Person-centred transition planning is recommended to more adequately prepare these youths for leaving residential child care, alongside specialised aftercare support in their young adult lives and improved inter-agency collaboration across the child and disability sectors.

Specifics of formation of a negative reaction in young children with Down syndrome

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Background: According to many experts, the connection between a mother and her child is essential for normal cognitive development. The aim of the research is to study the conditions for the formation of a negative reaction as one of the organizers of the child's psyche (according to R. Spitz) in children with Down syndrome.
Method: The methods of the research were inquiry approach, analysis of problem situations, the Toronto Alexithymia Scale TAS-20-R, the Leonhard-Shmishek test (adaptation of V.M.Bleicher), the Bass-Darka Hostility Inventory (version of A.G. Rezapkina), The Spielberger State-Trait Anxiety Inventory (adaptation Yu.L. Khanina).Participants were 37 toddlers and 22 mothers.
Results: Mothers of children with Down syndrome generally have average or high levels of anxiety. Mothers whose children express their negative reactions by gestures or screaming tend to be even more anxious.
Conclusions: The results of the research can be used by practicing psychologists and teachers to determine the objectives of the program for the development of child-parent interaction.

Pathways to post-secondary settings for students with intellectual disabilities

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Background: It is well established that people with intellectual disabilities are more likely to be unemployed, more dependent on social welfare, with an increased risk of living in poverty. A shift in policy at a national and international level has meant a significant increase of students with intellectual disabilities are attending mainstream secondary education in Ireland, though few successfully transition to further/ higher education or employment. This study aims to gain an insight into the typical transition support/guidance provided to students with ID as they prepare to complete their post-primary education in a mainstream setting.
Method: This mixed-methods study employed a sequential design. Results of a national survey of secondary school Principals were used to identify individual cases for nine qualitative interviews with school faculty. Individual analyses were merged for the purpose of triangulation.
Results: There was strong evidence that transition planning for these students is carried out by the Special Educational Needs Coordinator, rather than the Guidance Counsellor. As a result, transition planning tends to be very narrowly focused on traditional pathways into disability-specific services. The research highlights the overemphasis on academic progression amongst Guidance Counsellors to the exclusion of students with intellectual disabilities, who require more individualised and nuanced transition planning.

The becoming adult: Transition to adulthood for young people with intellectual disabilities

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Background: The aim of the study was to bring together multiple stakeholder perspectives to inform an understanding of transition to adulthood for people with intellectual disabilities and their families.
Method: Adopting a qualitative approach, three focus groups and six interviews were undertaken with participants with intellectual disabilities aged between 17 and 25. A further seven interviews took place with mothers and six with professionals. Data was analysed using thematic analysis.
Results: The analysis gave rise to four themes: the transition minefield; interdependence; the push and pull of adulthood; and aspirations bounded by reality. In light of these themes, principles of assemblage are drawn upon to demonstrate how different lines of affect shaped the becoming of young people and mothers during transition.
Conclusions: Transition is a time dominated by uncertainty and stress. A lack of support at the end of education ensures the "transition cliff

edge" persists. However, approaching transition through an assemblage lens brings to the forefront the interconnectedness of transition and highlights the need for professionals to take into consideration the multiplicity of elements and lines of affect which work together during this period. A creative approach to intervention is encouraged by exploring what might happen when existing lines are ruptured and new lines created.

Evaluating effectiveness of transition program in MINDS special education schools: From schools to post-18

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Background: Special Education (SPED) schools in Singapore had a school-to-work transition programme to help students ease into working life and adulthood. This study seeks to assess the strengths and weaknesses of the programme at MINDS SPED schools, the influence of family involvement and inter-agency collaboration on transition outcomes, and the extent to which the programme helped graduates to transit to work successfully.

Method: Semi-structured interviews and focus groups were conducted with 11 caregivers, 15 teachers, 17 transition planning coordinators and 16 graduates. With the exception of the graduates, all of the participants had to complete a questionnaire.

Results: The study is ongoing and results will be presented at the conference.

Conclusions: The findings would be used to augment the transition programme and improve the outcomes for future graduates.

mHealth developmental screening for preschool children in low-income communities

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Background: This study validated an mHealth-based developmental screening tool as a potential time- and cost-effective way of delivering services for preschool children.

Method: This cross-sectional within-subject study screened 276 preschool children from low-income communities using the mHealth PEDS tools. The mHealth PEDS tools' performance was then evaluated by comparing caregiver concerns according to the PEDS tools with results obtained using a reference standard assessment tool, the Vineland-3.

Results: The mHealth PEDS tools identified 237 (85.9%) of children at risk of developmental delay compared to 80.1% ($n=221$) of children identified with a developmental delay using the Vineland-3. Sensitivity of the PEDS tools was high (92.6%) with low specificity (22.5%) using US standardised criteria. Literacy skills were found to be most delayed, according to the PEDS: DM (89.3%; $n=142$) and Vineland-3 (87.1%; $n=134$). Low specificity of the prescribed criteria may require the implementation of adapted referral criteria within low SES settings.

Conclusions: The mHealth PEDS tools may still be valuable for preschool developmental surveillance of children within low SES settings. It is recommended, however, that children who are identified with a developmental concern undergo a second screen to reduce false positives.

A transition guide adapted to needs of youth with profound intellectual disability

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Background: Few resources are available to support families of youth with profound intellectual disability (PID) and professionals during planification of transition to adulthood. This study aimed to develop a transition guide built on available evidence, in collaboration with parents and professionals from health, school and community networks.

Methods: This research action used various methodological strategies with parents and professionals to prioritise what information and materials to include in the guide (e.g., surveys, interviews, focus groups). Finally, based on these results, a steering committee created the transition guide, which was validated by two experts in transition planning.

Results: The transition guide includes sections explaining strategies to plan the transition period for youth with PID. It also proposes three information sheets on legal and financial issues, as well as an observation grid to support identification of youth's life project. This collaborative approach allowed for a better understanding of the roles of the professionals involved and needs of these families.

Conclusions: This guide has potential to improve practices in transition planning and better support families through this period to allow a satisfying adult life. This guide can also be used in different contexts of practice and by various types of professionals.

Is phonological awareness related to pitch, rhythm and speech-in-noise discrimination?

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Background: Phonological awareness (PA) requires the complex integration of language, speech and auditory processing abilities. Enhanced pitch and rhythm discrimination have been shown to

improve PA and speech-in-noise (SiN) discrimination. The screening of pitch and rhythm discrimination, if non-linguistic correlates of these abilities, could contribute to screening procedures prior to diagnostic assessment. This research aimed determine the association of PA abilities with pitch, rhythm and SiN discrimination in children aged five to seven years old.

Method: 41 participants' pitch, rhythm and SiN discrimination and PA abilities were evaluated. Pearson correlation was used to identify associations between variables and stepwise regression analysis was used to identify possible predictors of PA.

Results: Correlations of medium strength were identified between PA and pitch, rhythm and SiN discrimination. Pitch and diotic digit-in-noise discrimination formed the strongest regression model (adjusted $R^2 = 0.4213$, $r = .649$) for phoneme-grapheme correspondence.

Conclusions: The current study demonstrates predictive relationships between the complex auditory discrimination skills of pitch, rhythm and diotic digit-in-noise recognition and foundational phonemic awareness and phonic skills. Pitch, rhythm, and digit-in-noise discrimination measures hold potential as screening measures for delays in phonemic awareness and phonic difficulties and as components of stimulation programs.

Early Intervention in the community for preschool children and their families

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Background: We will present a descriptive research project on Early Intervention, which we have been conducting in 12 public nurseries for children aged 2 to 5 belonging to the municipality, of which the foundation is part. The aim of this project is early detection and intervention of mental health issues in order to prevent developmental and emotional difficulties in young children and their families "at risk."

Method: To reach these objectives we used standardized questionnaires, screening tests, classroom observation and developmental diagnostic tools. We gathered the descriptive data from 1375 questionnaires during a period of four years. About 14.5% of all preschool children presented difficulties in emotional, behavioral, cognitive and/or speech development and were assessed by our multidisciplinary team.

Results: Prevalence of toddlers with emotional and/or behavior difficulties was 7%, while prevalence of toddlers with mixed developmental difficulties (such as impairment in language, cognitive, motor development and autism spectrum disorders) was 8%. After further diagnosis, these toddlers were referred to Early Intervention Programmes, Speech or Occupational Therapy or Infant Parent Psychotherapy.

Conclusions: In conclusion, we want to stress the importance of this community-based program, which resulted in early detection and treatment for 200 toddlers and their families "at risk" for mental health difficulties.

A model of supported transition for young people with intellectual disabilities

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Background: Young people with intellectual disabilities face discrete employment challenges in terms of educational qualifications, pathways and choices, work experience and independence skills. The purpose of this study was to examine the concept of "supported transition" for young people with intellectual disabilities to determine its efficacy to potentially inform the development of a national framework of transition for young people with disabilities moving from special schools to FE/HE and employment.

Method: A series of 1-1 interviews was conducted with students with intellectual disabilities (n=31), parents (n=18), school staff (n=8) and employment facilitators (n=2) to explore their experiences in accessing and progressing through post-school pathways to HE/FE.

Results: The findings demonstrate a strong correlation between support programmes, transition planning and positive transitions, which places the young person at the centre of the process by assisting them to explore their aspirations and make an "informed choice" about their future, thus avoiding lives in institutional day services.

Conclusions: This study highlights the essential components required to enable young people with intellectual disabilities make a seamless transition from compulsory education to FE/HE, and proposes a new model of "Supported Transition" with clear implications for the development of government policies for young people with disabilities in the Republic of Ireland.

Supporting social transition: Students' perspectives of a university virtual social group

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Background: With the global onset of Covid-19, universities have had to work quickly to accommodate any restrictions put in place within their own countries. This has led to college courses moving fully or partly online. In one university in Ireland, the decision was made to run a two-year course for students with an intellectual disability completely online until restrictions could be lifted. This meant that students would be expected to participate in all aspects of student life through a virtual platform. Students with intellectual disabilities often require varying levels of support for post-secondary transition, one of these being within the social domain. One such group aimed to support social transition and inclusion by facilitating a weekly virtual social group combining different peer groups with and without an intellectual disability.

Method: A survey was completed to gain the students' perspectives after one semester.

Results/Conclusions: Data gathered showed outcomes such as skill development, improved confidence and the development of new relationships with peers outside of each students' typical social group, among the benefits experienced. Online fatigue was highlighted as a difficulty. Other areas looked at were group size and structure with recommendations for the second semester.

Characteristics of development in young children in South Africa

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Background: Early childhood development is critical for later success. Description of children's developmental characteristics supports the implementation of early intervention services.
Method: Data was collected at a PHC clinic, with 353 caregivers and their infants aged 3 to 36 months.
Results: Overall positive diagnosis of developmental delay, with the BSID-III, was 51.8%. The effect of age and gender was determined. Prevalence of developmental delay increased with age from 33.1% for children under 12 months to 61.7% and 66.3% for children between 13- 24 months and 25- 36 months respectively. Females were 1.82 times more likely to have a negative diagnosis; 2.601 times in the adaptive behaviour and 2.301 times in the motor domains. One hundred and one (28.6%) participants across all age groups displayed superior social-emotional ability. One third of children presented with superior social-emotional skills, which could be attributed to familial structures. Another third presented with poor adaptive behaviour function, which may be due to cultural differences.
Conclusions: The outcomes of this study can inform intervention and public health policy in South Africa and other LMICs.

The impact of inclusive play on adaptive and challenging behaviors for young children with intellectual and developmental disabilities

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Background: The aim of this study was to understand the impact of Special Olympics Young Athletes (SOYA) on adaptive behavior skills and challenging behaviors for young children with intellectual and developmental disabilities living in four developing countries.
Method: Surveys were used to assess adaptive behavior skills and challenging behaviors of children with intellectual and developmental disabilities before and after (at eight weeks and 20 weeks) an eight-week SOYA intervention in Thailand, Bangladesh India and Pakistan. A control group was included consisting of children who did not participate in SOYA. Multi-level modeling for repeated measures was used to determine the impact of YA participation.
Results: Relative to those in the control group, children who participated in SOYA demonstrated significantly greater improvements over time in communication, daily living, and social-emotional skills; and significantly greater decreases in challenging behaviors.
Conclusions: SOYA appears to have positive impacts on key developmental skills that allow young children to better engage in their communities and can be a powerful intervention with the potential to change the developmental trajectory for young children with intellectual and developmental disabilities who may not have access to other early childhood development programs or interventions in their communities.

Transition of children with autism spectrum disorder: Heterogeneity of student's and family needs

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Background: The transition to school is undoubtedly a sensitive period for all families, and particularly for families with children with autism spectrum disorders. However, few studies document the relationships between the heterogeneity of child's clinical profiles along the spectrum, contextual factors associated with school's infrastructure and family adjustment. Our presentation will discuss the differential portraits of family needs during child transition to kindergarten in relation with those three variables.
Method: 68 families were interviewed within a six-month interval, using sociodemographic questionnaire, Developmental Behavior Checklist (DBC), International Family Needs Assessment (FNA).
Results: Preliminary results of the first interview (end of EIBI/start of school) revealed that children with ASD are more likely to be educated in a specialized class whatever their clinical profiles. All families expressed a high level of need for getting specialized services with stronger needs for parents of children in special class related to health, recreational activities and daily care.
Conclusions: This study highlights the need for varying levels of action to be taken by schools to foster inclusion for all children in ordinary kindergarten, regardless of their diagnosis. It also demonstrates parents' strong concerns for ensuring optimal educational, health and leisure support for their child.

POSTER PRESENTATIONS

The French version of the DABS: Translation process and preliminary results on content validity

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Background: The aim of this study was to do a French adaptation of the Diagnostic Adaptive Behaviour Scale (DABS). This is the first assessment instrument specifically developed to be reliable at the cutoff point that established significant limitations in adaptive behaviour and assist clinicians in the determination of intellectual disability.

Method: The DABS was adapted to French following the methodology proposed by Tassé and Craig (1999). Ten professionals took part to the translation process including two professional translators and eight experts on the field of intellectual and developmental disabilities. Thirty clinicians and academics working in the field of intellectual disability rated for relevance and clarity the instructions, item stems, and rating system of the translated version.

Results: The translation process ended when complete agreement among all translators was achieved, suggesting that the DABS-F provided a good translation and adaptation of the original instrument. Furthermore, the clarity of administration of the DABS-F was also evaluated with potential users. Finally, the analysis of the items' relevance suggested good content validity of the instrument.

Conclusions: The results of this study suggest that the DABS-F provides a valid adaptation of the original instrument, and is ready for additional psychometric field-trials and investigation.

Track 2: Families/Family Quality of Life

PRESENTATIONS IN A SYMPOSIUM

Relatives of people with profound intellectual and multiple disabilities (PMID)

Family quality of life of families with a child with profound intellectual and multiple disabilities

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Background: Children with profound intellectual and multiple disabilities require an extensive and continuous amount of support. This places a high burden of care on the primary caregivers, who are usually the parents and other family members. As this may have an impact on the family's well-being, it is important to examine and understand the Family Quality of Life (FQoL) of these families.

Method: The FQoL of families with a child with profound intellectual and multiple disabilities was measured using the Beach Center Family Quality of Life Scale, filled out by family members without profound intellectual and multiple disabilities aged 12 years and up. Multilevel models were used to analyse the total FQoL and subscale scores, to compare them between family members, and to examine related factors, such as family income, respondent age, and parental employment status.

Results: Preliminary results show that total FQoL score is high, with lowest score for the subscale of emotional well-being. Scores are similar between family roles. Various factors that influence the FQoL are identified.

Conclusions: Just as people with severe to profound intellectual disabilities have unique care and support needs, so do their families. By examining the FQoL of these families, this study aids in creating the care and support these families need.

Variables related to the quality of life of families with a child with intellectual disabilities

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Background: In order to gain a better understanding of variables related to the Family Quality of Life (FQoL) of families with a child with severe to profound intellectual disabilities, the aim of this systematic review is to categorise variables related to the FQoL of families with a child with intellectual disabilities.

Method: Five electronic databases were consulted, and critical appraisal tools were used to evaluate quality. To determine characteristics of the studies, variables, and theoretical concepts a data extraction and synthesis took place. The identified variables were categorised into four concepts of the FQoL.

Results: A total of 98 variables were found within 40 studies. Variables related positively, negatively, or both to the FQoL and were categorised within individual-member concepts (n=58); family-unit concepts (n=26); performance concepts (n=11); and systemic concepts (n=3). A total of five studies (13%) focused on individuals with severe to profound intellectual disabilities.

Conclusions: The FQoL of families that have a child with intellectual disabilities is (inter)related to several variables. However, it remained ambiguous to what extent the identified variables apply to families that have a child with severe to profound intellectual disabilities because the identified studies on these families were minimal. Additional research is required to fill these knowledge gaps.

Adult siblings in the picture!

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Background: The roles siblings fulfill in the lives of their brother or sister with profound intellectual disabilities are often changing in adult life. When parents are no longer able to fulfill caregiving roles, siblings may also take over some of their roles. The aim of this research project is to explore the roles siblings fulfill, their experiences and needs concerning these roles, and if and how their involvement contributes to the social contacts and participation of individuals with profound intellectual disabilities.
Method: Participants were recruited through different organizations supporting people with intellectual disabilities, on social media and trough interest groups. Siblings were asked to fill out an online questionnaire about which different roles they fulfill, how they fulfill each role, what benefits fulfilling this role has, and what challenges they face.
Results: We are sharing preliminary results during the congress.
Conclusions: This study is a first step into contributing to better information and support for adult siblings. Better collaboration with health care professionals, and advice for care organizations and governmental organizations.

Supporting decision-making

Reflections of parents about value of training and mentoring for supported decision-making practice

Christine Bigby[1], Jacinta Douglas[1], Elizabeth Smith[1], Terry Carney[2], Shih-Ning Then[3], Ilan Wiesel[4]
[1]La Trobe University, Living with Disability Research Centre, Bundoora, Australia; [2]Sydney University, Sydney, Australia; [3]Queensland University of Technology, Brisbane, Australia; [4]University of Melbourne, Melbourne, Australia

Background: To increase capacity of parents to enable adults with intellectual people to participate in decision making and improve their practice by using an evidence-based Support for Decision Making Practice Framework. The research questions were: 1) what were parents' reflections on training and the Framework and 2) did they apply learning (knowledge, skills and attitudes) from the Framework to their support practice.
Method: A social constructionist perspective was used, and data collected through in-depth and repeated interviews with 17 parents of adults with intellectual disabilities after they had completed a one-day training program in the Framework and participated in two to six mentoring sessions. Data were analysed using grounded theory methods.
Results: Training acted as a catalyst for parents to reflect more deeply on processes of decision support, assisted them to take a more deliberate approach to support, and prompted the use of steps and principles from the Framework associated with effective decision support.
Conclusions: The study highlighted the positive impact of training in an evidence-based practice framework and highlighted the value of investment in capacity building measures for parents to provide structure and guidance about support to ensure supported decision-making schemes realise their rights-based objectives.

Grappling with uncertainly: Parental strategies for supporting decision making

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[1]La Trobe University, Living with Disability Research Centre, Bundoora, Australia; [2]Sydney University, Sydney, Australia; [3]Queensland University of Technology, Brisbane, Australia; [4]University of Melbourne, Melbourne, Australia

Background: Supported decision making is a key mechanism to support the rights of people with intellectual disabilities to participate in decision making about their own lives. This study aimed to understand the issues that parents found difficult in supporting exploration of their adult child's preferences and assisting them to understand decision constraints or consequences. It also explored parental strategies for grappling with these.
Method: A social constructionist perspective was used, and data collected through in-depth and repeated interviews with parents of adults with intellectual disabilities. Twenty-three parents participated in three or more interviews. Data were analysed using grounded theory methods.
Results: Results fell into two categories. *Making the right decision* captured parental uncertainties about the "right decision" and concern about issues such as their adult's limited awareness of possibilities or impact of preferences on longer term goals. Parental visions for their adult's future informed their support strategies which centred around *Grappling with uncertainty*, and were about controlling, influencing or attempting to expand horizons of the adult.
Conclusions: This in-depth account of difficulties faced by parents and their strategies adds knowledge of the lived experiences of parents, important for developing capacity building resources and accountability mechanisms for supported decision-making schemes.

Paternalism to empowerment: All in the eye of the beholder?

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[1]Sydney University, Sydney, Australia; [2]La Trobe University, Living with Disability Research Centre, Bundoora, Australia; [3]Queensland University of Technology, Brisbane, Australia; [4]University of Melbourne, Melbourne, Australia

Background: The aim of this study was to explore decision support practices to determine whether, using the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) as the benchmark, it is possible to identify "purchase points" for assessing the degree of shift from paternalism towards empowerment of the person supported.
Method: A social constructionist perspective was used, and data collected through in-depth interviews with 55 dyads of a decision-maker with intellectual disability and their decision supporter, exploring decision support practices of supporters and experiences of decision-making by the people with intellectual disabilities. Data were analysed using grounded theory methods.

Results: The study found a lack of a clear basis for objective “outcomes” measures of compliance with CRPD objectives of empowering the person supported. Instead, the findings regarding the nuanced and subjective character of empowerment favoured a focus on participation by the person supported and reflection and deliberation by the person providing support.

Conclusions: The study supports realisation and evaluation of CRPD goals through training frameworks which increase participation of the person supported and encourage greater reflection and deliberation by supporters on how best to wisely interpret the will and preferences of the person supported.

A new model of key working in children's services

Developing a model of key working for use in a children and young people's disability service

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Background: Key working is an important feature of family-centred care, focusing on creating a central contact and support for families in the context of engagement with a multidisciplinary team. This paper reports the development of a new model of key working within the children and young people's service of a large urban-based disability service provider.

Method: A steering committee was formed within the organisation, with research support, to isolate the key components of effective key working in disability. The model was developed based on a review of the literature and a process of consultation with staff and families.

Results: The model identifies three levels of key working, reflecting varying levels of need. The levels are based on needs in six areas: level of contact, information provision, role in planning, coordination of support, provision of emotional support and advocacy. The model includes an algorithm that allows staff to identify the current level of key working required.

Conclusions: The model has been developed to allow for a responsive provision of supports based on the needs of the family, which promotes the key principles of family-centred care. The ultimate aim of the model is to engage effectively with families to promote children's development.

Staff experiences of a new model of key working in a children and young people's disability service

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Background: As a feature of family-centred care, key working is positioned to support staff to engage with families in a way that recognises their capacities and needs. This paper reports staff experiences of implementing of a new model of key working within a children and young people's disability service.

Method: The study used mixed methods, with staff experiences recorded through routine logging of the time and activities involved in key working and focus groups. An average of 22 staff from six disciplines (including management) took part in focus groups at two time points.

Results: Almost 1000 key working activities were recorded during the implementation of the model. Many required less than 30 minutes activity and clinical coordination was the most common activity. Early staff comments suggested a positive view, though initial challenges included the process of making initial contact with families. By the end of the project there was significant support for key working, though concerns were expressed relating to the workload involved.

Conclusions: Staff recommended that key working continue in the service, recognising that the elements of key working were part of the clinical toolkit. The model was perceived as acceptable and feasible, with the potential to support families.

Parents' experiences of a new model of key working in a children's disability service

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Background: Key working is a key feature of family-centred care, which has been discussed as a model for children's disability services. This paper reports parents' experiences of the pilot implementation of a new model of key working within the children's service of a large urban-based disability service provider.

Methods: The study used mixed methods, with parents' experiences recorded through completion of the Measure of Processes of Care (MPOC) and individual interviews at two time points. Overall, 20 parents completed individual interviews and 30 responded to the MPOC.

Results: Initially, parents had mixed views of key working, with concerns about access to clinical supports and some confusion regarding the new practices. By the end of the pilot, parents reported that positive relationships were formed with staff, but there were some concerns about the potential for relationships to break down. Parent interviews and MPOC responses suggested that key working was associated with experiences of family-centred practice.

Conclusions: Parents' experiences reflect the bedding down of the model, with evidence of adjustment to the new practices and some challenges in consistency and clarity. However, the study highlights the potential contribution of the model.

Developmental disorders and COVID-19

COVID-19: International anxiety levels in parents of individuals with developmental disorders

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Background: This global collaboration aimed to assess how individuals with neurodevelopmental disabilities and their families coped with the early stages of the COVID19 pandemic.
Methods: From April to August 2020, 10,642 families from 78 countries completed an online survey which included questions concerning anxiety, worries and coping at three time points (i.e., before the pandemic, when the pandemic started, and the time of survey completion). Data from 2956 typically developing siblings was also provided. A multilevel regression model was fitted to the data to investigate which factors specifically influenced parent anxiety levels over time, focusing on explanatory variables at three levels of data hierarchy: country (e.g., governmental decisions, mortality rates), family (e.g., living situation, education), and child's characteristics (e.g., diagnosis, medical problems).
Results: Increasingly complex models predicting group differences across time, revealed that diagnostic group and family characteristics were more important for explaining changes in parent anxiety than were country characteristics. Furthermore, there was evidence that specific worries interacted with diagnostic group and time to predict parent anxiety.
Conclusions: While these preliminary results are already very interesting, further analyses will be carried out with a view to inform and thus help better prepare institutions and governments for future crises.

Parental stress regarding children with developmental disorders during stressful events and COVID-19

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Background: We compared parental stress levels and life satisfaction of children with Williams syndrome, Down syndrome and autism spectrum disorders during two stressful events: school transition and during the COVID-19 pandemic.
Method: Parents of 60 children with either Williams syndrome, Down syndrome or autism spectrum disorder were recruited when their children were attending the last year of primary school in 2018, and these parents completed the following questionnaires again during the COVID-19 pandemic: the Genetic Syndromes Stressors Scale (GSSS; Griffith et al., 2011b) which measures parental stressors and the Satisfaction with Life Scale (Diener, Emmons, Larsen & Griffin, 1985), which assesses participants' global life satisfaction.
Results: We hypothesised that during both stressful events parents of children with a rare and complex neurodevelopmental disorder, such as Williams syndrome, would be more stressed compared to parents of children with more common developmental disorders, despite the fact that the disorders share a similar behavioural (autism spectrum disorder) or cognitive (Down syndrome) profile. In addition, it was predicted that across the different groups stress levels would correlate negatively with satisfaction of life.
Conclusions: The findings are discussed in the light of the implications for supporting children with neurodevelopmental disorders and their families during times of crisis.

Emotion regulation in the COVID-19 pandemic in individuals with neurodevelopmental disorders

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Background: Individuals with Williams syndrome frequently have emotional difficulties, but little is known about their emotion regulation (ER) profile. The COVID-19 SEN project provides a unique opportunity to study ER profiles in groups of WS compared to autism spectrum disorder.
Method: From April-August 2020, 10,642 families worldwide completed an online survey which examined the use and efficacy of 12 self-employed ER strategies. Here we focus on 245 individuals with Williams syndrome (M=15.9 years) and 624 with autism spectrum disorder with mild to moderate intellectual disability (M=11.3 years).
Results: Analyses revealed differences between the two groups in terms of how frequently specific ER strategies were used. Furthermore, several of the strategies were more efficacious for individuals with Williams syndrome compared to autism spectrum disorder. Moreover, while anxiety was linked to the use of several ER strategies in the autism spectrum disorder group, high anxiety in Williams syndrome was only associated with the increased use of repetitive behaviors.
Conclusions: We found distinct ER profiles in individuals with Williams syndrome compared to autism spectrum disorder concerning the use, but also their reported efficacy. It is hoped that this research will inspire further studies aimed at gaining insight into the ER profile of individuals with Williams syndrome.

Supporting the wellbeing of families with disabled children

Empowering families through a system-informed approach to developing wellbeing literacy

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Background: Despite the emergence of socio-ecological, strengths-based, and capacity building models, disability care, especially within

the early childhood space, remains primarily grounded in a deficit-based medical model. Language, diagnoses, and interventions focus on what children and families cannot do, rather than what might be possible, undermining the competence, mental health, and function of parents, children and broader communities.

Method: Nine parents of young children with delays or disabilities and five early intervention professionals participated in two separate focus groups and ten program records were randomly selected for review. Data from the three sources were thematically analysed.

Results: Findings suggest that parents developed a greater sense of hope, empowerment, engagement, and wellbeing, which occurred through the wellbeing literacy that was developed through the intervention, as participants learned how to embed wellbeing concepts and practices in their everyday routines and communications with their children.

Conclusions: Approaches to early intervention that incorporate systems informed positive psychology principles potentially are important for shifting the deeply embedded but problematic paradigms that dominate disability care.

Family Quality of Life when there is a child with disability: A call for strengths-based services

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Background: For the disability sector, current systems – including the most recent programs in Australia – are deficit-based. Assessment reports highlight "how disabled" the person is, rather than how supports can be provided to improve quality of life, inclusion and participation in community. Drawing on a positive psychology perspective, family quality of life (FQoL) reflects a sense of wellbeing for families living with disability, focussed on factors that help families adapt, rather than on negative factors. This study explored parent perspectives of their FQoL as they live with childhood disability, comparing the FQOL of families in preschool years to families with school-aged children with disability.

Method: Data from 122 families were collected and analysed using a mixed-methods approach, including a quantitative survey and interviews.

Results: Despite the deficit-focused view of disability, most families reported high FQoL and achieving family goals were important for them. Services, supports, beliefs and values help their FQoL.

Conclusions: Findings point to the benefit of strength-based, family-centered practices rather than deficit-based services. Unless we shift perspectives about disability, systemic factors will stop us from the world that all people – including those with disabilities and their families – want to live in.

Are peer support programs effective for parents of children with disability? A systematic review

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Background: For children with disability or chronic illness, parents/carers play a critical role in enabling or limiting their child's development. The parents'/carers' ability to provide warm, responsive, and structured care is impacted by their own wellbeing. Peer support programs for parents are an established approach that aim to build family capacity and support wellbeing. However existing evidence about the impact of such programs on well-being is inconclusive. This systematic review synthesizes recent evidence of the effectiveness of peer support programs in improving wellbeing for parents/carers of children with disability/chronic illnesses.

Method: Relevant articles published between 2011 and 2020 were identified using the CINAHL, MEDLINE, Embase, A+ education and PsychINFO databases. Covidence was used to screen and populate data extraction forms with indicators of impacts summarized through thematic analysis.

Results: Initial searches resulted in 4,366 articles, with 2,313 articles selected for further screening in Covidence. Results presented will include a summary of the overall findings and identified themes.

Conclusions: This systematic review provides an updated synthesis of the evidence for the effectiveness of peer support interventions for improving wellbeing in parents/carers of children with disability or chronic illness.

Energising and empowering families to build capacity through participation

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Background: Family engagement and empowerment contribute to measurable positive outcomes for young children with developmental delays or additional needs and their families. However, current policies and programs for disability care often rely on reactive, treatment-based, expert-provided services and need more tools to build parent participatory practices. This study aimed to test the impact of Pictability^{TM}, a tool designed to uncover a parent's strength-based vision and associated goals to implement this vision.

Method: This research combined the results from 120 participants who: engaged in traditional Individual Planning conversations, used the Pictability tool, or attended early intervention playgroup sessions (control). Semi-structured interviews at the initial planning/playgroup sessions and four to six months later were conducted and thematically analysed.

Results: Parents in the Individual Planning and Pictability groups were more engaged in planning and pursuing goals than the control group who emphasized getting professional advice. The Pictability tool supported parents to formulate goals for themselves, their family and child, and highlighted parents' role as change agents.

Conclusions: Findings illustrate that with the right tools, parents can experience a catalyst "doing" mindset at the start of their relationship with professionals. Implications highlight the need to re-examine how we support family participatory practices.

WORKSHOPS

Stigma in the lives of parents with intellectual disabilities: Inclusive research, artistic outputs and training resources

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Parents with intellectual disabilities face multiple disadvantages. Mind the Gap, the largest UK intellectual disabilities theatre company, collaborated with Royal Holloway University of London researchers, to use an inclusive qualitative research methodology to interview 22 parents with intellectual disabilities, and from their stories to develop artistic outputs (film, forum theatre, national touring theatre production, giant outdoor theatre events, photo-book) and training resources. Thematic analysis, conducted with continued involvement from researchers and participants with intellectual disabilities, to enhance research quality, developed four substantive themes from the research: 1) "positions of powerlessness," 2) "assumptions of incompetence," 3) "challenging assumptions and proving competence" and 4) "claiming power." Working with a user-led and artist-led research team has demonstrated the importance of "research impact"; translating research into powerful stories, theatre and films, which aim to influence professionals, tackle stigmatised attitudes, and help parents themselves to "take power back". Collaboratively with one of the ID researchers, we will present the themes from the qualitative analysis and our reflections on the inclusive research process, together with some of the artistic outputs and training resources (e.g., short films) for professionals generated from the project. Participants will have opportunity to reflect on the challenges, dilemmas and opportunities when working with parents with intellectual disabilities.

ORAL PRESENTATIONS

The impact of COVID-19 measures on children with disabilities and their families in Uganda

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Background: In this ongoing study we investigate parental perspectives of the impact of the COVID-19 response on children with disabilities in Uganda between April 2020 and March 2021.

Method: We collect phone interview data from 48 parents of children with disabilities enrolled in an ongoing study on a quarterly basis. We assess participants' knowledge and concerns about COVID-19, and the impact of COVID-19 and related measures on their quality of life.

Results: To date participants have been well informed about COVID-19 and try to follow prevention measures. They report difficulties in meeting daily basic needs, most had no income during the lockdown period; their economic situation has improved slightly during the semi-lockdown period but is still affected. Access to health and rehabilitation services has been affected, and parents report regression in their children's physical, emotional, and cognitive development. Parents struggle with home learning, lack of social support, and high stress levels since the onset of the outbreak.

Conclusions: The COVID-19 response has had a marked impact on the health, education, economic and psychosocial situation of children with disabilities and their families, and raises great concern about the long term effects of the measures on child health and development.

The psychometric properties of the Arabic version of family Quality of Life Scale (FQOL)

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Background: The aim of this research was to examine the validity of the Arabic version of the Beach Scale Family Quality of Life (FQoL) scale to measure families' quality of life in the Arab region.

Methods: Data from 320 families who include an individual with disabilities, of whim around half include an individual with an intellectual disability. Confirmatory factor analysis was conducted to examine the structure validity of the scale.

Results: The construct validity was examined by conduction confirmatory factor analysis. In this step, we examined whether the observed data would fit the hypothesized five-factor model of the FQoL scale.

Conclusions: This study showed indicators that confirm the validity and the reliability of the Arabic version FQoL

Answering the clinicians' questions: Do carers support or disempower patients with intellectual disabilities?

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Background: Patients with intellectual disabilities often attend medical appointments accompanied by a companion, either a family member or paid staff. Clinicians appreciate companions' involvement, but there is risk of over-relying on their contribution to the exclusion of the patient with ID. This research examined real-life healthcare interactions to determine how companions were involved in providing responses to clinicians' questions.

Method: Video and audio recordings were made of 24 English General Practice healthchecks where patients with intellectual disabilities attended with a companion. Quantitative analysis explored who clinicians selected to answer their questions and who answered. Qualitative analysis using Conversation Analysis examined in more detail how companions adopted different strategies to provide answers to clinicians' questions.

Results: The majority of clinicians' questions were directed at the patient with intellectual disabilities, and many were answered independently by the patient. When companions did intervene, their contributions covered a gradient from facilitative to “answering for” and over-riding the patients' own contribution.

Conclusions: Clinicians do attempt to focus on the patient with intellectual disabilities as their key informant during healthchecks. Companions can helpfully support the involvement of patients with intellectual disabilities, but can run the risk of infringing on the patient's speaking rights.

The impact of COVID-19 on people with intellectual disabilities, their relatives, and professionals

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Background: Knowledge about the impact of the COVID-19 pandemic on people with intellectual disabilities, their relatives and professionals is scarce.

Method: Following two rapid reviews to identify existing evidence, a qualitative methodology was employed, using semi-structured individual interviews with service users, mothers, and professionals. Data were analyzed thematically; one study used an interpretative phenomenological approach.

Results: All participants described their fear of becoming infected, and all stressed that they missed direct physical contact and the presence of people in their immediate vicinity. Furthermore, people with intellectual disabilities reported trouble in understanding and dealing with the new reality. Mothers explained their lives were, even more than usual, focused on their children's well-being. As a result, mothers had to put aside their own aspirations and needs. Moreover, they missed clear regulations applying to their situation and worried about future care. Professionals expressed an increased sense of responsibility, which was related to both the physical and mental health of service users.

Conclusions: The current study provides valuable insights into the experiences and needs of service users, relatives and professionals during the COVID-19 pandemic.

Remote support for families in formation of an active parents' position within family-centered model

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Background: The active position of parents is an important condition to improve the quality of life of a person with Down syndrome and his/her family. It is based on competence, awareness, attention to the child's abilities, interests and the recognition of his/her right to make a choice. It is important for parents to productively cooperate with specialists, consciously participating in a specialist-parent teamwork.

Method: The principles of Downside Up's family-centered model: support and consideration of the needs and abilities of the whole family, not only the child; comprehensive support: the family receives psychological, pedagogical, social, informational and methodological support; competence-based approach in the formation of skills and abilities of a person with Down syndrome of any age; support and development of parents' competence and active position of a person with Down syndrome.

Results: Parents of people with Down syndrome gain greater self-confidence, interact effectively with a child (adolescent or adult) with Down syndrome.

Conclusions: Variable remote formats of interaction with families make support more effective for parents, enlarge informational and methodological online resources for families, help to change the position of parents to be not only “the one who is receiving help” but also “the one who creates.”

Fatherhood—adults with profound intellectual disabilities: A qualitative study from Poland

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Background: Little is known about the experiences of fathers who care for adult children with profound intellectual disabilities. The aim of this study was to explore these experiences from their perspective. Parenting adult children with profound intellectual disabilities presents a type of fathering experience that differs from that commonly experienced by other fathers.

Method: Researcher conducted narrative interviews with 32 Polish fathers with adult children with profound intellectual disabilities.

Results: Through follow-up questions, researcher encouraged the interviewees to share stories of their personal experiences of fatherhood. The information was shared during the participant interviews using analytical methods, based on theoretical and methodological concepts developed within the biographical sociology framework outlined by Fritz Schütze (1977, 2012). The respondents were asked to share their thoughts about their experiences as fathers from past, present and future perspectives.

Conclusions: Gaining a better understanding of and uncovering details about the fatherhood experiences of men with adult children with profound disabilities is important so as to better understand ways to better support fathers in such situations. It is especially important to know about the ways in which these fathers perceive their experiences and to understand the social context that impacts their experiences and perceptions.

Challenging behaviors among persons with intellectual disabilities: Experience of carers and role of emotional regulation

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Background: This study presents data on the experience of carers working with persons with intellectual disability and challenging behaviors in Quebec. Faced with challenging behaviors, carers may experience a variety of emotional reactions such as anger, fear or anxiety, which can induce psychological distress and lead to burnout (Judd et al., 2016). However, skills among carers, such as emotional regulation (ER), contribute to a better management of the emotional load induced by stressful events (Compas et al., 2013). The objectives were to 1) describe the experience of Quebec carers and 2) test whether ER predicted the level of psychological distress.

Method: We administered an online questionnaire to 120 carers of persons with intellectual disability. A descriptive analysis showed the level of carers' exposure to CB per month ($M = 45.10$).

Results: The most reported types of challenging behaviors were the destruction of property and the verbal aggression. This analysis also highlighted a variety of perceived impacts such as stress, impotence feelings and exhaustion. Regression analysis showed a positive significant relation ($r = 0.66$, $p<0.001$) between ER and psychological distress.

Conclusions: This study provides important data about the experience of carers in Quebec. Our results also suggest that ER could be a protective factor against psychological distress.

Exploration of FQoL in persons with NTDs related disabilities and their family members in Ethiopia

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Background: The objectives of this study were to assess and compare the Family Quality of Life of persons affected by NTDs and their family members.

Method: A cross-sectional study was conducted in the Awi zone in Ethiopia. Persons affected and their family members were selected using purposive sampling. Family Quality of Life, SARI Stigma and Screening of Activity Limitation and Safety Awareness scales used for data collection. Data analysis consisted of simple descriptive and regression analysis.

Results: A total of 95 persons affected and 117 family members were included. The overall mean of the family quality of life score was 71.7. Persons affected had significantly higher mean Family Quality of Life scores than family members on all domains. Female gender, smaller family size and occupation were associated with lower Family Quality of Life.

Conclusions: Family Quality of Life is an important area to address because to provide appropriate support for persons affected and their family members. Efforts to improve the quality of life of families in which a family member is affected by leprosy, podoconiosis or LF should give priority to women and families with smaller family size.

Quality of Life during COVID-19: Do relatives of people with major care needs experience it differently?

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Background: Various studies have demonstrated that, before COVID-19, Quality of Life (QoL) of family members related to people with major care needs tended to be under more pressure than that of families not confronted with major care needs. These families may be under more pressure after the COVID-19 outbreak. The aim of this presentation is to provide insight into the QoL of the relatives of people with major care needs before the outbreak of COVID-19 and describe the influence of COVID-19 on their QoL.

Method: The QoL of 2,845 Dutch individuals (including 697 relatives of people with major care needs) was measured using an online questionnaire before and during the COVID-19 outbreak.

Results: In the situation before the COVID-19 outbreak, the QoL of people with and without a relative with major care needs are compared with each other. Specific attention is paid towards the differences in the change in QoL between these two groups of people.

Conclusions: The COVID-19 outbreak has affected the overall QoL of people both with and without relatives with major care needs, and these effects are unrelated to the burden of care for informal caregivers. Their living arrangements, however, do relate to the QoL of the relatives and the influence of the outbreak of COVID-19.

Impact of leprosy, podoconiosis and lymphatic filariasis on family quality of life in Ethiopia

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Background: Leprosy, podoconiosis and lymphatic filariasis impact individual quality of life. In contrast, family quality of life has not received as much attention despite evidence that families are also affected. This study looks at the impact of these diseases on family quality of life.

Method: The study used a cross-sectional design with a qualitative approach. Participants, persons affected and their family members were selected by purposive sampling. Data were collected between August and November 2017 in Awi zone, Northwest Ethiopia.

Results: A total of 86 participants included 56 participants in the in-depth interviews and 30 participants in the focus group discussions. We found that participation restrictions reduced productivity and marginalization were common. Discrimination in the communities occurred, often extending to family members of persons affected. Divorce and difficulties in finding a spouse were common for persons affected and their family members. While most people got social and physical support from their families, there were a few exceptions. In particular, persons with younger children seemed to lack social support.

Conclusions: This study revealed that leprosy, lymphatic filariasis and podoconiosis affect several dimensions of family quality of life. Many problems were reported related to stigma and poverty.

Burnout among parents of children with CCN: A scoping review informed by a stakeholder consultation

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Background: The challenges and demands facing parents of children with complex care needs have received increasing attention in the burgeoning research on parental burnout. Consequently, the objective of this scoping review was to investigate to what extent research addresses burnout among parents of children with complex care needs and to assess the relevance and coherence of research through a stakeholder consultation.

Methods: A participative approach including parents and healthcare professionals was used to design the study. Primary studies on burnout among parents of children with complex care needs were identified. The findings were extracted and compiled for synthesis and interpretation, guided by the stakeholder consultation. The stakeholder consultation was structured according to a Delphi-consultation method, involving parents of children with complex care needs (n=6), healthcare professionals (n=3), and researchers (n=3).

Results: Fifty-eight articles were eligible for inclusion, 62% were published after 2015. The stakeholders emphasized the need to further investigate the associated factors contributing to burnout and the lack of preventive interventions.

Conclusions: This study indicated that there is a growing acknowledgement of burnout in the context of parents of children with complex care needs. The stakeholder consultation suggests a broader approach than merely focussing on burnout, thereby increasing health and wellbeing of parents and families.

Bringing technology into the homes of children with profound intellectual and multiple disabilities to promote parent-child interaction

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Background: Parents of children with profound intellectual and multiple disabilities struggle to find suitable activities to undertake with their children. This study explores the usefulness of technological products to promote interaction and participation in the home situations of children with profound intellectual and multiple disabilities.

Method: Experimental case study design. Participants were four mothers and their children with profound intellectual and multiple disabilities. Baseline consisted of four 2.5-hour participatory observations, focused on parent-child interaction and activities that were undertaken. Next, families received a range of low-tech products with extensive user instructions and activity suggestions. During this intervention period four additional observations took place, followed by an evaluative interview with the parent. Thematic analysis was used to analyze observation reports and interviews.

Results: Themes are: Activities undertaken (solo and together), parent- and child communicative actions (initiations, responses, expressions), and use of the technology provided (product use, personal experiences). Each dyad reported positive experiences with at least one of the products. Similarities and differences between baseline and intervention conditions will be discussed for the four parent-child dyads.

Conclusions: Technology can mediate in improving the interaction and participation of children with profound intellectual and multiple disabilities at home, but parents are often unaware of the possibilities. Personalized instruction is recommended to optimize product use.

Family carers of older people with intellectual disability and the Irish National Carer's Strategy

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Background: People with intellectual disability are now living longer and, in Ireland, many are living at home ageing concurrently with parent(s) or sibling(s). The National Carer's Strategy (2012) is Ireland's social policy response to informal care and is underpinned by a vision to recognise, support and empower caregivers. This study examined the relevance of the Irish National Carer's Strategy to family carers of older people with an intellectual disability.

Method: Bacchi's What's The Problem Represented To Be? (WPR) approach to critical policy analysis was used. This approach examines the way policy formulates the problem it seeks to address, and the underpinning assumptions and accepted norms. The approach interrogates the silences resulting from the way the issue is problematised and the effects of the representation and requires consideration of how things could be different.

Results: Much the focus of the Strategy is not inclusive of older carers of people with intellectual disability, who experience a number of unique challenges. Some of its goals have little relevance to their lived experiences, and many of the identified supports are inconsistent with those actually available to these carers.

Conclusions: A new paradigmatic approach is required, embedding care in a concept of citizenship

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Experiences of siblings of people with intellectual disabilities: A cross-cultural qualitative study

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Background: Having a sibling with an intellectual disability can influence young people in various ways, yet research is limited by a focus primarily on Western contexts. This study addressed these gaps by investigating the rewards, challenges and support needs of siblings in Latin America, Africa and Asia-Pacific.

Method: Twenty-two siblings between the ages of 8 to 25 representing 16 countries across Latin America, Africa, and Asia Pacific participated in three focus groups during Special Olympics Regional Family and Sibling Workshops. Thematic analysis was used to analyze qualitative data.

Results: Results indicated positive themes related to valuing siblings with intellectual disabilities, close relationships, and personal growth. Challenging themes included stigma, complicated family dynamics, and personal difficulties. For supports needed, themes included future planning and services for siblings with intellectual disabilities.

Conclusions: Results support prior research describing both positive and challenging experiences for siblings. Notable differences include the need for greater quantity and quality of services for their siblings with intellectual disabilities, as well as the impact of societal stigma. Future research should explore the experiences of siblings of people with intellectual disabilities globally, particularly how societal views and lack of structural support for people with intellectual disabilities can influence the relationship.

“We care” parent capacity-building workshops for autism spectrum disorders: Supporting family quality of life

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Background: There is an estimated 353,880 people in Australia diagnosed with Autism Spectrum Disorder. Receiving an autism spectrum disorder diagnosis can have a significant emotional impact on parents and influence their Family Quality of Life (FQoL). “We Care” is a novel intervention developed to provide strategies to support families around the time of diagnosis. The aim in this study was to evaluate the impact of “We Care” on the parents' knowledge of autism spectrum disorders, FQoL and sense of control. Due to Covid-19, the program was changed to online delivery.

Method: Parents of children recently diagnosed with autism spectrum disorder (one year) were invited to participate in “We Care,” a series of three workshops (N=50). A battery of questionnaires (Depression Anxiety and Stress Scale; Pittsburg Sleep Quality Scale; Reaction to Diagnosis Interview; Beach Centre Family Quality of Life Scale) were completed at three time points.

Results: Significant differences in knowledge about autism spectrum disorders, sense of control in managing autism spectrum disorders, and the importance of self-care were reported. Impact of Covid-19 on family routines was discussed during workshops.

Conclusions: This study supports the importance of parent capacity-building following a new diagnosis. It provides valuable insights highlighting creative responses to the pandemic from the “We Care” team.

Developmental risks in vulnerable children from a low-income South African community

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Background: To describe the developmental risks, and its influence, in young children from a low-income South African community.

Method: An exploratory, cross-sectional research study design was employed. Developmental screening using the PEDS tools developmental screening tool was conducted during home visits with 126 caregivers and children between 0 and 42 months of age from a low-income South African community. Children who failed the rescreen were referred for diagnostic assessment. A binomial logistic regression was used to determine the effect of developmental risks on developmental outcomes.

Results: Seventy-three percent of children screened were identified with a possible developmental delay (n=59) according to caregiver-report using the PEDS tools. The regression model was statistically significant (χ^2 (3) $=$ 34.902, $p<0.001$) with exposure to multiple languages ($p<0.05$; odds ratio 3.810, CI 1.2-12.4) most indicative of potential developmental delay. Older children (19–42 months) were also more at risk of developmental delay ($p<0.001$) than younger children (0–18 months).

Conclusions: Healthcare professionals serving these vulnerable populations should create awareness amongst caregivers about the effect of developmental risks, in particularly multiple language exposure, on development.

Effects of the pandemic on the mental health of carers of people with intellectual disabilities: Qualitative findings

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Background: Recent UK Covid-19 lockdown restrictions resulted in reduced access to educational, professional and social support systems for children with intellectual disabilities and their carers. The aim of this study was to gain insight into the ways parents of children and adults with intellectual disabilities experienced the first 2020 lockdown period.
Method: As part of a larger study (see preceding Abstract), sixteen parent carers of children (N=8) and adults (N=8) with intellectual disabilities (who lived and were cared for at home) were interviewed. The recordings of these interviews were subjected to a thematic analysis.
Results: A number of themes were identified relevant to stress and coping with similarities and differences observed when comparing the two samples. All parent carers experienced increased burden and stress. However, some also described a positive impact of lockdown conditions on them as well as on their son or daughter's well-being.
Conclusions: These findings are discussed in the light of our survey results on parental coping. Suggestions for future service provision during pandemic conditions are proposed and we consider the policy implications of these two sets of findings.

Effects of the pandemic on the mental health of carers of people with intellectual disabilities: Quantitative findings

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Background: The measures implemented to manage the COVID-19 pandemic have been shown to impair mental health. This problem is likely to be exacerbated for carers. This study aimed to evaluate the impact of the pandemic on the mental health of carers of children and adults with intellectual disabilities.
Method: Informal carers (mainly parents) of children and adults with intellectual disabilities, and a comparison group of parents of children without disabilities, completed an online questionnaire. Almost all of the data were collected in May-June 2020, while strict lockdown conditions were in place.
Results: A high proportion of carers of both children and adults with intellectual disabilities had clinical levels of anxiety and depression. Differences from a comparison group of carers of children without disabilities were 2 to 3 times greater than reported in earlier pre-pandemic studies. Positive correlations were found between objective stress scores and a variety of mental health and coping outcomes. Despite their greater mental health needs, carers of those with intellectual disability received less social support from a variety of sources.
Conclusions: The results suggest that the pandemic exacerbated carers' mental health problems. The policy implications of these findings will be considered alongside the results.

Building better services for people with an intellectual and/or developmental disability and multiple, complex needs post-COVID-19

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Background: The aim of this research was to promote understanding of the impacts of Covid-19 on the health and wellbeing of people with an intellectual and/or developmental disability who also fall within the Multiple, Complex Needs (MCN) Framework developed by Community Living British Columbia (CLBC). CLBC is the crown agency responsible for intellectual disability supports and services to adults with intellectual disability and their families in British Columbia.
Method: Four virtual focus groups were held with a range of paid service providers who work with people with an intellectual and/or developmental disability and MCN. In total, 23 people participated in the focus groups. The focus groups were digitally audio-recorded, transcribed verbatim, and coded thematically.
Results: Covid-19 didn't cause health inequities, but laid bare existing health inequities and problems with the broader systems of care for people with an intellectual or developmental disability and MCN. There were multiple risk factors that exacerbated health inequities. A lack of availability and access to appropriate housing and reliable, disability-informed health information were significant contributors of health inequities for this population.
Conclusions: This research contributes to scientific knowledge by advancing intervention and system-level recommendations that mitigate the risk of health inequities for people with an intellectual and developmental disability and MCN.

Early childhood development risks and protective factors in vulnerable preschool children

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Background: The aim of the research was to describe the risks and protective factors influencing early childhood development in vulnerable preschool children.

Method: A cross-sectional research design was employed. Data was collected in a low-income community in South Africa. Caregivers with children (n=276) between the ages of three years and six years 11 months (mean 51.57 months; SD ± 12.4) whose children were in a preschool were invited to participate in the research study. Participants were divided into two groups, children with developmental delays and children without a developmental delay.

Results: The study sample included high risk, vulnerable preschool children, with a developmental delay prevalence of 80.1% (221/276). Families included were exposed to an average of five (SD ±1.86) environmental and/or biological risks. According to a logistic regression model, three factors were significantly associated with increasing resilience amongst children with no developmental delay: living with both parents (p<.031, OR 4.5, 95%CI 1.2-17.2), caregivers having at least completed Grade 8 to 12 (p<.027, OR 11.9, 95%CI 1.4-10.5) and parents being married (p<.023, OR 5.1, 95% CI 1.3-20.9).

Conclusions: Important protective factors in low-income communities like caregiver education, living with both parents and parental marriage can inform public health messaging and other population-based interventions to support early childhood development.

Israeli families of children with disabilities during the 2019 Coronavirus pandemic

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Background: The impact of the 2019 coronavirus pandemic has had major implications for all groups in society, and especially for people with disabilities and their families. This study aims to explain family distress and family QoL among Israeli families of children with disabilities during the COVID-19 pandemic based on their resources and by family centers' operation.

Methods: A sample of 182 parents of children with disabilities participated in the study (60% with intellectual disabilities). Parents completed an online survey at the beginning of the 2019 coronavirus pandemic in Israel.

Results: Family Quality of Life was predicted by family recourses, family sense of community and the family center's operation. Family centers' operation includes services provided by the family centers, family's satisfaction with services, sense of community in the family center's community, and family leadership. Furthermore, a sense of sharing between parents and the family center moderates the association between low family resources and family distress. Family center's services moderates the association between low sense of community and family distress.

Conclusions: Family centers have an important contribution to enhanced family quality of life and decreased family distress in times of national crisis, especially for families with low personal and social resources.

Adults with intellectual and developmental disabilities and their families: Staying connected during COVID-19

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Background: The COVID-19 pandemic and restrictive measures enforced in residential settings have resulted in changes in daily routine and modified the ways families can interact with and provide support to adults with intellectual and developmental disabilities residing in supported accommodation. Yet, the impact of these changes has not been empirically explored.

Aim: To explore the experience and perspectives of family caregivers on how they have interacted with and supported their relatives residing in supported accommodation during the pandemic.

Method: Changes in communication modes, frequencies, and types of informal support were measured using a cross-sectional and anonymous online survey completed by 108 family caregivers.

Results: Most family caregivers adopted remote communication technologies; however, these were not perceived to be effective in filling the gap created by reduced face-to-face contact. While families were able to provide emotional support and advocacy using remote communication technologies, they were limited in their ability to provide significant social support. They expressed a need for additional support from staff to enable continuity of the multifaceted dimension of social support for people with intellectual and developmental disabilities.

Conclusions: Novel strategies and policies should be developed to ensure the continuity of family contact and informal support in the context of COVID-19.

Regulation of behavior and emotions in young men with Fragile X syndrome (FXS) and familial stress

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Background: Research on behavioral phenotype in FXS indicates that challenging behaviors do occur also in adults with FXS but showing a decrease of impulsive and aggressive behaviors (Cornish 1996, Greenberg et al. 2012). This explorative study examines how parents of adult young men with FXS experience the behavior of their sons and what effects this behavior has on family satisfaction or stress.

Method: Problem-centered interviews (Witzel 2000) were conducted with a total of nine parents whose sons with FXS were between 20 and 35 years old. The interview data was evaluated by content analysis (Mayring 2016).

Results: The described behavior problems are often caused by changes in the daily routine or transitions. The respondents have developed a range of reactions and measures to the behavior over time, which are used with varying degrees of success. Also, the sons with FXS learn over time strategies to deal better with their impulsive reactions.

Conclusions: The results show that the challenging behavior described by the parents fits very well into existing descriptions of a behavioral phenotype. Overall, the familial stress situation decreases as the sons with FXS grow older, and the families describe their situation as satisfactory for the most part.

Connecting locally: Do non-disabled adult siblings have a role in supporting social inclusion?

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Background: This original study explores the role, if any, of non-disabled adult siblings in supporting the social inclusion in their neighbourhood of their adult sister/brother with intellectual disability, and if present the nature of that role.

Method: A multiple dyad case study design was employed. The sample (n=16) included adults with intellectual disability over 40 years and a sibling nominated by them. Participants with intellectual disability lived in a range of supported living arrangements and neighbourhood types. Each sibling pair engaged in two individual and one joint semi-structured interviews. Data from dyad case reports were analysed using reflexive thematic analysis.

Results: The multiple factors influencing the nature of siblings' support roles were interpreted in five themes. Non-disabled siblings offered mainly practical support for local engagement that was shaped by the family context. Some held a sense of obligation to their sister/brother with intellectual disability, leading to fixed patterns of contact that did not facilitate making local connections. Sibling pairs engaged in leisure activities that were chosen and enjoyed by both, led to some adults with intellectual disability developing new acquaintances.

Conclusions: Siblings are well placed to facilitate social inclusion, given their local knowledge and networks. Detailed implications for practice are discussed, alongside recommendations for further research.

Burden and growth during COVID-19: Parents of children with and without disabilities

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Background: The COVID-19 pandemic and the measures taken to contain it have had a disproportionate impact on families of young children with disabilities. This study examined factors associated with burden and growth among parents of young children with and without disabilities in Israel.

Method: An online questionnaire was completed by 675 parents of young children, 95 of whom had a disability. Participants completed measures on burden, growth, family functioning, informal social support and perceived adequacy of educational services.

Results: Greater burden was found among parents of children with disabilities, while parents of children with and without disabilities reported on similar levels of growth. Support outside the household was lacking for both parent groups. Educational services were perceived as severely inadequate, especially for children with disabilities. Lower levels of family functioning, greater support from spouse and lower perceived adequacy of educational services were found to be associated with greater burden and lower growth.

Conclusions: The results point to the importance of the family system for sustaining the wellbeing of its members in lockdown situations. Further, the findings highlight the importance of planning for such national and global emergencies.

Siblings of young adults with intellectual disabilities: Resilience, future orientation and Family Quality of Life

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Background: Researchers in the field of disability are showing a growing interest in the impact of having a person with disabilities among family members on family quality of life, and on a positive future life designing.

The study proposed here explores the relationships between positive attitudes towards current and future challenges and family quality of life (FQoL) in siblings of children and adolescents with intellectual disability (ID).

Method: The Italian version of *the Beach Center Family Quality of Life Scale* (FQoLS; Park, et al., 2003) was proposed to 47 siblings of a person with intellectual disabilities (age range 18 to 35 years; 16 brothers and 30 sisters). Resilience and future orientation were also measured (Sgaramella et al., 2015; Foti et al., 2019).

Linear regression analysis was applied to determine whether these dimensions are predictors of FQoL they experienced.

Results: Results indicated that siblings with higher levels of resilience reported higher levels of FQoL. Similarly, siblings with higher future orientation reported better levels of FQoL in several diverse dimensions. Specific patterns characterized brothers and sisters.

Conclusions: These results may help service providers to develop new intervention strategies for families with a member with ID, fostering their resilience and future time perspective and ultimately promoting their FQoL.

Attachment psychoeducation to boost self-efficacy in parents of children with severe disabilities

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Background: Achieving high levels of parenting self-efficacy (PSE) is not always evident for parents raising children with extensive support needs because of their limited (behavioral) feedback. However, PSE can be targeted by interventions, such as psychoeducation. The current study piloted a micro-intervention offering psychoeducation on attachment and studied its outcomes on PSE and parents' perceptions of attachment.

Method: The three-week online study included 16 parents of children (4 to 10 years old) with a severe or profound intellectual disability. Daily diary measures and one-time questionnaires were combined in a mixed-method design (with focus on the quantitative data).

Results: Overall, PSE did not significantly differ during pre- and post-measures. Parents' perceptions of attachment only showed small shifts over time, mainly in the strength of their answers. Some parents used more attachment-related words in the post-measure diary questions. Parents were positive about the psychoeducation video series as it stimulated their learning and reflection and it offered them personal meaning (such as feeling acknowledged).

Conclusions: Though no significant changes occurred over time regarding PSE, the micro-intervention was clinically relevant for these parents. Further research is needed to study which types of parents benefit the most from the micro-intervention and for whom additional support is warranted.

Number of adult siblings of persons with intellectual disabilities across the life span

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Background: Adult siblings of persons with disabilities have been overlooked. A descriptive quantitative analysis about the caregiving roles of siblings was conducted. The initial question was related to the number of siblings that persons with disabilities have in different age groups. There is no register, neither the health sector nor a representative study with persons with disabilities (n=22.000) offer this data. In consequence, a random sample could not be used.

Method: As existing data on the population of siblings of persons with disabilities is not available, an alternative approach has been chose based on a secondary analysis in which data from other contexts is analyzed. Most adult persons with intellectual disabilities work at sheltered workshops, regardless of their housing forms. So they might be able to provide personal data from persons with disabilities of different ages. Three sheltered workshops which collect these data were located and they were willing to provide anonymous data (n=2415). Results are compared with the general population.

Results: The number of siblings of persons with disabilities are evaluated across the life span and will be presented.

Conclusions: The results demonstrate the need for a representative study of family data and social relations of persons with disabilities.

Perspectives of persons with intellectual disabilities, siblings and parents about FQoL and family relationships

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Background: The present study aims to understand the perceptions of persons with intellectual disabilities, their siblings and parents about Family Quality of Life (FQoL) and family relationships.

Method: Qualitative methods were used with all the participants: more specifically, focus groups, semi-structured interviews, and photo-elicitation interviews.

Results: Results show that family relationships emerge as the most important domain for good FQoL. Despite this common aspect, there are differences between the perspectives of persons with intellectual disabilities, siblings, and parents. Also, at different stages of the family's life cycle, there are specificities to be taken into account, particularly in later phases, with concerns about the future of the person with intellectual disabilities.

Conclusions: When exploring more about quality of life in families of persons with intellectual disabilities, it is important to consider the perspectives of different family members. It is also relevant to identify the domains that comprise FqoL. since they can be the target of more detailed evaluations and later interventions to improve the quality of life in these families.

A prec(ar)ious balance? The complex family lives of families living with care-intensive children

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Background: Primary aim is to gain more insight into fitting, sustainable forms of cooperation with families with care-intensive children, taking into account what each person involved needs to feel taken seriously. What are both the vulnerabilities and strengths of these families and how can coordination and cooperation between all family members, care professionals and systems contribute to a better balance between surviving and living a good life?

Method: Care-ethical case research is chosen, in which we collaborate with those involved, and in data collection and analysis use is made of ethnographic and phenomenological methods. This design is

interactive, interpretive and reflexive, whereby we recognize that the process, content and outcomes are highly dependent on a complex interplay of people, views, emotions, situations, positions and relationships. Therefore a joint, dialogical exploration of everyday complexity and collaboration has been chosen, also because the approach is to support the (collaborative) relationships by means of the research.

Results/Conclusions: Through our contribution we would like to create space for an exchange about (potential) pitfalls and gains for this challenging way of conducting collaborative research within highly complex and personal contexts, and invite members of the audience to contribute from their own (research or personal) experience.

Robot Luna enhances quality of life for families with parents with intellectual disabilities

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Background: The UN Convention on the Rights for Persons with Disabilities affirms the rights of people with intellectual disabilities to start a family and calls for appropriate assistance to these parents in the performance of their child-rearing responsibilities. Support can be delivered by professionals, but also by robotics. In this study we investigated the development and use of a special designed robot “Luna” to support parents to enhance family quality of life.

Method: Participatory Action Research was conducted to explore together with parents their desires for support. A co-creation group with parents, professionals and designers examined the support needs of parents. Next, five families, together with professionals and designers followed different iterative cycles to design, test and adapt robot Luna. At start and after the last cycle family quality of life was measured.

Results: Results of stage one showed that parents indicated three important ingredients for support: support should be independent, without judgement about their parental capacities, and it has to ameliorate family quality of life. We will present results of the second stage of research.

Conclusions: Based on the results of this study, recommendations will be made for designing the future robot Luna to enhance family quality of life.

Quality of life of family members of people with intellectual and developmental disabilities before and during COVID-19

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Background: The COVID-19 pandemic entails risk factors for the quality of life of family members of people with intellectual and developmental disability, such as a higher care burden, stress and a decline in social support. The aim of the study is to monitor the consequences for family members' quality of life during (the phasing-out of) the measures and “the new normal.”

Method: We employed a mixed methods design. Throughout the project, we worked together with experience experts. Questionnaires were filled out by 350 family members in October 2020. Ten were interviewed. Results from October 2020 were compared with results from measurements in 2019 and June 2020.

Results: Family members' quality of life is relatively good and did not change much over time, but approximately 10% suffers from the situation. Although contact with relatives with intellectual disabilities living in a health care facility is limited, the majority is able to express their love and care. Involvement in the measures taken by care organizations, helps family members to cope with the situation.

Conclusions: The study provides insight into risk and protective factors for family member's quality of life during the COVID-19 pandemic. These insights can contribute to ease their current situation.

Who will take over my responsibilities? A qualitative study among relatives of people with intellectual and developmental disabilities

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Background: All relatives who take intensive care of a family member with an intellectual and developmental disability think about the question: “Who will take over my responsibilities, if I can no longer do it?” The aim of this project is to develop a tool that can help relatives of people with intellectual disabilities with thinking about this and taking concrete steps.

Method: A quick scan was performed to identify existing resources for relatives. Interviews were conducted with relatives and experts in the field. Interviews were analysed using thematic analysis. The entire project was carried out together with experience experts.

Results: The question “What if I can no longer do it?” is relevant in many contexts. Relatives worry about getting older, passing away, becoming ill and becoming overloaded. Relevant themes in thinking about this are awareness, care and housing, emotional coping, social network and recording.

Conclusions: Relatives of people with intellectual disabilities differ in how they deal with the question “What if I can no longer do it?” Information and advice, practical resources and sharing experiences with other relatives can be helpful for relatives to find solutions that fit their and their family members' situation best.

Parents' need-related experiences and behaviors when raising a child with Down syndrome

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Background: Research suggests that parenting a child with Down syndrome brings about major and unique challenges to parents' psychological needs. Parents have to deal with increased emotional, physical and financial demands, often resulting in a higher level of parental stress (Phillips, Conners, & Curtner-Smith, 2017). This qualitative study provides insight in the experiences and behaviors of parents when raising a child with DS. The Self-Determination Theory (Ryan & Deci, 2017) is used as a framework to understand how these experiences and behaviors relate to the psychological needs for autonomy, relatedness and competence.

Method: Eleven parents of children with Down syndrome, aged 4 to 23, participated in an in-depth interview concerning their parental experiences and behaviors.

Results: The thematic analysis identified six themes of parental experiences and three themes of parenting behaviors.

Conclusions: First, the results provide a deeper understanding of the challenges and opportunities for the well-being of parents when raising a child with Down syndrome. Second, this study gives insight in how these parents adjust their parenting behaviors to support the psychological needs of their child with Down syndrome. These findings identify important targets for parent support, as they can promote both parental well-being and needs-supportive parenting of the child with Down syndrome.

Mothers of children with a disability and their life experience: A qualitative study

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Background: Some parents share their personal experience through ego-documents. Ego-documents are documents in which the reader is confronted with a person who describes events from his/her own perspective. The aim of this study is to examine ego-documents describing the mother's experience after giving birth to a child with a disability.

Method: A qualitative study was conducted of ego-documents written by mothers of a child with a disability. Inclusion criteria: Dutch books written by mothers from 2005 up to 2020. Exclusion criteria: Ego-documents written by other relatives or in other languages.

Results: In total nine books were qualitatively analysed. The three important themes found were: 1) feelings, for example, grief, pride, connectedness; 2) beliefs for example, in the possibilities of the child, that they are important for their child; 3) social behaviours and intentions for example, sad behaviours/intentions, wanting to be there for their child and moments of transformation.

Conclusions: Parents with a child with a disability are confronted with hopelessness, ignorance, sadness, fear of the unknown and negative judgements. Over time the parents experience new perspective with possibilities, accepting limitations, discovering the qualities of your child and discovering qualities of themselves as parents. Parents describe their experience: from loss to acceptance.

Becoming an activist: The power and the pain of parental advocacy for inclusive education

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Background: The aim of this research was to tell the story of the Queensland Collective for Inclusive Education (QCIE), a parental advocacy group in Queensland, Australia. Collective parental activism is recognised as a powerful driver for inclusive education reform; understanding how parent collectives develop and the impact on parents of this work is critical to inclusive education reform moving forward.

Method: Collective narrative methodology was used to gather and retell the story of QCIE. Collective narrative weaves the stories of individuals into a story of the whole. Ten parent members of QCIE participated in group and individual interviews and to the re-storying of the collective narrative.

Results: QCIE's story paints a picture of a committed, strategic and collaborative group of individuals. It also highlights the considerable effort and stress associated with parent activism. Key themes in the group's formation include shared commitment to inclusion, leadership, personal growth, relationships, and sustainability.

Conclusions: Findings reinforce the critical role of the parent movement in inclusive education reform but also the pressing need for allies so that advocacy for inclusive education is sustainable and not so heavily dependent on parents.

POSTER PRESENTATIONS

Scoping review of eHealth interventions to support parents of children living with autism

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Background: eHealth services can be a valuable and often more accessible option than in-person interventions to help parents manage challenges associated with raising children living with autism spectrum disorder. This scoping review aims to assess the literature on current eHealth resources available to provide education and support for parents raising children with autism spectrum disorder to aid in future intervention development.

Method: The methodology is guided by Tricco et al.'s PRISMA-ScR checklist. Search procedures were established in consultation with university librarian and include searches of six electronic library databases. Abstracts and full text articles were assessed by four reviewers; two of whom also arbitrated disagreements.

Results: Search results and key findings will be presented. Findings will include information on the study designs, sample characteristics, nature of the eHealth interventions, and parent-related outcomes.

Conclusions: Information will be provided summarizing the literature on the use of eHealth interventions and strategies to support families of children living with autism spectrum disorder and related parent outcomes. This information will be valuable to understand how eHealth strategies can be utilized in community settings to provide parents with needed supports and resources. This can ultimately contribute to improved quality of life for children and their families living with autism spectrum disorder.

Partner-oriented projects: Attitude of parents having a child with an intellectual disability

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Background: Parental stress and psychological distress are particularly prevalent among parents having a child with an intellectual disability. A satisfying marital relationship can act as a protection factor for psychological health. This study investigates partner-oriented projects of parents having a child with an intellectual disability.

Method: Overall, 47 mothers and 37 fathers completed individually the Personal Projects Analysis Grid (Little, 1983) administered during a semi-structured interview. These latter were recorded and transcribed, and a thematic content analysis was performed by two independent coders, using emerging codes. Among parents, 17 mothers and 17 fathers retained, in their five most important projects, at least one partner-oriented project, which were submitted to a deeper analysis.

Results: Commitment and dispositional optimism emerged as two central themes regarding the participants' assessment of their partner-oriented projects and served as two classification axes. The analysis highlighted four categories of parents' attitude regarding their partner-oriented projects: purposeful skeptic, nonchalant skeptic, purposeful optimist, nonchalant optimist.

Conclusions: Parents' awareness of their attitude toward their projects could potentially help them to question their underlying motivations, discuss with their partner, and get involved in more intrinsic projects which can support their psychological health, and enhance the quality of their intimate relationship.

Physical activity project profiles of parents having a child with an intellectual disability

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Background: Research has shown that physical activity helps to cope with stress and prevents its adverse effects on physical and mental health. Despite these benefits, many parents don't practice such activity due to their other obligations. Until now, few studies have investigated the link between physical activity and the experience of psychological distress among parents having a child with an intellectual disability. Yet, parents having a child with an intellectual disability are known to experience more stress and distress than general population and could benefit from incorporating such activity in their life. This study explores the personal projects of these parents related to physical activity.

Method: Overall, 47 mothers and 37 fathers participated in a semi-structured interview to complete Little's (1983) Personal Project Analysis Grid. Following a repeated reading of transcripts, two coders proceeded to a thematic content analysis.

Results: Only 32 parents considered physical activity as one of their five most important personal projects. Five profiles of parents emerged: need an 8th day, why not tomorrow, it's beneficial, it's enjoyable, a life or death matter.

Conclusions: These profiles highlight issues faced by some parents and could lead to implement specific resources or interventions to support them in their projects.

Enabling school success but struggling with quality of life: Families in Canada and Australia

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Background: The positive involvement of families in raising a child with special needs often comes with a high level of stress for parents and negative outcomes on family quality of life. However, studies describing parents' involvement to prevent their children from being excluded or dropping out of school, and the impacts of these actions on their family quality of life are surprisingly scarce. The studies reported in this poster probed these parenting experiences in two countries.

Method: Both studies used in-depth interviews and qualitative analyses. One homed in on activities by which Canadian parents help children with disabilities to transition from kindergarten to grade one ($n = 8$). The other investigated private tutoring as learning support for Australian children perceived to have literacy learning difficulties ($n=9$ parents).

Results: In both contexts, parents spoke of their use of resources external to the school (themselves or tutors) to enable their child's academic inclusion. Financial sacrifices, parental advocacy activities are omnipresent from the moment of school entry, with multiple ramifications for quality of life.

Conclusions: The findings point to inadequacies of school support for inclusion of children with special needs. They suggest levers for action that might increase familial quality of life.

Emotional discourse of immigrant parents of child with autism during the service trajectory

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Background: The reality of families living with a child with autism spectrum disorder can be challenging, but also rewarding. In either case, parents can go through a lot of emotions during the different transitional milestones that come with the developmental particularities of their child (i.e., the announcement of the diagnosis or the transition from specialized services to school). Difficulties can be added when parents are immigrants and therefore may not have sufficient social support or knowledge about the healthcare system. The current study investigates the emotional discourse, psychological adaptability, and resilience in parents who have a child with autism spectrum disorder.
Method: Eighteen immigrant families were interviewed about their experiences within the service trajectory in an area of Montreal, Canada. Emotional responses were extracted using thematic analysis to explore the various emotional stages and challenges that parents can go through, from the announcement of the diagnosis up until transition to school. Coping mechanisms and resilience behaviors are also reported.
Results/Conclusions: The findings of this study are essential to guide the support needs of parents during the trajectory of early childhood for families who have a child with autism spectrum disorder.

Effects and predictors of successful supervision order trajectories in families with mild intellectual disabilities

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Background: Children with mild to borderline intellectual disabilities and children of parents with mild to borderline intellectual disabilities and multi-problems are at high risk for unsafe parenting. These children are overrepresented in youth care and youth protection (McConnell, 2017). A family supervision order (FSO) can be imposed by a judge, to protect the child and support the parents. Practice has shown that an FSO in most families with mild to borderline intellectual disabilities lasts longer than two years. However, little is known about the effects of FSOs (Albright et al., 2019). The aim of this project is to investigate the effect of an FSO on the safety of youth, and which child and parent characteristics predict duration and success of an FSO.
Method: In a sample of N=137 of youth with mild to borderline intellectual disabilities, aged 0-18, with an FSO in the Netherlands, their closed casefiles were coded at start and ending of the FSO. Predictive factors were intellectual disabilities, behavioral and psychiatric problems, and adverse childhood experiences (ACEs) of both youth and parents were measured using a structured coding system. Inter-rater-reliability was high (mean Kappa = .78). Data are currently being prepared for regression analyses.
Results/Conclusions: Definitive results on effects and predictive characteristics will be presented in the poster.

Satisfaction of parents of children with autism spectrum disorder with perceived social support

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Background: Social support can have a considerable influence on the lives of parents. This study examines whether parents are satisfied with the social support obtained.
Method: A total of 161 Quebec parents of children with autism spectrum disorders participated in this study. They completed the Perceived Social Support Questionnaire assessing the availability and the degree of satisfaction with the social support obtained.
Results: Parents have up to four people available to provide them with esteem support, informational support, emotional support as well as material or financial support. Overall, 11% of parents are very satisfied, 38% of parents are satisfied, 28% of parents are somewhat satisfied, 14% of parents are somewhat dissatisfied, 8% of parents are dissatisfied, and no parent is very unsatisfied.
Conclusions: The rates of parents who are very satisfied are quite similar for all forms of social support. The rates of parents who are very dissatisfied are more variable, and show that the main support with which parents are dissatisfied is material or financial support. There therefore appears to be a lack of resources offering material support, such as respite centers, and a lack of financial resources, including government grants available to parents of children with autism spectrum disorders.

Analysis of the basic situation and needs of people with intellectual disability in China

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Background: From October 1st to November 30th, 2019, the Chinese government conducted a survey on people with disabilities who hold the second-generation disability identification card of the People's

Republic of China in the national basic database of the disabled population.

Method: The total number of people with disabilities in this survey is 34,800,215, of whom 3,067,015 were intellectual disability, accounting for 8.81 percent. Based on this survey, this article analyzes the conditions and needs of people with intellectual disabilities.

Results/Conclusions: It mainly includes the following aspects: 1) disability status, including disability category, disability degree, education level and age distribution; 2) regional distribution, including regions, urban and rural areas; 3) the family economic status, including poverty, housing and social assistance status; 4) employment and social security, including employment, forms of employment, reasons for non-employment, access to pension insurance and medical insurance; 5) health status, including status of illness within two weeks, treatment after illness, participation in recreational and sports activities, and access to rehabilitation services. In addition, this article also analyzes the status of women and children with intellectual disabilities.

Empowering families through technology: A health project to reduce the TAND treatment gap (TANDem)

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Background: Tuberous sclerosis complex (TSC) is a multi-system genetic disorder associated with variably complex TSC-associated neuropsychiatric disorders (TAND; e.g. autism, self-injury, academic difficulties). TAND is of significant concern to families, but is under-identified and under-treated. Community-based participatory research identified three priorities for TAND research. First, the need for a self-complete, quantified version of the TAND Checklist (de Vries et al., 2015); second, to have the checklist as a smartphone app; third, to receive TAND management advice following app completion.

Method: TSC family and professional stakeholders, technology developers, global TSC stakeholders, and emerging TAND researchers aim to address these three priorities. Stages of the project include: development and validation of a quantified, self-complete TAND Checklist (TAND-SQ) within a smartphone "app," generation of consensus clinical guidelines for management of TAND clusters, and development of a Global TAND Consortium via networking, capacity-building and public engagement activities.

Results: Here we outline the study protocol, impact loop and stages of the TANDem project over the next four years.

Conclusions: A successful project will transform the TAND landscape worldwide; empowering families through an easily accessible digital solution to identify TAND needs and providing the TSC community with consensus guidelines to prevent, treat and manage TAND manifestations.

Parent motivations to enrol their children in a play program Singapore

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Background: As part of a more extensive study, this investigation presents parents' motivations to enrol their children with varying disabilities in a research-based play program in Singapore. The aim was to understand these parents' perspectives on their child's play.

Method: Forty-six parent responded to an open-ended questionnaire consisting of 21 questions. Additional interviews with eight parents provided further information through after observing their child in play. The analysis identified eight themes: Understanding of disability, Knowledge of their child, Parent's beliefs on play, Experiences at home, Social engagement, Behavioural challenges, Child's interest, and Child's identity and agency.

Results: The themes revealed that most parents entered the program because of their children's social and communicative struggles. Most parents recognized their children's positive characteristics, but emphasized the child's difficulties. They highlighted concerns about communication, friendship and difficulties caused by behaviour. Parents who had attended 10 or more sessions provided additional feedback expanded views and changed their perspective on their child's identity and agency.

Conclusions: This study enabled an understanding of parents' motivation to engage their child in unstructured play. The themes that emerged will support parents. Understanding play allows considering a focus on their child's interest and creative engagement beyond behavioural support.

It is not possible to care 24 hours a day: Burden of families due to COVID-19

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Background: Families have had to make extensive efforts during the COVID-19 pandemic to provide individuals with intellectual and developmental disabilities the supports they needed. This study analyzed the impact that COVID-19 and the response measures implemented by the Spanish Government have had on families of individuals with intellectual and developmental disabilities.

Method: Data on 323 family members (M=52.3 years old; DT= 10.5; 53.8% mothers) were collected through an online survey, which was focused on analyzing family quality of life and service provision during lockdown.

Results: Three out of four families stopped receiving services or experienced significant changes in their provision. Among family members who spent the lockdown with the person with intellectual and developmental disabilities (n=274), 66.3% experienced more stress due to burden of care. More than half of the families (51.8%) also experienced difficulties in providing the supports that the person with intellectual and developmental disabilities needed during lockdown. These difficulties were even higher (76.6%) among those families whose children were attending online classes.

Conclusions: Support services for people with intellectual and developmental disabilities should have been considered essential services during lockdown. The failure to receive supports has resulted in families having to assume a multitude of roles to support their family member with intellectual and developmental disabilities.

Relation between dispositional mindfulness and mental health of parents and their child's behaviors

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Background: Studies have shown links between parents' and child's adaptation. Likewise, mindfulness, a mental state where individuals pay attention deliberately, without judgment to the present moment, has been associated with mental health in many populations. Few studies have examined the action mechanisms of mindfulness among parents of a child with an intellectual disability. Establish among the latter population the relation between dispositional mindfulness and mental health of parents, and their child's problematic and adaptive behaviors.

Method: A sample of 83 parents (47 mothers, 36 fathers) receiving services for their child with an intellectual disability completed individually a self-reported questionnaire.

Results: Parents' stress and distress are correlated to their child's problematic behaviors. No significant relation is observed with parents' well-being as well as child's adaptive behaviors. Moreover, parents' dispositional mindfulness is significantly related to their mental health, but not to the child's behaviors.

Conclusions: Child's problematic behaviors could be a reaction to parents' actions and may exacerbate their stress and distress. However, because adaptive behaviors are more predictable since they relate to the child's condition, their effects could be less detrimental on the parents' mental health. Studies are needed to understand the action mechanisms of parents' mindfulness on their child's behaviors.

Caring together, learning together: Co-creating sustainable family participation in Educational Sciences

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Background: This pilot study investigates how families with children with complex care needs can participate in the bachelor program Educational Studies.

Method: Methods of participatory action research will be used. Families with children with complex care needs are involved during all stages of the research and the resulting educational intervention. Interviews and focus groups will be held, and a first analysis presented to the participants. Following, in co-creation families, adolescents with complex care needs, university staff and students develop an educational intervention.

Results: By July 2021 we will have gathered and analyzed data from individual interviews with stakeholders and heterogeneous focus groups. Therefore we will know how families would like to be involved in Educational Sciences and which learning outcomes for students and families can be achieved with different kinds of family involvement.

Conclusions: To our knowledge, involvement of families with children with complex care needs and other relevant stakeholders in all stages of research and the resulting educational intervention has not been done yet. Through participation, families determine what and how students should learn, and future professionals are skilled to emphasize and attune to the needs of families.

Track 2b: Individual QOL/Outcomes/Systems of Support

PRESENTATIONS IN A SYMPOSIUM

Observing the quality of staff practice

Reviewing observational methods for measuring the quality of support

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Background: Building on work by Mansell and Beadle-Brown, our Australian program of research identified predictors of good Active Support in supported accommodation services for people with intellectual disabilities and illustrated the benefits of using observational methods to measure practice. This paper provides an overview of observation as an approach to measuring the quality of practice and its value to managers and regulators

Methods: A scoping review of literature published from 2000 to 2020 identified observational measures of the quality of practice in intellectual disability services, evidence about the benefits of using observation, and problems relying on paperwork or process measures.

Results: The Active Support Measure originally developed by Mansell and Elliot in 1996 has been the most frequently used observational measure of staff practice in services. Few studies have directly compared observational to other measures of quality, but overall the literature suggests that the quality of practice is overstated when it is self-reported or relies on process as an indicator of quality.

Conclusions: If the benefits of observational methods for measuring and reporting on the quality of practice are to be more widely adopted by organisations and regulators, then simple and easy to use measures are needed.

Developing the "Observing Staff Support Tool" for regulators and managers

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Background: The Active Support Measure (ASM) has been used by researchers to measure the quality of staff support. Exploratory factor analysis (EFA) indicated the ASM measures two factors: Supporting Engagement in Activities and Relationships with the Person being Supported. Although the ASM has been used successfully by researchers to conduct observations, it requires extensive training to complete. As such, it is not easy for regulators, managers or others not trained in research to use. The aim was to develop a simple and valid observational tool that can be used by non-researchers and is based on the conceptual framework of the ASM.
Method: A mixed-methods design was used. Building on an EFA of the ASM, items and guidelines were developed and then tested for validity and reliability through several stages involving review by experts, managers, and field testing in services.
Results: The new tool consists of eight main items and two additional items scored on a 3-point scale. Preliminary findings suggest the tool has acceptable psychometric properties.
Conclusions: The new tool offers a simple and easy way for managers and regulators to assess the quality of staff practice using observation.

Psychometric evaluation of the active support measure

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Background: The Active Support Measure (ASM) is the most frequently used observational measure of quality of staff support for people with intellectual disabilities in supported accommodation. The ASM comprises 15 items. Studies show that ASM scores predict service users' levels of engagement. Despite being used in numerous studies, the ASM's underlying factor structure has not been examined and our aim was to test its psychometric properties.
Method: Exploratory factor analysis (EFA) was conducted on the ASM using a dataset of 884 people with intellectual disabilities living in Australian group homes, collected between 2010 and 2018 as part of a study to identify Active Support predictors. Rasch analysis further tested the dimensionality and the consistency that response options behaved across items.
Results: EFA indicated that 10 items loaded on two factors. These factors were Supporting Engagement in Activities and Relationship with the Person. Cronbach's alpha was .94 and .78. Rasch analysis supported multidimensionality, indicated 10 items should be retained, with response options (scores of 0-2) behaving consistently across items.
Conclusions: The ASM measures two dimensions of the quality of support. A revised 10-item version will be easier for researchers to use and can form the basis for a tool for non-researchers.

Relational quality of life of people with profound intellectual and multiple disabilities (PMID)

Parents' concerns about being outlived by their child with profound intellectual and multiple disabilities: A qualitative study

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Background: People with profound intellectual and multiple disabilities have a growing life expectancy, and the chance that they outlive their parents increases. Parents express concerns about being possibly outlived by their child with profound intellectual and multiple disabilities. Since little is known about the nature of these concerns, we aimed to explore these concerns.
Method: We interviewed 27 parents of persons with profound intellectual and multiple disabilities and analyzed the data thematically.
Results: Almost all parents expressed concerns about being outlived by their child with profound intellectual and multiple disabilities and most hoped to outlive their child with profound intellectual and multiple disabilities. The uncertainty regarding the future fulfilment of roles they fulfilled in their child's life contributed to their concerns. These roles related to the expertise of their child, advocating for their child, and attention for their child. Some parents felt they and their child were inseparable and some–mostly the ones with a child living at home–felt irreplaceable, and experienced feelings of despair about being possibly outlived by their child.
Conclusions: Our study provides insight into the nature and gravity of parents' concerns, and may support professionals to listen to the feelings and thoughts of parents in a non-judgmental way. The division of parents' concerns into roles helps to address future support gaps for people with profound intellectual and multiple disabilities.

The importance of longstanding relationships for the QoL of persons with profound intellectual and multiple disabilities

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Background: In this qualitative study, we explored Quality of Life (QoL) of persons with profound intellectual and multiple disabilities.

Method: We interviewed seven physicians, 11 professional caregivers and five mothers, and conducted focus groups with the parents of 16 children and adults with profound intellectual and multiple disabilities. We analyzed the data thematically.

Results: Physicians reported on a positive influence of relationships on the QoL of persons with profound intellectual and multiple disabilities, especially emphasizing the importance of parent-child relationships. In addition, professional caregivers emphasized the dependency of persons with profound intellectual and multiple disabilities on them to reach (good) QoL. Parents underscored the importance of relations for their child's QoL. Moreover, they were convinced that the ability to assess their child's QoL required a longstanding relationship with their child.

Conclusions: Our conclusion is that (longstanding) relationships are essential for the QoL of persons with profound intellectual and multiple disabilities, because of their dependency on others for all activities in daily life. The emphasis on relationships as a prerequisite for (good) QoL of persons with profound intellectual and multiple disabilities requires that we reconfirm the importance of parents in the lives of their children. Furthermore, good QoL demands conditions – such as time and proximity – that enable professional caregivers to form relationships with persons with profound intellectual and multiple disabilities.

Relational dignity: A life worth sharing

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Background: In discussions on Quality of Life (QoL) of persons with profound intellectual and multiple disabilities, *dignity* is used in various ways. A mother stating, "My child has no dignity anymore because over the past years, his QoL only deteriorated," contrasts with a physician stating, "I believe each human being, including your son, has dignity." Based on different conceptualizations of dignity, different treatment plans may follow. The objective of this presentation is to highlight four conceptualizations of dignity, with a particular focus on relational dignity.

Method: Theory on dignity is applied to persons with profound intellectual and multiple disabilities.

Results: Whereas each human being has intrinsic dignity (the physician quoted above), claiming that each life is worth living, relational dignity highlights that the life of a person with PIMD is worth sharing. We will clarify that relational, more than intrinsic dignity, reflects quality of life. Relational dignity rests on the experiences of others sharing the life with the person with PIMD (the mother). During the presentation we will discuss the joy such sharing brings, but also what it costs, financially and otherwise.

Conclusions: For the sake of good care for persons with profound intellectual and multiple disabilities, it should be clear which concept of dignity is used.

Domestic violence and abuse against adults

Social workers' conceptualisations of domestic violence and abuse against people with intellectual and developmental disabilities

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Background: To explore how qualified social workers in the UK conceptualise domestic violence and abuse against adults with learning disabilities.

Method: Semi-structured interviews and vignettes were used in doctorial research to explore social workers' conceptualisation of domestic violence and abuse (DVA) against adults with learning disabilities. The data was analysed using thematic analysis. In this presentation, I will focus on the theme relating to social workers' understanding of the vulnerability of victims.

Results: Findings suggest that participants viewed vulnerability as an acquired, rather than inherent, quality which resulted from the victim's individual lived experience of trauma and interactions with others. Whilst participants conceptualised that life events made individuals more susceptible to DVA, they were less likely to explore the victim's experience of systemic sources of oppression and how these contributed to the victim's experience of abuse. This understanding of vulnerability led workers to formulate interventions which sought to address the individual victim's awareness of risk and harm from the relationship, focusing on the victim changing their behaviour to minimise harm.

Conclusions: As well as focussing on the individual interventions, practitioners need to also acknowledge and address the role of systemic oppression in DVA experienced by adults with learning disabilities.

Violence against women with learning disabilities by non-disabled partners: Is this grooming?

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Background: To explore the similarities between the domestic violence experiences of women with learning disabilities and those of other disabled people who experience "grooming" as part of disability hate crime.

Method: Semi-structured in-depth interviews were conducted with 15 women with learning disabilities. The women were asked about how the violent relationship began, how it developed, their experiences and those of their children.

Results: The women's accounts revealed a common pattern of relationship formation (the abusive partners moving the relationship along very quickly at the outset and moving themselves into the women's homes) which parallels the behaviour of some perpetrators of disability hate crime.

Conclusions: Adult women in violent relationships are generally expected to exert their autonomy and make decisions to reduce risks to themselves and their children. But we understand that vulnerable adults who have been groomed are often unable to exert autonomy. Therefore, health and social care professionals need to be more pro-active in trying to protect women from domestic violence.

Intimate partner violence and IDD: Understanding client needs in a domestic violence shelter

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Background: Individuals with intellectual and developmental disabilities are at heightened risk of intimate partner violence (IPV), yet this widespread problem has received limited attention in scholarly research. IPV-focused service structures, such as domestic violence shelters, often fail to adequately address the needs of survivors with intellectual and developmental disabilities. This study provides a profile of individuals with intellectual and developmental disabilities seeking residential domestic violence services.

Method: A retrospective case study review was conducted covering a six-year service period in Freedom House, a domestic violence shelter with disability-focused services. The study examines key demographics along with familial, social, and contextual aspects of IPV among women with disabilities, with a particular focus on the clients with intellectual and developmental disabilities and non-disabled clients whose children had intellectual and developmental disabilities.

Results: IPV survivors with intellectual and developmental disabilities and survivors with children with intellectual and developmental disabilities have multifaceted and unique needs that impact the interventions utilized with this population. IPV interventions must be comprehensive in accounting for health, safety, and social needs.

Conclusions: Domestic violence service providers must take an individual's full disability profile into account when addressing the problem.

Adverse (childhood) experiences in the lives of people with intellectual disabilities (ID)

Adverse childhood experiences (ACEs) and family context factors

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Background: Adverse Childhood Experiences (ACEs) are an overlooked risk factor for behavioural, mental and physical health disparities in children with intellectual disabilities and borderline intellectual functioning. Moreover, these children are strongly under-represented in global ACE research.

Method: To gain insight into the presence of the 10 original ACEs and related family context variables in a convenience sample of children with intellectual disabilities and borderline intellectual functioning in Dutch residential care, a case-file study was conducted. 134 case-files of children with intellectual disabilities ($n=82$) and borderline intellectual functioning ($n=52$) were analysed.

Results: Results will be presented at the congress; the prevalence of ACEs appeared to be considerably higher than in the general population.

Conclusions: Increased awareness to the impact of ACEs and family context factors is urgently needed in practice, policy and prevention for children with limitations in cognitive and adaptive functioning and their families.

Resilience in the face of adversity: How people with intellectual disabilities deal with challenging times

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Background: People with intellectual disabilities are at an increased risk of experiencing adversity throughout the entire lifespan. However, little is known about how people with intellectual disabilities are able to manage adversity successfully. The process of effective negotiating, adapting to or managing significant sources of stress and trauma is called resilience. The current research project aims at studying resilience in people with intellectual disabilities to better understand and promote the process of resilience in people with intellectual disabilities.

Method: A total of 12 guided photovoice interviews will be conducted with people with intellectual disabilities. To fit the strengths and difficulties of people with intellectual disabilities a "guided photovoice" procedure will be used in the period from September 2020 to April 2021. Also, 12 interviews will be conducted with a person from the social network of the person with intellectual disabilities.

Results: Various themes will be identified with regard to resilience in people with intellectual disabilities through thematic analysis.

Conclusions: The current studies provide a first insight in resources of resilience in people with intellectual disabilities. These findings can be used to adapt policies and interventions leading to more efficient and effective practice, thus increasing the quality of life in people with intellectual disabilities.

Sexual exploitation in young people with intellectual disabilities: Background, living conditions and support needs

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Background: Sexual exploitation is a public health concern and a foundational issue in safeguarding young people, however little is known about the prevalence, background, living conditions and support needs of young victims. Young people with intellectual disabilities are at increased risk for sexual exploitation. Despite some signs of growing awareness, this heterogeneous and vulnerable group is still highly unrecognized, while the adverse effects of sexual exploitation are detrimental. The disproportionate risk faced by young people with intellectual disabilities highlights the need for filling the gaps in knowledge concerning background, living conditions and support needs of these young victims of sexual exploitation.

Method: In a systematic review, the current state of the literature on sexually exploited young people is assessed, with a special focus on intellectual disabilities.

Results: Insight is given into studies on sexual exploitation to give an in depth understanding of background, living conditions and support needs. Preliminary results will be presented.

Conclusions: The results of the current study will contribute to the understanding of sexual exploitation in young people (with intellectual disabilities) and to the recognition of signals by professionals, the development of matching (preventive) support programs and to help mitigate negative outcomes.

COVID-19 IDD: A global survey of family and staff

The global experiences of staff working in intellectual and developmental disabilities services during the COVID-19 pandemic

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Background: The aim was to explore the global experiences of staff working in intellectual and developmental disabilities services during the COVID-19 pandemic.

Method: 1842 staff members completed an anonymous online survey in 12 countries regarding their experiences during the pandemic in August and September 2020. The majority reported working in organisations with over 100 staff. All questions were closed items and included two standardised scales examining mood.

Results: Almost all staff reported receiving a policy or guidelines on COVID-19 for people with intellectual and developmental disabilities, and the majority were satisfied with these guidelines. Information and training were provided to most staff on social distancing, prevention, PPE and isolation. Staffing issues reported by more than half of respondents included reorganising staff shifts, increases in staff numbers on sick leave, and staff requested to take on new tasks. While satisfaction rates were high with the availability of PPE, respondents expressed dissatisfaction with the timing of this equipment. Less than half of all respondents were provided with information on the psychological impact of providing support during the pandemic, and a minority reported the introduction of peer support programmes.

Conclusions: Experiences from this global survey reveal significant disturbance in the delivery of disability services during the pandemic.

The global experiences of family members supporting a person with intellectual and developmental disabilities during the COVID-19 pandemic

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Background: To explore the global experiences of family members supporting a person with IDD during the COVID-19 pandemic.

Method: 1912 family members completed an anonymous online survey in 12 countries regarding their experiences during the pandemic in August and September 2020. All questions were closed items and included two standardised scales examining mood.

Results: Family members reported avoiding healthcare facilities during the pandemic; general dissatisfaction with the level of support they and their family member received; changes in staffing support to their family member including an increase in new casual staff; a decline in the number of people they typically might ask for support in their caring role; and diminished income and reduced employment. Levels of anxiety and depression were low for most family caregivers and few reported receiving any information on psychological support. Those who did not receive information on psychological support indicated they would have welcomed this type of support.

Conclusions: The experiences of family members illustrate that many felt unsupported throughout the pandemic and dissatisfied with the available support provided. These patterns were observed globally and reveal an urgent need to provide appropriate and timely support to family caregivers.

Caregivers' experiences of COVID-19 in different living arrangements for people with intellectual and developmental disabilities

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Background: To explore family and staff perceptions of the experience of COVID-19 in different residential living arrangements for people with intellectual and developmental disabilities.

Method: 3754 family members and staff working in intellectual and developmental disability services completed an anonymous online survey in 12 countries regarding their experiences during the pandemic in August and September 2020. Data were analysed to explore experiences in the family home, independent living, community group homes (CGH), and residential centres (RC).

Results: Those supporting people with intellectual and developmental disabilities in the family home were least likely to receive policies, information and training, and reported least satisfaction in these areas. They also reported the lowest levels of COVID-19 testing for the people they support. Those supporting people with intellectual and developmental disabilities in CGH and RCs reported the highest testing levels for both caregivers and the people they support, the highest level of restrictions in terms of visitors, and were least likely to report communication difficulties due to IT issues. Those supporting individuals in RCs had the highest reporting of COVID-19 symptoms, highest use of psychotropic medications for mood, and highest use of environmental restraint during the pandemic.

Conclusions: Global trends reveal specific observations by living arrangement options in the manner in which the pandemic was addressed.

WORKSHOPS

Enhancing peer and self-advocacy for people with profound and multiple intellectual disabilities

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People with profound and multiple intellectual disabilities are typically not included in self- or peer advocacy groups, and therefore are absent and “forgotten” when it comes to representation and inclusion in key decisions about the rights and needs of people with intellectual disabilities. Campaign 4 Change is a self-advocacy group supported by Achieve Together (a social care provider organisation), in which people with profound multiple and intellectual disabilities are central to the group.

Contribution: The focus of the workshop is to share how people with profound multiple intellectual disabilities can be included and actively involved in self/peer advocacy groups, and for those groups to be all the richer for that contribution. This allows for people with profound disabilities not to be forgotten or ignored and to be present when key decisions are made about their rights, needs and lives. This requires creativity and significant reasonable adjustments to ensure people with multiple disabilities can travel to, attend and access meetings both in person and virtually. I will describe how barriers and challenges can be overcome so people with profound multiple intellectual disabilities can be included and involved more widely in advocacy circles.

Storysharing® for friendship, wellbeing, recovery

Nicola Grove[1,2]

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Description: Storysharing (https://storysharing.org.uk) is a simple way of enabling children and adults with severe and profound disabilities to share their experiences with others. It is a co-productive approach, supported by 20 years of research and practice, which focuses on active participation as teller and audience. This workshop will demonstrate the ways in which Storysharing can be used in different contexts, with particular emphasis on its value in promoting recovery and resilience during the pandemic. It contributes to scientific knowledge by applying the theory of "small stories" in narrative research in a new way. This is a population whose communication challenges have traditionally meant that stories are told about them or for them, but not by them. Telling your own story enables you to make your voice heard.

Contribution: participants will learn how the choice of conversational techniques can support or inhibit the capacity to narrate, and the development of reciprocal friendships, emotional well being, recovery and resilience.

An art-based approach to imagining "a good life"

Meike Heessels[1], Maaike Hermsen[1], Anja Zimmermann[1], Sofie Sergeant[2], Lisanne Den Heijer[1], Rob Jacobs[1], Diana Rodenburg[3], Manon van de Plas[1], Lotte Kint[1], Toine van de Berg[4], Loes Dijker[4], Meike Croonen[5], Sanne Gruyters[1]
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Description: What does "a good life" mean to adolescents with intellectual disabilities? And what does it mean to the people who are important to them and who influence them in their life decisions? And finally, how do their images of a "good life" match the images of care organizations? In this art-based project we explored images of a good life by means of visual methods. People with intellectual disabilities, family members and support professionals drew and shared their images of what is a good life in several creative sessions. This process was captured in a short movie by Multimedia team Pluryn, that will be used as a dialogue starter in care organizations.

In this workshop, we will share the methods and principles we used in a self-experiential way. Participants explore their images of a "good life." Furthermore, we will share the images created throughout this arts-based project by means of an exposition.

Contribution: The workshop contributes to applied knowledge of supporting people with intellectual disabilities, their loved ones, and professionals in exploring and appreciating their images of a good life.

Using pictorial resources to help people with intellectual and developmental disabilities cope with the COVID-19 pandemic

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Description: Easy-read Covid-19 information and resources provided by national agencies are insufficient in supporting understanding and coping for people with intellectual and developmental disabilities. We will demonstrate the use of Books Beyond Words (pictorial resources for people who find pictures easier to understand than words). Since the start of the pandemic, we have developed 13 pictorial stories, covering a range of issues including coping with lockdown, testing for coronavirus, advance care planning, mental health, domestic abuse and bereavement, as well as guidance for families and carers. They were made freely available online. The supporting text has been translated into five other languages. The new resources have been used by over 100,000 people in the UK and beyond. We will present the resources and their use, including video footage of their practical use via Zoom, as well as feedback from users.

Contribution: User feedback has been overwhelmingly positive, showing that using the pictorial resources can help people with intellectual and developmental disabilities to understand the practical implications of the pandemic and discuss their feelings. Carers/supporters benefit from some information about how the pictures can be used. This workshop will give attendees an opportunity to learn more about using pictures when supporting people with intellectual and developmental disabilities through the pandemic.

Community "Accessible Recreation"

Karin Stiksma[1], Sofie Sergeant[2]
[1]Joint Projects, Apeldoorn, The Netherlands; [2]Disability Studies in Nederland, De Meern, The Netherlands

Description: How can we achieve the goal of all citizens have access to the recreation sector? In the prevailing protocols for the recreation sector, created during the COVID-19 pandemic, initially there was no attention for people with disabilities. Therefore Joint Projects started a preliminary study in the Netherlands together with many stakeholders: scientists, experts by experience, branch organizations, day attractions, government, funds and interest groups. That resulted in a transdisciplinary community. Through online roundtables, focus groups and surveys, we explored the conditions for inclusive recreation activities and venues, and we searched for inspiring good practices. The results from this preliminary study will be used as a fundament for a more extensive participatory action research project. The studies have one goal: to raise awareness and positive change towards a more accessible recreation sector for all.

Contribution: In this workshop the engagement of many stakeholders will be explained. The joint ambition of realizing accessible recreation requires a third space: a safe space in which all new partners develop new rules, communication means and strategies. Through the workshop we invite the participants to discover with us how a transdisciplinary community gives people voice and gives all stakeholders opportunity to learn from each other. We will elaborate on conditions for social validation processes and shared leadership, and why these are prevailing mechanism for change in society.

ORAL PRESENTATIONS

How do family or staff support mutual understanding between patients with intellectual disability and health staff?

Deborah Chinn[1]
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Background: When individuals with intellectual disabilities attend medical appointments they are often accompanied by a companion (family member or paid staff). This research aimed to track the contribution of companions in communication support in real life health consultations, to identify how their participation arose and how it was received by the other parties.
Method: Video and audio recordings were made of 24 patients with intellectual disabilities attending an English NHS General Practice health check with a companion. Recordings were analysed using Conversation Analysis, a method of discourse analysis that examines how social activities and identities are enacted through interaction. This presentation focuses on how companions intervened to promote mutual understanding between patients with intellectual disabilities and healthcare practitioners (HCPs) using the CA framework of "repair."
Results: Situations arose where companions were invited to address issues of mutual understanding either by the patient or HCP. More commonly, companions were observed to monitor the unfolding interaction and to intervene to address potential or actual breaches of intelligibility on their own initiative.
Conclusions: Companions can helpfully mediate between the patient with intellectual disabilities and HCPs, but their interventions run the risk of allowing other participants to abdicate from more active engagement in ensuring mutual understanding.

Housing design for adults with intellectual and developmental disabilities: Modification tool

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Background: Safe, affordable, person-centred housing is a key social determinant of health. However, a lack of such housing contributes to this population's struggle to be included meaningfully in the community.
Method: We will discuss an existing housing design tool for adults with intellectual and developmental disabilities who exhibit behaviours that challenge. The current tool includes design recommendations based on a literature review and case studies of four supported houses in Ontario.
Results: Staff and residents in supported housing often find useful solutions to modify their homes to minimize/mitigate/prevent behaviours that challenge, without sharing successful modifications with the healthcare or construction sectors. This tool aims to aid this communication and drive innovative design solutions.
Conclusions: There is a need to tailor design and maintenance recommendations to common events in the lived experience of people with IDD, for example moving between houses or changes in social services. This session is a continuation of an interdisciplinary research on housing design for adults with IDD, funded by the Ontario government.

The contribution of Self-Determination Theory to transforming long-term care for people with intellectual disabilities

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Background: The care and support of people with intellectual disabilities provide ample room for both satisfaction and frustration of basic psychological needs (i.e., autonomy, relatedness, and competence). Self-Determination Theory research may help to identify areas of need frustration that limit users of such care to develop self-determination as well as potential for satisfaction that might be leveraged to optimize the outcome of care, support, and treatment.
Method: This symposium contains three recent studies on the basic needs, autonomy support, and motivational processes. The applicability of these research outcomes for the clinical practice of people with intellectual disabilities will be discussed.
Results: In addition to a qualitative study on the meaning and support for the basic needs of people with severe or profound intellectual and multiple disabilities, results of a longitudinal study into the basic needs, motivational processes, and well-being of people with mild to borderline ID will be presented. Finally, preliminary findings of an effect and implementation study on an intervention aimed to increase the awareness of including the client perspective will be presented.
Conclusions: The studies presented in this symposium will all demonstrate the value of focusing on basic psychological needs and motivational processes among people with intellectual disabilities.

Examining a community health worker training program on intellectual disability

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Background: Community health workers (CHWs) are lay members of communities trained to deliver health education and support to other community members. Because they are trusted within their communities, CHWs are uniquely positioned to support health promotion for vulnerable populations, including individuals with intellectual disability. The aim of the present study was to evaluate the efficacy of an inclusive health training for CHWs.
Method: We piloted a CHW training on inclusive health with 36 participants (67% aged 26-45 years; 75% female) in Guatemala in July 2020. Participants completed pre- and post-training surveys concerning their knowledge and attitudes towards individuals with intellectual disability.

Results: Paired sample t-tests indicated that following the training, participants felt more confident in their ability to provide services to ($t(20)=-3.2$, $p<.01$) and communicate with ($t(21)=-3.5$, $p<.01$) individuals with intellectual disability. Similarly, participants also felt more comfortable around individuals with intellectual disability ($t(22)=-3.2$, $p<.01$) and had a better understanding of their health needs ($t(20)=-3.6$, $p<.01$).
Conclusions: Findings indicate that inclusive health trainings may contribute to greater knowledge and more positive attitudes among CHWs toward individuals with intellectual disability. Such trainings have the potential to build community capacity to address the health needs, healthcare access, and stigmatization of individuals with intellectual disability.

Practical clinical steps in setting up team formulation sessions in an adult intellectual disability service

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Background: Psychological Formulation is a core competency of Clinical Psychology. However, its application among other Multi-Disciplinary Team (MDT) members in Adult Disability Services has been underexplored. Team Formulation offers an avenue where other professionals can engage in Psychological Formulation, in order to more clearly understand their roles, their co-worker's roles, and most importantly their understanding of their clients.
Method: This paper looks at the practical steps of how Team Formulation sessions have been applied in the host institution, and can be applied in clinical practice; through the initial setup, the role of facilitator, and a working template for its application in the clinical field.
Results/Conclusions: This paper reviews the processes and methods for setting up Team Formulation sessions, including the noted successful procedures while also addressing the potential obstacles in the implementation. Future research and the development of Team Formulation sessions in Adult Disability Services is also considered.

Addressing community inclusion through assistive technology

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Background: Using Way2Be, an assistive technology, increase the independent accessing of community resources by people with intellectual disabilities.
Method: Quasi-experimental research using real-time information and feedback on frequency and the types of activities being participated and engaged in gathered through an app, including changes in independently accessed and managed community-based activities.
Results: Changes in the types, frequencies and person-initiated activities over time will be reported, as well as data on feasibility and accessibility of app use by adults with intellectual disabilities. Additional data will be reported on how families and staff may be adjuncts to support such activities.
Conclusions: Concerns about safety and availability of just-in-time support are often barriers to increasing participation in community-based activities. The approach here demonstrates how these barriers may be overcome.

Psychometric validation of the Positive Outcome Scale-2 (POS-2) in an Irish cohort

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Background: There are few valid and reliable measures of quality of life available for use with people with intellectual disabilities. The current study involved the examination of the Positive Outcome Scale 2nd Edition's (POS-2) validity and internal consistency. The POS-2 is a self-report and observer interview, and was utilised with 85 people who have intellectual disabilities accessing a specialist adult intellectual disabilities service.
Method: The reliability and validity of the scale was investigated through item-level analysis and sub-scale analyses of construct.
Results: Demographic details such as age, gender, working status, living arrangements, and disability characteristics were not significantly associated with outcomes on the POS-2 for self or observer report.
Conclusions: This presentation will outline specific reliability analyses for the total group and future directions. Quality of life is a multidimensional concept and is often difficult to measure through psychometrics. This study provides further support for the use of the POS-2 in intellectual disability services and settings.

Marrying into it: The role of sibling-in-laws for adults with intellectual and developmental disabilities

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Background: Siblings-in-laws (SILs), or the spouses of individuals with a brother or sister with intellectual and developmental disabilities, have been overlooked in social support literature. This study examined 1) the extent of social support provided by SILs, 2) if extent of social support influenced SIL's perceptions of the individual with IDD, and 3) predictors of higher levels of social support.
Method: Participants included 99 SILs who completed a web-based survey. Participants rated the extent of tangible, informational and emotional support they provided from *Never* to *Very Frequently*. Descriptive and inferential statistics were used to analyze data.
Results: Respondents provided more extensive emotional support (vs. tangible and informational). Overall, respondents had positive

perceptions of sibling-in-laws with IDD; however, increased emotional support was associated with negative perceptions. Predictors of increased support included marriage quality, involvement with the disability community, and decreased parental ability to provide care for offspring.

Conclusions: Many SILs provide social support—particularly emotional support, which was associated with negative perceptions. SILs must be meaningfully supported to avoid burnout. Findings provide insight into factors associated with more extensive support. Targeted interventions can increase SILs' marriage quality and involvement in the disability community and, in turn, secure more extensive support for adults with intellectual and developmental disabilities.

Variability in behaviour intervention receipt by children with autism spectrum disorder

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Background: Behaviour interventions based on Applied Behaviour Analysis (ABA) constitute evidence-based interventions for improving outcomes in children with autism spectrum disorder; however, receipt of behaviour interventions may be variable. As there is limited research examining this variability, this study aimed to identify patterns of behaviour intervention receipt by children with autism spectrum disorder.

Method: Parents of 43 children with autism spectrum disorder, recruited from a children's hospital in Canada, participated in semi-structured interviews on lifetime service receipt. Elicited data were organized into service use maps to identify patterns, supplemented by examination of interview text.

Results: Overall, 83.7% of children used behavioural intervention services, with 32.6% receiving Early Intensive Behavioural Interventions (EIBI) and 81.4% receiving goal-focused ABA (gf-ABA) blocks. Only one child with a late autism spectrum disorder diagnosis (>5 years) received EIBI. The number of gf-ABA service blocks ranged from 0-4 per child. Of the total sample, 53.5%, 2.3% and 27.9% received behaviour intervention services from public providers only, private providers only, or a combination thereof, respectively.

Conclusion: This study identified substantial variability in receipt of gf-ABA and EIBI. Further study is needed to identify drivers of this variability beyond age of ASD diagnosis and evaluate the impact of public versus private service provision.

Quality of life of persons with intellectual disabilities under the COVID-19 pandemic in Japan

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Background: The current study aimed to examine the impact of the COVID-19 pandemic on the quality of life (QoL) of persons with intellectual disabilities in Japan.

Method: Using a qualitative study design, 25 persons with intellectual disabilities and 10 parents were interviewed. Participants with intellectual disabilities lived independently, with their families, and in group homes. Interview data were analyzed by thematic analysis to find out how persons with intellectual disabilities and their parents have had restrictions in their lives.

Results: Depending on the decisions made to avoid the risk of infection by persons with intellectual disabilities, their parents, and service providers, persons with intellectual disabilities experienced some restrictions in work and leisure activities. Specifically, parents tended to focus on having a small range of activities of their children and staying out of trouble with others. However, parents also noticed that long-term restrictions in activities might impact on physical and emotional well-being of their children.

Conclusions: Persons with intellectual disabilities were more or less restricted from normal activities. These restrictions were caused by not only the characteristics of their disabilities but also social pressure. The implications of the study are discussed to improve the QoL of persons with intellectual disabilities and their support during difficult times around the world.

Decision-making with persons with profound intellectual disabilities: Resources and challenges in professional practices

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Background: People with profound intellectual disability challenge common ideas of participation and decision-making, and some claim that for this group decision-making is not realistic or possible.

Method: The overall aim is to highlight crucial conditions for participation and supported decision-making when service users' autonomy is challenged, and illuminate what this tell about the agency/citizenship of people with profound intellectual disability. The following research question is to be answered: *What are the crucial conditions for participation and supported decision-making when service user's autonomy is challenged, and what does it tell us about the citizenship and agency of people with profound intellectual disability*? The presentation builds on data from an ongoing case study within the CHAPAR project, applying practice research and sensory ethnography. Four persons with profound intellectual disability their family members and staff are participating.

Results: Data from observations, dialogue meetings and interviews were analysed as a whole, and identified two essential conditions for participation and supported decision-making, *relational* and *organisational/structural*.

Conclusions: Both the relational and organisational conditions for agency put forward the complexities embedded in how citizenship is *lived, practiced and crafted* in everyday life. This also highlights how

relational and organisational/institutional conditions interact and amplify each other.

A review on the conceptualization and measurement of Quality of Life in individuals with autism

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Background: We focused on the subjective and multidimensional nature of the Quality of Life (QoL) construct. The present study reviewed to what extent these two characteristics are incorporated in the growing autism literature on QoL by examining the nature of the informants and the domains assessed in the questionnaires.
Methods: We conducted a systematic literature search, extracted the relevant data from 113 included publications and mapped the instruments' sub-scales onto the multidimensional Schalock framework.
Results: More parent-reports than self-reports were administered, with parents reporting a lower QoL compared to autistic individuals themselves. In total, 53 different questionnaires were used to assess QoL. Fifty-five percent of their subscales measured one single QoL domain, with Self-determination, Material well-being, Social inclusion and Rights being under-studied. Thirty-eight percent of the subscales included items that could not be mapped on any of the domains, typically because they measured impairment instead of QoL.
Conclusions: A broad range of instruments is used to measure QoL in autistic individuals, and the extent to which they are accessible for individuals across the spectrum and measure QoL in a multidimensional manner is variable. Researchers and clinicians should be aware that QoL domains were selected and operationalized differently by different instruments.

Relationships matter

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Background: Despite Scotland's learning disability strategy recognising the importance of relationships, and a raft of rights-based policy, people with learning disabilities still do not enjoy relationships on an equal basis. This research aimed to uncover the factors that relate to maintaining different kinds of relationships and being in intimate relationships.
Methods: During 2019, SCLD developed the “How's Life?” survey with a range of partners, to ask people with learning disabilities in Scotland how they felt about different aspects of their lives. A self-complete questionnaire was designed to be completed by people with learning disabilities, with or without support. A total of 1232 responses were received. Chi squared was used to determine correlations between relationships and other aspects of people's lives.
Results: Having the right support and having high levels of choice over how time is spent were both associated with being able to see family, friends, and partners as often as people wanted. However, neither were associated with being in an intimate relationship.
Conclusions: The research improves understanding of the importance of both support and choice in the maintenance of different kinds of relationships and creates an added urgency to understand what factors are associated with being in intimate relationships.

“Looks like my brain is awake, it is working”: Benefits of artistic activities for adults with intellectual disabilities

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Background: Adults with ID are often described as having a sedentary lifestyle and a lack of stimulating activity in an isolated environment. Artistic activities are an interesting avenue to promote their occupational engagement. Even if the potential of artistic activities is well documented, it is not used often with adults with intellectual disabilities. This study wished to document the benefits of artistic activities based on music, dance, and theatre for adults with intellectual disabilities attending a community organization.
Method: This was a qualitative study. Individual interviews were conducted with adults with intellectual disabilities, their parents and the activity managers. A focus group was conducted with the organization's professionals. The occupational therapist's notes taken during the activities were also analyzed.
Results: Participation in artistic activities had positive benefits for adults with intellectual disabilities in their physical, cognitive, affective and spiritual dimensions. The activities help them develop their self-esteem and their feeling of belonging to the group. The interview showed that the parents were proud and they learned about their child's capacities.
Conclusions: When the daily lives of adults with intellectual disabilities lack meaningful activities, using artistic activities is a relevant strategy to improve their engagement in the long term in a project adapted to their capacities.

Pathways to friendship: Maintaining friendships and community inclusion during the COVID 19 pandemic

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Background: A statewide social inclusion initiative, *Pathways to Friendship*, uses consultation, training, and evaluation to establish and maintain friendships between people with and without intellectual and developmental disabilities. A “friend” is defined as a person who

is unrelated, not paid to spend time with the participant, and not receiving services.

Method: Provider agencies receive technical assistance, training and share ideas and encouragement. Facilitators target support to participants with intellectual and developmental disabilities, fostering friendships and increasing community inclusion. Baseline surveys were administered in 2017, with follow-ups in 2018, 2019 and 2020. Data is collected at the participant and organizational level.

Results: Baseline data indicated that approximately 45% of participants did not have a friend that met the definition and another 25% “didn't know.” Most participants had not engaged in interest exploration or relationship mapping. Participants' time in the community included activities not optimal to making connections (e.g., shopping), and frequently in disability-specific endeavors such as self-advocacy groups.

Conclusions: While initial follow-up indicated that 27% of participants with intellectual and developmental disabilities had made a new friend without disabilities, the pandemic with its resulting quarantine altered the progress of developing friendships. This presentation will explore the adjustments implemented by *Pathways* to maintain inclusion for those with intellectual and developmental disabilities.

Artistic participation of persons with profound intellectual and multiple disabilities leading to participation?

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Background: Art programs used in disability services are mostly oriented towards therapeutic and leisure outcomes, little is known about the artistic output of these programs and the output in a more broad context, e.g. in relation to participation of persons with disabilities. We want to describe the application of art programs for people with profound intellectual and multiple disabilities, whereby we specifically elaborate on music therapy in relation to participation.

Method: Information concerning artistic activities is searched for in practice and in scientific literature. To gain more insight into the use and benefits of music therapy, we set out an explorative online survey asking various stakeholders to share their experiences. The questionnaire focused on the content and the effects on participation of music therapy.

Results: We describe scientific and practical knowledge available about artistic activities for people with profound intellectual and multiple disabilities and differentiate into activities aimed at casual leisure, serious leisure and (semi-)professional performance. Information regarding the application and effects of music therapy will be presented at the conference.

Conclusions: The results of this study provides a first understanding of artistic activities, specifically in the form in which music therapy is offered to persons with profound intellectual and multiple disabilities and its relation to the participation of adults with profound intellectual and multiple disabilities.

Ecological conditions and organisational culture in group homes

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Background: The Group Home Culture Scale measures organisational culture in group home services for adult persons with intellectual disabilities. Organisational culture is an important mediator variable for residents' quality of life. The aim of this exploratory quantitative study is to uncover how characteristics of an assistance team, of team members, and of residents affect the seven dimensions of organisational culture.

Method: As part of the testing of the German GHCS version, context variables are collected in 14 group home teams (e.g., team size, average age and qualification of staff, residents' support needs). Group-related indicators are obtained and correlated with the team scores on the GHCS dimensions.

Results: Team size correlates highly negatively with all dimensions except “social distance from residents” and “valuing residents and relationships.” Insufficient communication within the team and indicators of the level of ID correlate highly negatively with the dimensions “supporting well-being“ and “social distance from residents.“ The level of professional education in teams has a positive effect on the identification with the residents.

Conclusions: Hypotheses can be generated about the specific relationships between characteristics of the team, team members and residents, and dimensions of organisational culture that influence residents' quality of life.

Community transitions and quality of life: A Canadian study

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Background: Research on the impact of deinstitutionalization or community transitions on quality of life of persons with severe intellectual and developmental disabilities is limited and inconclusive. Our study aimed at describing changes in the quality of life of a sample of Canadians with severe intellectual and developmental disabilities and complex care needs who were transitioned from an institutional setting in the city of Winnipeg (Manitoba, Canada) to a variety of community homes in the province of Manitoba.

Method: A pre- post-transition longitudinal study design was implemented to measure the impact of community transitions on the quality of life of 59 persons with severe intellectual and developmental disabilities. Quality of life assessments were conducted at two time points (Time 1: pre-transition and Time 2: at least 6 months post-transition) by using a standardized tool, the San Martin Scale.

Results: Compared to the pre-transition study group, the post-transition study group showed higher scores in all dimensions of quality of life, as well as in global quality of life.

Conclusions: This empirical study provides evidence of improved quality of life in persons with intellectual and developmental disabilities following deinstitutionalization. Implications for practice, policy and research are discussed.

Health, function and participation effect quality of life in children with intellectual disability

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Introduction: Many children with intellectual disability live with comorbidities and difficulties with functioning and participation in the community. This study examined their impacts on quality of life (QoL) for children with intellectual disabilities.

Methods: Caregivers of children (aged 5 to 18 years) with intellectual disability and autism spectrum disorder, cerebral palsy, Down syndrome and Rett syndrome reported on their child's comorbidities, functioning, frequency of community participation and QoL. The Quality of Life Inventory-Disability was used to measure QoL on a 100-point scale. Linear regression was used to evaluate relationships with QoL.

Results: Recurrent child pain (−4.97 95%CI −8.21, −1.72), night-time sleep disturbances (−4.98, 95%CI −7.23, −2.73), daytime somnolence (−8.71, 95%CI −11.30, −2.73) and seizures that occurred at least weekly (−7.59, 95%CI −13.50, −1.68) had negative impacts on QoL. Children with greater dependency for managing personal needs and more limited eye contact when speaking experienced poorer QoL. More frequent community participation was associated with a 3-point gain in QoL for each additional point in participation frequency (coefficient 2.67, 95%CI 1.56, 3.78).

Conclusions: These data suggest that evaluation and management of pain and sleep disturbance and support for community participation could be high priorities in improving QoL of children with intellectual disabilities.

How to develop "ID-inclusive" self-report instruments: Results from a systematic review

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Background: Persons with intellectual disabilities (ID) may have difficulties providing reliable and valid accounts of their personal experiences through self-report instruments, and adaptations are needed to accommodate difficulties such as problems with reasoning, verbal expression, reading, abstract thinking and judgment. The authors systematically reviewed 25 years of peer-reviewed research literature on the adaptations needed to develop "ID-inclusive" self-report measures. Recommendations for developers, researchers and clinicians will be presented.

Method: A search of research databases identified 49 studies that met inclusion criteria. A framework synthesis approach was used to analyse and summarise the data.

Results: A total of 161 recommendations were assigned to a newly developed framework for the development of "ID-inclusive" self-report instruments. Specific recommendations were made about the process of item generation, creation of content (including language, response options and supportive visualisation factors), piloting draft versions, application in clinical and research practice (including formal procedures and the role of the interviewer), and ongoing development.

Conclusions: The review offers much-needed practical guidance for clinicians and researchers on how to develop "ID-inclusive" self-report instruments. However, for many topics involved in instrument development, definitive answers are lacking. Recommendations for future research on instrument development for use with people with intellectual disabilities are presented.

Collaborating to enhance person-oriented care: The Dutch quality framework

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Background: In the Netherlands all stakeholders have committed themselves to the Dutch quality framework 2017–2022, which aims at enhancing the quality of life of persons with intellectual disabilities through person-oriented care. However, it has become clear that implementing this vision to a large diversity of persons with disabilities is a big challenge to professionals and policymakers. Therefore, the umbrella organization VGN initiated the development of national quality guides on special target groups.

Methods: An action research design in which knowledge networks, professionals, researchers, parents and other stakeholders are involved. In online meetings the available practice-based and evidence-based knowledge is collected and discussed. In an iterative process, the quality guides are cocreated and tested in the field.

Results: The quality guides describe key elements of the knowledge and skills which are needed to provide effective and ethically sound care: e.g., vision, values, target groups, and key components of care, which can be customized to own context and local conditions by the Dutch care organizations.

Conclusions: The national quality guides will provide a value-based description which will enable professionals as well as policymakers to enhance person-oriented care and thus contribute to a better quality of life of service users with intellectual disabilities.

COVID-19 and the need for accessible information in Australia: Is it any different in other countries?

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Background: When COVID-19 information was required in Australia the website of the Australian Health Department published press releases and complex fact sheets only. Similar observations have been seen in other jurisdictions.
Method: A retrospective analysis of COVID-19 Easy Read or Easy English materials developed in Australia was completed. These were collated according to topics covered, time from information being released to being available in accessible formats, what reading age they equated to and access on websites.
Results: Content from March 2020 to August 2020 identified that one service produced 124 COVID-19 documents in Easy English. This compares to 25 documents that the Australian Government and state governments combined published in Easy Read. Most COVID-19 information was not available in accessible formats. For example: extensions to government financial support and local council services. Additionally, none of the resources were available in print.
Conclusions: The pandemic has highlighted the need for clear, well-established processes to create evidence-based, best-practice Easy English documents. Only then will Australia meet its obligations under Article 21 of the UN CRPD. Australia is not alone in breaching these obligations. There remains significant work to be done internationally to ensure critical and emergency information is accessible for our diverse communities.

Leveraging intellectual disability knowledge and understanding of the person for optimal outcomes

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Background: It is well-established that individuals with intellectual and developmental disabilities face far worse outcomes than their nondisabled counterparts across a broad range of health indicators and social determinants of health. The current global advocacy movement advancing the rights of individuals with intellectual and developmental disabilities has prioritized a high level of choice of the individual.
Method: Optimal health and life outcomes require the combination of a commitment to the rights of the individual with a responsibility to provide support commensurate with individual capacity and based on research and knowledge of intellectual and developmental disabilities.
Results: This presentation will highlight the detrimental outcomes for a 61-year-old woman with Down syndrome as supported by a choice-driven residential model. The presenter will share by contrast, the outcomes for the same individual when supported by the author's person-first model of support.
Conclusions: This person-first model is founded on the combined understanding of the person, and knowledge of intellectual and developmental disabilities. A philosophical belief that individuals with intellectual and developmental disabilities are capable of learning and they are worthy of being taught provides the foundation for wholistic, evidence-based practice throughout the lifespan. This model is based on three pillars of engineering the environment, promoting skill development and maintenance, and staff supports, demonstrating the efficacy of a knowledge-based approach.

The role of service providers in supporting social inclusion in neighbourhoods of adults with intellectual disabilities

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Background: This study examined the role of service provider organisations in supporting social inclusion in neighbourhoods of adults with intellectual disabilities. How CEOs/service leaders understand social inclusion was explored, alongside the development (if any) of organisational policies. Also explored were actions that had been tried, or interventions tested, to support adults with intellectual disabilities to participate in their neighbourhoods.
Method: A mixed-methods survey design was employed. Forty service leaders (64% response rate) completed this national online survey. Follow-up telephone interviews were completed with a 15% random sample. Size of service provider varied from less than 200 to over 1500 adults with intellectual disabilities served. Data were analysed using a combination of descriptive statistics and qualitative content analysis.
Results: Specific organisational policies regarding social inclusion in neighbourhoods were uncommon. Service initiatives ranged from supporting individuals' personal goals, to projects supporting groups to engage locally, and organisation-wide social inclusion strategies involving new service delivery models. Multiple diverse outcomes were reported, and a range of challenges/barriers were identified.
Conclusions: Shifting to new service models requires clarity of mission/values, with clear staff recruitment, education, and re-deployment plans. Multiple facilitators and barriers exist to social inclusion in neighbourhoods. Implications for practice are discussed, alongside recommendations for further research.

Improvisational theater or comedy and autistic people: A scoping review

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Background: The use of improvisational theater or comedy (improv) with autistic populations was explored, including as an intervention. The scarcity of research necessitates a broader insight into the topic on theatre-based improvisation or play. The purpose of this review was to uncover what is known about autism in relation to improvisation within a practice of theater, comedy or theater-based play.

Method: This review used scoping review methodology. The search was conducted in four databases and using relevant keywords (e.g., autism, anxiety, improvisation, theater, comedy). 796 papers were found, reduced to 59 for full-text reads. 28 articles were included.

Results: The review has shown a lack of research in this area. Most papers demonstrated autistic people have the abilities to make-believe, and gain social communication skills and self-development. Additionally, interventions can lead to acceptance of autism.

Conclusions: There is a clear need for further research. Autistic people can reduce their inhibition and feel liberated from social burden of the neurotypical world. Improv was found as empowering and an equalizer for neurotypical and autistic participants. Increasing autistic people's coping, self-management skills, enabling failure and risk can help with anxiety and stress and provide a better quality of life.

Vocational rehabilitation and quality of life of people with intellectual disability

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Background: This study evaluated quality of life (QoL) outcomes of Taipei vocational rehabilitation services (VRS) and explored the meaning of employment for people with intellectual disability, autism and living with mental disability.

Method: A Single Group Repeated Measures Design was employed using a QoL Questionnaire with four domains: Satisfaction, Productivity, Empowerment and Community Integration. A face-to-face survey was conducted every three months between February and December 2020 in Taipei, Taiwan; 283 adults (132 adults with intellectual disabilities, 63 with autism and 88 with mental disability) participated in the baseline (T1). An additional four focus groups collected qualitative data among 21 adults.

Results: The domains of Satisfaction and Productivity showed significantly higher values at T2, T3, T4 than at T1, unlike the domains of Empowerment and Community Integration. Qualitative data showed that the participants were eager to be employed in order to become financially independent and feel psychological and social fulfillment.

Conclusions: Both quantitative and qualitative data indicated that having attractive paid work is critical to the participants' QoL and empowerment, which is to be taken into account in the future development of VRS.

Understanding the social processes that impact care in disability services

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Background: The present study aimed to explore the experiences of adults with intellectual disabilities, and staff, of social processes that impact upon quality of life in residential services.

Method: Using a qualitative design, six adults with Intellectual disabilities who live in residential services and six staff working in the same service were interviewed. Thematic analysis was applied to analyse the findings.

Results: Three themes emerged: 1) Complexity of relationships between adults with Intellectual Disabilities and staff; 2) Challenges to delivering person-centred care; and 3) Shared needs, which pertained to more training and emotional support.

Conclusions: This research found that it is not enough to have a system of quality of care guided by the principles of person centeredness alone to ensure the best possible quality of life for adults with intellectual disabilities. Rather, consideration of the cultural and contextual factors that impact upon the lives of adults with intellectual disabilities needs to be built into the values and practices of disability services.

Learning from COVID-19: Facilitators and barriers of everyday functioning and wellbeing in autism

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Background: This Co-produced Community Knowledge Exchange project captures the lived experience of autistic adults during the COVID-19 pandemic.

Method: Two autistic panels (advisors, n=5; reviewers, n=5) contribute to design, direction and review of knowledge exchange activities and outputs. Mixed methods involve qualitative interviews (n=20) to identify key areas of impact using thematic analysis to identify overarching themes, and surveys (n=200) of thematic priorities for the community. The International Classification of Functioning, Disability and Health (Bölte et al., 2014) framework underpinned the personal and environmental factors that were either helpful or detrimental to coping with COVID-19 related disruption to everyday functioning, routines, and wellbeing, from the perspective of autistic adults and advocates.

Results: The project is underway, with final analysis completed mid-June 2021. Preliminary knowledge suggests COVID-19 restrictions for autistic adults are both helpful (e.g., reduced social demands) and challenging (e.g., increased social isolation; reduced access to health and social care; intolerance of uncertainty).

Conclusions: To our knowledge, this is the first study to identify facilitators and barriers of major transitions (e.g., COVID-19) and their impact on everyday functioning, routines, and wellbeing of autistic adults. The findings offer real-world impact to support autistic people throughout COVID and transitions to post-COVID life.

Disability mainstreaming and inclusion in development and humanitarian practice in Ireland

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Background: Persons with intellectual and other disabilities are at risk of being left behind in development and humanitarian practice. International non-governmental organisations (INGOs) play an important role as convenors of humanitarian assistance and development interventions. This study aimed to explore the role of INGOs in disability mainstreaming and inclusion, linking to responsibilities based on the Convention on the Rights of Persons with Disabilities, the Sustainable Development Goals, and its overriding principle to leave no one behind.
Method: Qualitative exploratory study based on key informant interviews with 17 informants in 11 Irish INGOs (2 disability-focused, 9 mainstream) and Irish Aid, the main State donor.
Results: INGOs acknowledge their role and responsibility to mainstream disability, however, challenges persist, especially with regards to knowledge and resources dedicated to disability mainstreaming. INGOs are increasingly reaching persons with disabilities, but more coherent and strategic approaches are needed, and gaps in data and knowledge need to be addressed.
Conclusions: Disability mainstreaming and inclusion in development and humanitarian practice still requires further attention. There is a need for exchange of best practices and knowledge. Furthermore, State donors and INGO champions can facilitate and guide efforts to ensure participation and social inclusion of persons with disabilities.

A broad perspective on Snoezelen: A systematic review

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Background: First, we provide an overview of the use of Snoezelen in different target groups and settings. Second, we describe the relation between characteristics of the intervention and the effect(s) of Snoezelen on persons who are involved in the intervention.
Method: A systematic literature review has been conducted. Studies were included if Snoezelen focused on experiencing sensory stimuli (stimuli one can hear, see, feel, smell and taste) in an environment specially adapted for Snoezelen and, if needed, with a support person.
Results: Snoezelen is used in various target groups, such as persons with an intellectual disability, dementia, traumatic brain injury, and women in labour. Snoezelen is most often practiced in residential settings. The majority of studies lack details on the application. The purpose of using Snoezelen is divers; most frequently mentioned are reducing problem behaviour, promoting relaxation and increasing engagement.
Conclusions: Snoezelen is used in various settings, in different target groups with different intended effects. We intend to discuss the implications of a highly divers intervention on conducting future research on the use of Snoezelen as a meaningful intervention for people with profound intellectual and multiple disabilities.

The use of snoezelen in persons with PIMD: An international survey

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Background: The aim of the survey is to describe the application and experienced effects of snoezelen in persons with profound intellectual and multiple disabilities. The presentation aims to discuss the process of developing an international survey and to present preliminary results.
Method: This cross-sectional survey study involved constructing an international questionnaire based on a literature review and practice-based experiences. Participants include (health care) professionals and parents and other relatives of persons with profound intellectual and multiple disabilities. The survey consists of questions regarding the setting in which snoezelen takes place, characteristics of the intervention and persons applying snoezelen, positive or negative factors related to the use of snoezelen and effects experienced by practice.
Results: Preliminary results involve a description of the aim(s) of using snoezelen, the application of sensory stimuli, the multisensory environment and subjective effects of snoezelen on persons participating in snoezelen, including the support person.
Conclusions: We intend to discuss the use of an international survey and the value of this method in learning about the worldwide use of snoezelen in persons with profound intellectual and multiple disabilities. Its implications for conducting future research on the effects of snoezelen on people with profound intellectual and multiple disabilities and their support persons will also be discussed.

The impact of COVID-19 on social inclusion for older adults with intellectual disability in Ireland

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Background: This study explored the impact that COVID-19 restrictions and service closures had on social inclusion for older adults with intellectual disability in Ireland.
Method: Data was drawn from Wave 4 of a nationally representative longitudinal study of adults with intellectual disability aged 40+ years.

Data collected prior to the first COVID-19 lockdown in Ireland (n=559) was compared with data collected post-lockdown (n=180). Within the second group, 62 individuals, were also included in Wave 3 of the longitudinal study three years previously. Longitudinal analysis compared this group's Wave 4 (post-lockdown) social inclusion data with previously collected Wave 3 data. Data examined included contacts with friends and family, loneliness, access to and use of technology.

Results: Comparisons show similar rates of contacts with family and friends and loneliness among the Wave 4 pre/post lockdown groups; while access to and use of technology increased substantially. Longitudinal comparison showed that, while contacts with family and friends were largely maintained, very frequent contact with friends was reduced for some.

Conclusions: Adapted service provision and increased access to technology may have helped to mitigate the impact of COVID-19 restrictions on social inclusion for some adults with intellectual disability during the first wave of the pandemic.

Developing protocol for self-determination group intervention for adult with intellectual disability

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Background: Self-determination (SD) is regarded as an adult outcome for people with intellectual disabilities (ID). Students with ID in western countries learn SD knowledge and skills through the systematic curriculum in schools. However, the SD curriculum is rarely available in any setting in Hong Kong. This study aims to develop a protocol for the SD enhancement group intervention for adults with ID and their caregivers.

Method: A panel review and pilot study were adopted. An expert panel was formed by seven members, including three adults with mild ID, two caregivers and two experienced social workers, who reviewed the framework, content and specific instructional materials for the intervention. In the pilot study, a trial intervention group was conducted with six members with mild ID who were living in an adult residential home.

Results: The protocol was finalized according to the experience and date collected from the pilot study and the fidelity of the structure was achieved.

Conclusion: The experience accumulated in the protocol development will be discussed. The later full-scale research study with a randomized controlled trial design will also be introduced.

Social network engagement for more quality of life for people with a severe intellectual disability

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Background: People with a severe intellectual disability need support in almost all aspects of life. A strong and engaged network is needed to provide the right level of support. The aim of the study is to improve the Quality of Life (QoL) via an E-health network tool.

Method: We have developed an E-health engagement tool to improve the QoL of people with a severe intellectual disability. The application is designed to stimulate the network to be engaged in daily QoL activities. These activities contribute to defined targets, related to QoL domains, and are scored to reflect the perceived appreciation of the client.

Results: In the paper, we report the outcome of an effect study in which we deployed the tool in 50 social networks. At the start, we measured the QoL and identified areas for improvement. The tool was subsequently deployed to engage the social network to work along these QoL targets. After three months, the QoL was again measured to determine its effectiveness.

Conclusions: E-health has shown its potential to support social networks in providing the daily support to people with an intellectual disability. A focused methodology, along defined QoL targets, stimulates the engagement of social network members.

Gender variant autistic adults: What are their experiences and needs?

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Background: The current professional literature suggests a link between gender variance (GV), gender dysphoria (GD) and autism. One large study of people with gender dysphoria found 7.8% were on the autism spectrum. The relationship between autism and gender non-conformity is not yet understood. This research aimed to explore the lived experiences of gender variant (GV) autistic people.

Methods: Fourteen UK-based gender variant adults with an autism spectrum diagnosis were recruited from social media and support groups. The participants took part in semi-structured interviews exploring their experiences and support needs. Analysis was by IPA.

Results: Five super-ordinate themes emerged from the analysis of the transcripts: 1) Experience and self-perception, 2) Social rules, autism and gender identity, 3) Resilience, 4) Attitudes towards us, 5) Support. GV autistic adults often faced doubt and disbelief about their gender identity due to autism. Societal prejudice, discrimination and ignorance often affected the participants' ability to live congruently or access treatment and support. Healthcare professionals were not always knowledgeable and effective in supporting this population.

Conclusions: The findings suggest GV autistic adults are often dismissed and undermined. More qualitative research incorporating the views of GV autistic adults is required to inform professional literature and practice guidance.

Attitudes on sexual health among people with intellectual disabilities: A systematic review

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Background: The sexual health of people with intellectual disabilities continues to be at risk. Attitudes can play an important role in sexual health promotion. Recently, the sexuality research focus shifted from a predominant focus on barriers to the inclusion of attitudes from people with intellectual disabilities. The current systematic review aims to provide an overview of research concerning attitudes of people with intellectual disabilities regarding the broad concept of sexuality, to find new leads in the promotion of sexual health of people with intellectual disabilities.

Method: A systematic review was conducted, searching eight databases based on the PICO-approach. Following the PRISMA-statement, two independent reviewers selected original and peer-reviewed studies based on predetermined criteria in a title, abstract, and full-text round. Studies were assessed for quality with the Mixed Methods Appraisal Tool. Data-analysis was conducted through a meta-synthesis.

Results: Supportive and restrictive attitudes from people with intellectual disabilities were reported on the following themes: sexual behavior, sexual identity, intimate relationships, barriers to sexual expression, received sex education, and received sexuality support.

Conclusions: Results point towards implications for research and practice, regarding support and education of people with intellectual disabilities on their sexual health to improve the promotion of sexual health among people with intellectual disabilities.

Understanding the experiences of Canadian Special Olympians at track and field competitions

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Background: The aim of this presentation is to share direct experiences of individual athletes with developmental disabilities.

Method: A mixed methods approach was used to analyze the interview transcripts from athletes who shared their experiences of participating in track and field/athletics events.

Results: The results suggested the emergence of several important themes including friendships, confidence, a sense of belonging, and support for participating in an inclusive community that appear to have contributed directly to the perception of improvements in quality of life for the individual athletes and their families.

Conclusions: These findings support the idea that participation in athletics may be an important avenue for improved quality of life in individuals with developmental disabilities.

Deep Down: Curation of an online art exhibition of persons with Down syndrome

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Background: This presentation links to the opportunities of an online museum exhibition to give access to disabled artists and develop social inclusion through audience development.

Method: 150 artworks from artists with Down syndrome worldwide are part of an exhibition in Mexico in 2019. Due to Covid19, it was impossible to explore further exhibition sites or enhance the artists' experiences. These artworks provided rich insights into the world of people with Down syndrome. The artworks were analysed and coded based on their visual content to create insights.

Results: From the 150 artworks, six main themes emerged from patterns, such as visual conversation topics and artistic vocabulary. Seven themes appeared: Symbolic transformation, Cultural connections, Artistry and aesthetics, Outsider art, Abstract connections and Togetherness. These themes present captured how participants describe their perception of their respective worlds. They present the spine of the exhibition and present topics for dialogue.

Conclusions: For many cognitively disabled people, Covid 19 brought social exclusion. With social media as a growing integral part of everyday life, digital art museums can provide important connections. Access to online platforms provide opportunities and minimise disadvantages of disabled artists. These platforms encourage audience education and social inclusion, and enhance disability art in museum study

Life story work as the basis for person-focused practice in Drammen Municipality, Norway

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Background: To gain insight into the impact of offering life story work (LSW) as a basis for person-focused practice in home-based and daily services for people with IDD, to increase service users' subjective perception of QoL, self-determination, and participation in the development of the service they receive.

Method: The study is a replication and contains a qualitative method triangulation. The data collection included pre-questionnaires used before interviews collecting contextual data about participants. Pre-post interviews with semi-structured interview guides, with "open" and "closed" questions, allowed both exploratory and explanatory questions to be answered. Weekly reports during eight weeks of LSW, written by both storyteller and interlocutor. The pilot defines the implementation phase with courses for staff and people with intellectual and developmental disabilities, further developing the model of LSW and an evaluation sheet.

Results: The pilot has resulted in data from 16 participants. The implementation phase starts in March/April 2021and will lie on the pilot, a new national guideline, and main objectives for Drammen municipality. Drammen municipality provides home and day services to about 300 people with intellectual and developmental disabilities, spread over approximately 18 service locations.

Conclusions: The results will be available at the congress and provide important pointers for developing policy, practice, and research priorities.

Life after day centres: Peer learning among people with intellectual disabilities

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Background: Research aimed to understand how people with intellectual disabilities were learning to navigate the new landscape of social care with declining day services. One specific aim was to explore how people were learning from each other in making the personalisation agenda work for them.

Method: Ethnographic case studies were conducted in one rural and one urban area of England and of Scotland. Local advisory groups of people with intellectual disabilities and their allies helped with access and methods. Interviews and focus groups were conducted with 43 people with intellectual disabilities; managers, staff and volunteers from 29 organizations were also interviewed. Researchers spent time with participants in their diverse settings. Data were analysed thematically and iteratively.

Results: People with intellectual disabilities were learning from immediate peers and wider networks, often supported by family and local schemes, and gaining skills and confidence in building lives in their communities. Peer learning ranged from ad hoc to structurally supported with some peer mentoring/support programmes in evidence and self-/advocacy groups playing a key role.

Conclusions: Peer learning in life after day centres often requires supportive people, supportive structures and time to build sustained engagement with a network. There are many missed opportunities for learning.

Homelessness and people with intellectual disabilities

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Background: The aim of this research is to more fully understand the factors that lead to homelessness for people with intellectual disabilities, their experiences while homeless, and their support needs to move out of homelessness.

Method: A systematic review of international studies examining homelessness among people with intellectual disabilities was undertaken. CINAHL, MEDLINE, PsycINFO and Sociological Abstracts databases were utilized. The search produced 259 papers, and following screening a total of 13 papers met the inclusion criteria and were included in the full review for detailed quality appraisal using the Critical Appraisal Skills Programme (CASP) tool and analysis to identify the key factors and the care and support required.

Results: People with intellectual disabilities can experience homelessness and some of the reasons differ from those experienced by the general homeless population. The themes identified from the analysis of the data were 1) Pathways into homelessness, 2) Experiencing homelessness, and 3) Routes out of homelessness.

Conclusions: People with intellectual disabilities become homeless due to multifactorial issues. Specific policy and practice responses are required. The identification of people within homeless services and their care and support concerns remains challenging, impacting upon assessments, interventions, care and supports. Psychosocial assessments, interventions and supports are necessary to assist people with intellectual disabilities to leave homelessness.

2019 Special Olympics World Games experience: The perspective of athletes with intellectual disabilities who participated

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Background: The present work aims to describe the experience of participating in the SO World Games, from the perspective of the athletes.

Method: For this purpose, two athletes were interviewed by an Inclusive Research Group, using photo-elicitation interviews.

Results: The photographs chosen by the participants were related to the following moments: competition, contact with other cultures, medal ceremony, social moments, flight, and return to Portugal. The medal ceremony was very mentioned by the athletes as a significant moment. The reception at the airport, when they returned, was another important moment, because they felt valued by their country.

Conclusions: In conclusion, the athletes enjoyed their experience in the SO World Games, experienced very enriching and memorable moments, and considered that had a positive impact on their lives. Also, the photo-elicitation interview is a very rich and promising data collection method, since it allows exploring the perceptions of the participants in an in-depth way.

Sharing implementation experiences in a Community-of-Practice for reducing involuntary care

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Background: Embedding evidence based innovations aiming to reduce involuntary care is a challenge for organizations. Communities-of-Practice with implementation workers and stakeholders facilitate sharing and discussion of insights and experiences to inform implementation efforts. Normalization Process Theory may shed light on the nature of implementation determinants and strategies that are shared in practice.

Method: This participatory action research within a community-of-practice included professionals of four organizations, experts-by-experience, and researchers exchanging best practices with implementation processes, theories, and research evidence. Transcripts of seven meetings and documents about local implementation processes were analyzed in Atlas.ti.

Results: Determinants that facilitate or hinder implementation processes in long-term care, especially regarding methods reducing involuntary care, as well as prior experiences with implementation interventions and strategies will be described.

Conclusions: Implementation of innovations to reduce involuntary care are fraught with ethical and practical dilemmas, concerning safety and freedom issues of residents and their care professionals. Implications of the findings will be discussed with regards to the way in which Communities-of-Practice may help organizations to successfully implement methods to reduce involuntary care.

Evaluating an assessment tool to map wishes, influencing factors and dynamics regarding social relations

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Background: This research project evaluates an assessment tool, which maps 1) the needs and wishes concerning social relations, 2) the risk- and protective factors on an individual, interpersonal, organizational, community and socio-political level, and 3) the past, present and future dynamics regarding social relations. Information to complete this tool is gathered from the person with a disability, a network member and a professional.

Method: The evaluation focusses on: 1) the acceptability and feasibility of the tool and 2) whether the tool can identify leverage points for interventions to enhance social relations. The tool was implemented in 10 cases within ambulatory home-based services. Evaluation will consist of questionnaires administered to professionals, persons with a disability and network members. Direct content analysis will be used to analyze the results.

Results: The acceptability, feasibility and its possibility to identify leverage points for intervention were identified and described from the three perspectives.

Conclusions: By evaluating the assessment tool, adaptations will be made for amelioration and for implementing this tool both in 1) future research, to gain more insight in risk- and protective factors and dynamics concerning social relations and in 2) daily practice as a step in an intervention trajectory to enhance social relations.

Reported communication challenges for adults with intellectual disabilities giving evidence in court

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Background: Giving evidence in court can be a challenging experience for any witness. Communication plays a key role in a witness's ability to give evidence and participate in the court process. Research suggests that the current process of cross-examination within the UK adversarial system can negatively impact on eyewitness testimony. Adults with intellectual disabilities can be further impacted by: limitations in recall abilities; suggestibility to leading questions; difficult question types used by advocates; and unfamiliar language used within the court setting. However, most research carried out on communication challenges for adults with intellectual disabilities when giving evidence has used psychology based experimental methodology.

Method: This current research aims to address the gap of research with actual witnesses by examining 19 court reports written by Registered Intermediaries in Northern Ireland, identifying communication difficulties for victims, witnesses and defendants with intellectual disabilities.

Results/Conclusions: Findings show a wide range of difficulties for the adult witness and also difficulties resulting from communication used by communication partners, the advocates.

Spheres of exclusion? Services for persons with intellectual disabilities and complex support needs

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Background: Complex support needs of persons with intellectual disabilities are being intensively discussed in Germany. Person with complex needs seem to have a high risk of being referred to and to remain in specialized institutions. For such institutions the term 'sphere of exclusion' is proposed here to underline their impact on individual living conditions.

Method: The presentation is based on sixteen semi-structured interviews with persons with intellectual disabilities and complex support needs and their support workers, that were analyzed referring to the quality of life model of Schallock et al. (2016) and the sociospatial theory of social work (Früchtel et al., 2013).

Results: Institutions that can be identified as “spheres of exclusion” appear regularly in the German disability support system. Results show that persons living in such institutions have a significantly lower quality of life and smaller social spaces in comparison to persons living in smaller facilities or their own flats.

Conclusions: The results to be presented here improve the understanding of the occurrence and effects of excluding settings in the context of services for persons with intellectual disabilities and complex support needs. In addition, they contribute to the discussion on the development of (inclusive) services for the target group.

Sounds of silence: AAC users' experiences of self-determination and autonomous decision making

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Background: The main aims of this research were: a. to offer the opportunity to enable teenagers with complex communication needs to sound their voices that usually go unheard; b. to explore the experiences regarding self-determination (SD) and autonomous decision making of teenagers using augmentative and alternative communication (AAC).

Method: Participants: Nine teenagers between the ages of 11 and 19, with disabilities who independently use AAC for speech (laptop, iPad, eye gaze system).

Procedures: Parents were addressed first and following their consent, participants' consent was received. The researcher interviewed each adolescent individually at home or at school. Measures: Semi-structured interviews were audio-taped and transcribed.

Results: Teens shared the social barriers they experience to voice their preferences, choices, decisions and participation in many life domains. They emphasized the importance of hearing their voices, and the advantages assistive technology offers them, to enhance their quality of life enabling them to vision their future.

Conclusions: There is a continuous need for society, especially professionals working with these adolescents, to dedicate thought and time to enhance skills and opportunities to enable these teens to voice their thoughts and feel they are an integral part of society, with equal rights to participate through-out their life span

The experiences of people with intellectual disabilities in England and Scotland during COVID-19

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Background: The research aim was to collect evidence on the experiences of people with intellectual disabilities in England and Scotland during the COVID-19 pandemic.

Method: 69 in-depth interviews were held with people with disabilities, of which 13 were conducted with adults with intellectual disabilities, and three with caregivers of children. Interviews were conducted remotely during the first wave of the pandemic, with follow-up interviews conducted in early 2021. In addition, 28 interviews were held with disabled people's organisations and other key informants.

Results: People with intellectual disabilities have found themselves isolated during the pandemic, with day centres, drama groups, and other such meaningful activities ceased. This has impacted their physical and mental wellbeing. Social care structures have seemingly dissolved, and we have seen a reversion to the family as the provider of social support. Government messaging has been inconsistent and confusing, especially with regards to vulnerability status. Public health campaigns have rarely provided accessible information for people with intellectual disabilities. Third sector organisations have stepped in, where needed and where possible, but their capacity is stretched.

Conclusions: People with intellectual disabilities have been neglected during the COVID-19 pandemic, and their voices must be heard during any future response to this or other crises.

Participation of adults with profound intellectual and multiple disabilities: A scoping review

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Background: According to the Convention on the Rights of Persons with Disabilities, participation also applies to adults with profound intellectual and multiple disabilities. The aim was to obtain an overview of available knowledge in the domains of participation of these adults that can be used in practice and for future research.

Method: A systematic search was performed using four databases. The studies included were available as full text, written in English, peer reviewed, and specified results of adults with profound intellectual and multiple disabilities. The studies were divided into the domains of participation (Hanzen et al., 2017): "Experience and Discover," "Inclusion," "Involvement," "Leisure and recreation," "Communication and being understood," "Social relations," and "Self-management and autonomy." The quality of the studies was analyzed with the Mixed Method Appraisal Tool.

Results: Preliminary results will be presented at the Congress. It will be highlighted in which domains of participation knowledge, related to general knowledge, assessment and interventions, is available. In addition, the quality of the studies will be presented.

Conclusions: The overview of the available knowledge in the domains of participation of adults with profound intellectual and multiple disabilities provides information for use in practice and gives a starting point for drawing up a research agenda related to this domain.

An investigation into intellectual disability nursing interventions and their impact

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Background: There is a lack of clarity on effective interventions that can be carried out by intellectual disabilities nurses (Mafuba 2009, 2013). A scoping literature review by Mafuba *et al*. (2020) categorised intellectual disabilities nursing interventions into three themes: effectuating nursing procedures, enhancing impact of services, and enhancing quality of life. The objective of this research was to identify intellectual disabilities nursing interventions and their impact on health and healthcare of people with intellectual disabilities.

Methods: Mixed methods evaluation methodology was used (Creswell and Plano-Clark, 2011). Qualitative and quantitative data was collected using an online survey questionnaire and follow up interviews. Voluntary response sampling (McCombes, 2020). Thematic, descriptive statistical, and inferential statistical analyses were undertaken.

Results: Intellectual disability nurses ($n = 228$) from seven countries reported a wide range of interventions. Participants provided case vignettes of the positive impacts of their interventions.

Conclusions: Findings demonstrate that intellectual disabilities nurses play important roles in improving the health and healthcare experiences of people with ID. Further research is needed to determine the effectiveness of intellectual disabilities nursing interventions across the lifespan.

Improving sexual communication among direct support staff: The development of a team training

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Background: Direct support staff find it difficult to communicate about sexuality-related topics with clients with an intellectual disability. This results in an omission of the topics or reactive behavior. From a sexual health standpoint, it would be more beneficial to provide proactive support on these topics. Whether an individual support staff member provides active support does not only depend on their knowledge and skills, but also on environmental factors such as support from and communication with colleagues. Currently most schooling is focused on the individual professional. A team training was therefore developed that focuses more on increasing sexual communication between colleagues by addressing possible issues and barriers within the team and stimulating team members to find solutions themselves.

Method: A pilot-study was conducted to investigate whether the training indeed contributes to a higher self-efficacy and more positive attitudes towards sexual communication, and more proactive sexual communication among colleagues and with clients with an intellectual disability.

Results/Conclusions: (Preliminary) results and conclusions will be presented at the conference.

Improving participation of adults with visual and severe/profound intellectual disabilities

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Background: A new intervention, Care for Participation+, was developed in order to improve the participation of adults with visual and severe/profound intellectual disabilities. The aim was to examine the effects of this intervention on the participation of these adults.

Method: We performed a pilot non-randomized controlled trial. The intervention group (n=16) was compared to control groups providing care as usual (n=13), or, implementing one element of the intervention (n=14). Effects were measured on: 1) participation, with a questionnaire of quality of life; and 2) (initiatives for prompting) active involvement, by observation during activities within ten dyads comprising adults with visual and severe/profound intellectual disabilities and direct support professionals.

Results: With regard to the quality of life, no effects of the intervention were shown. In the intervention group, the adults' active involvement and the number of initiatives of direct support professionals to stimulate their involvement exceeded those within the control groups.

Conclusions: The intervention had positive effects on the active involvement of adults with visual and severe/profound intellectual disabilities and direct support professionals' initiatives to stimulate this involvement. Despite barriers related to implementation issues, the first results of the intervention are promising. In future research, analyses from other perspectives, on an individual level, will be performed.

The experience and risk of homelessness for people with intellectual disabilities and/or autism and their families

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Background: Research evidence on the experience of homelessness for people with intellectual disability is limited, yet evidence from front-line staff in the disability and homelessness sector attests to the fact that people with intellectual disability and/or autism and their families are experiencing homelessness.
Method: A mixed methods study with a disability service provider as a case study site, explored the experiences of staff, families and individuals with disabilities who access housing services.
Results: A combination of economic dependence and an over-reliance on the private rental market was found to lead to instability of tenure and repeated cycle of homelessness. In addition, lack of suitable affordable social housing was the primary reason for return to residential services. These and other findings will be discussed.
Conclusions: There is a need to reduce bureaucracy of the housing system, increased education and training among staff in the sector, and a specific recognition of the needs of people with intellectual disability in housing policy.

The new Australian individualised disability funding scheme-NDIS: Outcomes for adults with intellectual disabilities

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Background: To explore the outcomes of the NDIS planning process from the perspectives of adults with intellectual disability and their families.
Method: Quantitative and qualitative data were collected using mixed methods in four connected studies comprising a questionnaire (19 participants); semi-structured interviews (20 family groups); focus group (four adults with intellectual disabilities); and case studies (two adults with intellectual disabilities and their families).
Results: The new funding system supported some elements of a life more aligned to that of similar aged peers, such as independent living and developing skills to work towards this. There were a number of elements of quality of life that were of concern, such as friendships and personal relationships. There were also limited opportunities in education and open employment. The opportunities that were available to the adult with intellectual disabilities were affected by stakeholders' differing views of disability.
Conclusions: There is a need to develop more understanding and acceptance of what it means for everyone to live an ordinary life, but also to develop the skills and support of all stakeholders to ensure such a life is available to all.

Meaningful moments of interaction with persons with profound intellectual disabilities: Reflections from direct support workers

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Background: Persons with profound intellectual disabilities (PID) often depend on professional care. Consequently, their quality of life is affected by the quality of interactions with direct support workers. In the present study, the quality of the interaction between a person with PID and a direct support worker is investigated by exploring when direct support workers perceive an interaction with a person with profound intellectual disabilities as meaningful.
Method: Five direct support workers working with children aged 5 to 18 years with profound intellectual disabilities were interviewed in open, in-depth interviews, focusing on their perceptions of meaningful moments of interaction with persons with profound intellectual disabilities. Data were analyzed using Interpretative Phenomenological Analysis.
Results: Preliminary results show that, according to the direct support workers, meaningful moments of interaction relate to experiencing an emotional connection with persons with profound intellectual disabilities and contributing to the wellbeing and development of the capabilities of the person with profound intellectual disabilities.
Conclusions: Meaningful moments of interaction are appreciated by direct support workers and presumably contribute to the quality of life of persons with profound intellectual disabilities. Future research is needed to study these meaningful moments of interaction in more detail and explore the value of these moments of interaction for persons with profound intellectual disabilities themselves and their relatives.

A group intervention for improving time management in people with intellectual disability

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Background: The aim of this study was to evaluate the Swedish version of the Let's Get Organized (LGO-S) intervention, aiming to support time-management habits and organizational skills, by exploring possible enhancements in time management skills and satisfaction with daily occupations, in people with time-management difficulties due to intellectual disability.
Method: A pre-test post-test design study including 23 adult participants with mild intellectual disabilities who reported difficulties in daily time management affecting their functioning in daily life negatively. Instruments used: Assessment of Time Management Skills (ATMS-S), Weekly Calendar Planning Activity (WCPA-SE) and Satisfaction with Daily Occupation measure (SDO-13). Intervention: The group intervention contained ten occasions one per week. Data was

collected pre-and post-intervention, and 3- and 12-months follow-ups.

Results: The main preliminary findings were significant changes, post-intervention and at 3- and 12-months follow-ups in organization and planning, and at the 3-month follow-up in time management skills. The results at 12-month follow-up indicated sustainability in outcomes measured by ATMS-S. A non-significant but positive trend was observed in other outcomes between pre- and post- intervention.

Conclusions: Improvement with indicated sustainability in in organization and planning and in time management skills might be possible for persons with intellectual disabilities when participating in LGO group intervention.

The development of a health communication tool in Wales: A three-stage parallel mixed methods study

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Background: To determine the views of people with intellectual disabilities and other relevant stakeholders concerning the most important areas of information to be included in a health communication tool (HCT) and to use this information to develop an All-Wales HCT.

Method: A three-stage parallel mixed-methods study comprising a review of existing HCT, focus groups with people with intellectual disabilities (n=22) and an online survey (n=208 stakeholders). Participants in the focus groups and survey were asked to rank potential areas of information in terms of their importance to patient safety. Data were analysed both using descriptive statistics and thematically.

Results: There was agreement between the focus group and survey participants regarding key information to include in a HCT namely health needs, preferred communication, overall support needs and additional information particularly important for the individual. There was also agreement that ideally the document should be no more than four pages long.

Conclusions: A four-page document, easily recognisable by people with intellectual disabilities and key stakeholders, and accompanied by guidelines for completion was proposed and is now being implemented across Wales.

POSTER PRESENTATIONS

Self-determination enhancements after deinstitutionalization of people with higher support needs

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Background: Opportunities for self-determination are restricted for people with intellectual disability, especially for those with higher support needs. The aim of this work is to analyse changes in self-determination for people with higher support needs after a deinstitutionalization process.

Method: This work is part of a longitudinal study called "My Home," which is carried out in Spain. The study analyses the observed benefits after a deinstitutionalization process. This work presents the results obtained in the Resident Choice Scale (Hatton et al., 2004) by 15 adults with intellectual disabilities and extensive support needs (M=49.8 years old; DT= 10.6). Data were collected in two different moments (while they still lived in the institution and six months after their relocation into the community). MIMIC models and paired samples T-Test were performed to analyse pre-post differences using the Smart-PLS software.

Results: After relocation, individuals with intellectual disabilities show more opportunities to decide about home and household routines, personal appearance and possessions.

Conclusions: Individualized supports provided at community settings enhance the self-determination of people with intellectual disabilities and extensive support needs. However, in Spain, this population is still more likely to remain institutionalized. The implementation of public policies to promote their right to independent living is imperative.

Implementation of UN CRPD Article 19 in the Czech Republic: Mapping the availability and nature of community-based services for people with intellectual disabilities

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Background: People with intellectual disabilities are less likely to be realising the right to live and participate in the community. Part of a wider project on improving quality and outcomes for people with intellectual disabilities, this study explores the availability and nature of community-living services in the Czech Republic.

Method: Interviews were conducted with service providers of all registered social care services for people with disabilities in three Czech regions. Interviews mapped size, location, nature and target client groups. For services that met at least a basic definition of community-living, questions also explored user needs, staffing and type of support provided.

Results: Preliminary findings indicate that: many services do not meet the definition of community-living; creative solutions are needed to support people with intellectual disabilities in the community; registration category is not a good indicator of service type; and few people with more severe intellectual disabilities are living in the community.

Conclusions: Such a systematic mapping of services will permit more accurate monitoring of UN CRPD Article 19 and provide the basis for evaluation of the quality and outcomes of community-living services.

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The influence of lack of self-awareness on Quality of Life in people with cognitive disabilities

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Background: The lack of self-awareness in patients who have suffered a brain injury is a widely documented aspect. However, it is not well known how this process may affect the quality of life (QoL) and multidimensional models, such as the one proposed by Schalock and Verdugo (2013), and been used even less often. The objective of this poster is to analyze the influence of self-awareness on the of QoL in people with brain injury and check the differences, depending on who answers the scale.

Methods: Both professionals ($N=300$) and relatives ($N=265$), and the users themselves ($N=260$) completed the Scale of Quality of Life for Brain Injury (CAVIDACE) and an evaluation of the lack of self-awareness of deficit using The Patient Competency Rating Scale (PCRS).

Results: Significant positive correlations were found between the QoL of the patient and the lack of self-awareness in the emotional well-being domain ($r(147)=.236$, $p=.004$). However, when the evaluation was carried out by professionals and relatives, all the significant correlations found were negative in personal development ($r(164)=-.321$, $p.00<1$) and self-determination ($r(164)=-.385, p<001$).

Conclusions: It has been shown that lack of self-awareness exerts an important influence on QoL. Therefore, it is important to study more about this phenomenon and intervene early.

Mixed methods systematic review of literature to inform the development of "sustainable safe staffing" improvement resource in intellectual disability services for NHS Improvement

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Background: In the UK the Department of Health in England focused on making fundamental changes in how decisions on ensuring sustainable safe staffing levels within health provider services are made following the Francis Report (2013). Within the intellectual disability context, determining sustainable safe staffing is problematic because of the disparate nature of services. It is difficult to envisage how universal guidance could be operationalised because of the complex interaction and interfaces between the public, private, voluntary and independent sectors, acute general and mental health hospital settings, intellectual disability specialist acute services, generic community services and specialist community intellectual disability services. This mixed methods systematic review of literature summarised evidence on sustainable safe staffing levels for multidisciplinary intellectual disability teams, and identify themes of relevance to intellectual disability teams, and the delivery of sustainable, safe and effective care for people with intellectual disabilities in order to inform the development of setting-specific sustainable safe staffing guidance for provider organisations.

Method: The Joanna Briggs Institute's (JBI) systematic review protocols were used to appraise studies. The PRISMA process was used to select the literature for review. Meta-synthesis was used to produce the synthesised findings. Foundational coding families of cause, context and process were used as a framework (Glasser, 1978) for presenting the findings.

Results: No empirical evidence was located that directly relate to sustainable safe staffing. Three core themes—*service models*, *standards of care* and *resources*—were identified.

Conclusions: The concept of sustainable safe staffing in intellectual disability services must be clearly understood from the very complex nature of the models of care, the extent of the number professionals and healthcare agencies involved in meeting the healthcare needs of people with intellectual disabilities. Without an appropriate *service model* of healthcare provision, clear *standards of care*, and adequate processes for deploying *resources* sustainable, safe, effective and efficient staffing may be challenging or unachievable.

Talking Mats in NHS Grampian

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Background: Talking Mats is a visual framework that uses picture symbols to help people communicate more effectively. Under the Equality Act 2010, services have a legal duty to make reasonable adjustments to remove barriers that make it difficult for people to access services because they have a disability.

Method: We provide training three to four times a year to NHS Grampian and third-sector staff. It is a useful tool for having conversations about likes/dislikes of meals, how they are managing/not managing personal care, and also getting to know someone and understanding their views about discharge. It is used within the multidisciplinary team for looking at personalised timetables and understanding personal goals.

Results: More training has increased awareness of the benefits of Talking Mats as more staff are using this tool. This has led to person-centred care and individuals feeling more empowered. Talking Mats is not suitable for everyone due to their cognitive ability, and symbolic understanding is required.

Conclusions: There is other accessible information used, but there is not another tool similar to Talking Mats. This now ensures best practice use of accessible information with individuals across the learning disability sector in Grampian.

Improving the health of people with intellectual disabilities using a public health nursing approach: Systematic literature review

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Background: The avoidable disparity between the health, and the healthcare outcomes of people with intellectual disabilities as compared to that of the general population has been acknowledged over many years (Kerr, 2004; Kavanagh et al., 2017). These disparities could be improved through appropriate interventions. In the UK, the lack of role clarity of the professionals working with people with intellectual disabilities has been consistently identified as one of the most common barriers to better healthcare outcomes for people with intellectual disabilities (Mafuba & Gates, 2015). Primary healthcare services have an important role in meeting the health needs of people with intellectual disabilities but there is a lack of evidence as to the roles ID nurses play in meeting these needs. The purpose of this mixed methods systematic literature review was to summarise evidence on the role and impact of interventions by ID nurses in meeting the public health needs of people with intellectual disabilities.

Methods: The Joanna Briggs Institute's (JBI) systematic review protocols were used to appraise literature. The PRISMA process was used to select the literature for review. Empirical (quantitative, qualitative, mixed methods) studies, synthesised evidence (literature reviews) and opinion papers ($n = 36$) were included in the review. Meta-synthesis was used to produce the synthesised findings.

Results: High-impact areas identified include; surveillance, public health intelligence, policy/strategy development, policy/strategy implementation, health improvement, health promotion, health education, health improvement, assessing effectiveness, enhancing effectiveness, co-ordination, strategic leadership, professional leadership, clear/visible/accessible leadership and scholarship.

Conclusions: ID nurses, employers and commissioners of health services need to have an agreed dialogical definition of public health. Research is needed to clarify ID nurses' specific contributions in mitigating the determinants of health, and the high rates of premature mortality in this population.

Public health: Community intellectual disability (ID) nurses' perception and experience of their role – An exploratory sequential multiple methods study

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Background: People with intellectual disabilities experience higher but avoidable morbidity and mortality rates (Robertson et al., 2017; Heslop et al., 2014), and depend on others for their health and healthcare outcomes (Campbell & Martin, 2009). In the UK, ID nurses play a pivotal role in implementing health policies which impact on the health and healthcare outcomes of people with intellectual disabilities. This research sought to describe how community ID nurses perceive, and enact their public health roles, and also sought to explain the "moderators" of these roles.

Methods: This was a three-stage exploratory sequential multiple methods study involving documentary, Grounded Theory and survey methods.

Results: There were inconsistencies in public health role expectations in community ID nurses' job descriptions and person specifications. The public health roles were academic, health education, health prevention, health promotion, health protection, health surveillance, healthcare access facilitation, healthcare delivery, leadership, and policy development and implementation. The moderators of public health role enactment by community ID nurses identified in this study were complex and extended beyond current explanations of role theory. Some of the correlates of the moderators of public health role enactment by community ID nurses included role clarity in job descriptions, periodic review of role expectations, role perception, perceived role value, community ID nurses' perceptions of employing organisations' priorities, and community ID nurses' perceptions of employing organisations' knowledge of the public health needs of people with intellectual disabilities, band, and finally, the type of employer.

Conclusions: There is a need for clarity of community ID nurses' public health roles locally, and nationally. It is important that relevant organisations have structures that can respond appropriately to public health policy changes in order to meet the often complex and co-morbid health needs of PWID.

Evaluating supported living and residential care for adults with intellectual disabilities

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Background: To understand how the quality and costs of services for adults with intellectual disabilities vary between supported living and residential care.

Method: The project is a cross-sectional study with a largely quantitative design. It involves 100 participants in supported living and 100 participants in residential care across a variety of providers. To ensure multiple perspectives are considered, information is gathered via a combination of interviews and questionnaires at four levels: 1) participants with intellectual disabilities (self-reported and proxy data); 2) provider organisations; 3) the residential or supported living settings; 4) family members. Outcomes of interest include quality of life, choice, control, finances, employment, community and wellbeing.

Results: As the research is on-going, preliminary results will be presented.

Conclusions: This study will provide up-to-date evidence to enable commissioners, family members, people with intellectual disabilities and other stakeholders to make evidence-based decisions in relation to housing for adults with intellectual disabilities. This is necessary as service models and commissioning practice have changed considerably since the last substantive research in this area took place. Furthermore, understanding which factors are most strongly associated with quality of life in supported living and residential care will enable providers to develop and improve their services.

Social vulnerability assessment in adults with intellectual disabilities

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Background: The Test of Social Vulnerability-22 items (TV-22) is a measure specifically designed for adults with intellectual disabilities. Social vulnerability refers to the ways in which an individual is at risk of being victimised. The poster presents 1) the psychometrics properties and 2) the implementation outcomes (acceptability, appropriateness, fidelity of utilisation) of the TV-22.

Method: 1) 29 adults with intellectual disabilities answered the TV-22. The reliability and validity of the measure were assessed. 2) 31 special education professionals (8 psychologists, 11 educators, 12 special education center managers) administered the TV-22 during an interview with an adult with intellectual disabilities. The fidelity of utilisation of the TV-22 was evaluated on these interviews. Semi-structured interviews were also conducted with the professionals to assess the acceptability and appropriateness of the test for their clinical practice.

Results: 1) Performance on the test was shown to be internally consistent and stable over time. 2) Psychologists stand out for a more rigorous utilisation of the measure. Specific training on the test is recommended for other professionals. The TV-22 was seen as useful and appropriate by the professionals.

Conclusions: Results provide precious insights into the implementation processes of a new measure in the special education field.

Transforming technology to improve the lives of adults with intellectual disabilities

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Background: COVID-19 has forced people to stay at home and keep social interactions at a minimum. For people with intellectual disabilities who depend on structured social contact, the situation is having a significant impact on their mental health and well-being. While general society has pivoted towards the use of technology to continue to socialise, these technologies are often out of reach for people with intellectual disabilities. Our project engaged people with intellectual disabilities in a co-design process to identify challenges they face in the pandemic and design practical solutions with their direct input.

Method: A two-phase qualitative methodology was followed. In Phase 1, three online focus groups were run with eight people with intellectual disabilities to gain insights into their daily challenges. In Phase 2, three online workshops were run to co-create digital solutions, exchange design ideas, validate use cases and evaluate prototypes.

Results: Three main challenges were identified: daily planning, social gatherings and entertainment. Bespoke functional prototypes were built based on these challenges and distributed to participants in free use trials.

Conclusions: Technology can play an important part in the everyday lives of people with intellectual disabilities. Concepts such as resilience, relationship building, planning, scoping and co-creation are crucial to shaping tools, methodologies and solutions to match their desires.

Intellectual disability and dementia: Understanding the effectiveness of psychosocial interventions

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Background: The study aim was to identify effectiveness of psychosocial interventions with people who have an intellectual disability and dementia.

Method: This mixed-method participatory action study used goal-setting theory with 16 participants with intellectual disability and dementia, and 22 social care staff across 11 sites. Five co-researchers with intellectual disability were part of an inclusive research team collecting data using existing and bespoke tools, including photovoice. Psychosocial interventions included: music playlists, reminiscence, animal therapy, robotic animals, and design changes. Analysis used descriptive and inferential statistics and framework analysis.

Results: 74% of individual goals met or exceeded expectations with reduction in some "as required" medication. Qualitative findings include themes of enabling care and interventions as tools for practice. Photovoice provided insight into previously unreported fears about dementia. This poster combines an easy-read and pictorial summary of the study. Recommendations are made to maximise wellbeing and ensure the perspectives of people with dementia are heard: medication review, design changes to the home of a person with dementia, staff training, and talking about dementia more with people who have an intellectual disability.

Conclusions: Individualised psychosocial interventions have potential to reduce distress or agitation in persons with intellectual disability and dementia, and to increase quality of life.

Technology & Me: Technology's role in the inclusion of adults with intellectual disabilities

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Background: This paper is based on our Irish Research Council New Foundations-funded study "Questions of Inclusion: what inclusion means for adults with an intellectual disability in Ireland and the role technology plays in their inclusion." The study objectives were to 1) Establish the types of inclusion and exclusion adults with intellectual disabilities experience, 2) Identify what supports, especially technology, needed to improve inclusion and potential for sectoral *Inclusion Champions, 3)* Make recommendations to develop strategies and tools (especially digital) to improve inclusion.

Method: Fifty participants will be recruited for focus groups hosted with our Intellectual Disability Partners. Participants will be self-consenting adults with a diagnosed intellectual disability aged 30 years and above. This paper will examine the core question of the role of technology in people with intellectual disabilities' inclusion during the COVID-19 crisis. We are pivoting to include online methods to engage with the intellectual disability community. Ethical approval sought from institution's Ethics Committee.

Results/Conclusions: We will present preliminary findings to one of our study's core research questions; the precise ways in which technology is being used and supporting people with intellectual disabilities' inclusion during the crisis.

Is a picture worth a thousand words?: Guided photovoice in persons with intellectual disabilities

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Background: People with intellectual disabilities are often excluded from participation in research, whilst research has the potential to enhance positive change. Guided photovoice was introduced to fit the needs of persons with intellectual disabilities who have difficulties dealing with communicational and technical challenges. In the current study a detailed description of the guided photovoice procedure is presented.

Method: In guided photovoice the participant, together with a researcher, explores the environment and takes photos of a specific theme. A total of 12 participants with intellectual disabilities were interviewed using guided photovoice.

Results: Through guided photovoice, the participants were able to take control in a physical manner as opposed to other strategies that depend on verbal communication skills. By aiming the camera at a specific subject, the participant can determine the topic of conversation. Guided photovoice led to the discovery of previously unknown sources of resilience.

Conclusions: Guided photovoice helps to better understand the perspective of people with intellectual disabilities and the results can help to improve their quality of life. Based on the responses of people with intellectual disabilities, specific suggestions will be presented on how to use guided photovoice in cooperative research with people with intellectual disabilities.

Scoping review: Contribution of intellectual disability (ID) nurses

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Background: The objective of this scoping review was to summarise evidence on the contribution of intellectual disability nurses to improve the health and well-being of children, adults and older people with intellectual disabilities, now and for the future. There is a lack of clarity on effective interventions that can be carried out by intellectual disabilities (ID) nurses (Mafuba 2009, 2013).

Method: The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (for Scoping Reviews) (PRISMA-ScR) process and Joanna Briggs Institute (JBI) guidance was used to select the literature for review and to present the literature review report (Trico et al., 2018).

Results: We included 53 publications in this review. We identified a wide range of interventions (154) undertaken by ID nurses in a variety of settings across the lifespan. We categorised the ID nursing interventions into three themes: effectuating nursing procedures, enhancing impact of services, and enhancing quality of life.

Conclusions: Findings advocate for high quality research being essential in determining the impact and effectiveness of ID nursing interventions across the lifespan. We recommend that a searchable online compendium of ID nurse interventions be established and regularly updated. This will provide opportunities to engage more effectively in evidence-based practice.

Power and support in digital inclusion of an adult with intellectual disabilities: A case study

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Background: Caregivers can act as both support and gatekeeper to internet access and use by adults with intellectual and developmental disabilities. This study investigated micro-level interpersonal factors influencing access and use of the internet by an adult with intellectual and developmental disabilities to explore the balance and interplay of power and support around the processes of digital inclusion.

Method: Taking a case study approach, perspectives of three key stakeholders were gathered via interviews: the person with intellectual and developmental disabilities, his mother, and a paid support worker. Perspectives and experiences were contrasted using Systemic Functional Linguistic analysis (of discourse) to explore the ways power and support were represented in the language of negotiated digital inclusion.

Results: Dynamics between the parent and person with intellectual and developmental disabilities and between the parent and paid staff clearly influenced digital inclusion, and were affected by varying positions and perceptions of power to allow, disallow and monitor access and use of the internet. These key relationships had the power to shape and drive internet access and use, but incomplete understanding of online risk was apparent in the person with intellectual and developmental disabilities' account.

Conclusions: Carer training is needed to enable them to better support the development of digital competence, confidence, resilience and risk awareness in people with intellectual and developmental disabilities.

Fulfillment of rights of children with intellectual disability and comorbid conditions

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Background: The aim of this study is focused on evaluating individual quality of life (QoL) related personal outcomes (more specifically, outcomes related to the Rights domain) in children and young people with intellectual disability and other associated conditions.

Method: The Rights subscale of the KidsLife Scale was administered to 153 participants with intellectual disability aged 4 to 21 years old (M=12,7; SD=4,5). In addition to intellectual disability, one third of participants had autism spectrum disorder, another third had Down syndrome and the other third had cerebral palsy.

Results: The three groups showed positive outcomes, although those with comorbid Down syndrome obtained statistically significant higher scores than participants with autism spectrum disorder. Gender, type of schooling, level of intellectual disability and level of support needs were significant predictors for the group with comorbid autism spectrum disorder.

Conclusions: Children with intellectual disability and autism spectrum disorder have benefited the least from advances in QoL and rights fulfillment. They suffer the most situations of exclusion, misinformation, and greater violation of their rights in comparison with other groups. There is an urgent need to monitor the implementation of the Convention on Rights of Persons with Disabilities for people with intellectual disability through assessment instruments with adequate evidence of reliability and validity.

Assessing implementation of the PTR-YC model by community-based educators: Their point of view

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Background: Challenging behaviour in children with autism spectrum disorder can hinder their responsiveness to well-established programs such as EIBI (Jang et al., 2015). In spite of widespread interventions for challenging behaviour (McDonald & McGill, 2013), challenges remain regarding their implementation in community-based services (Grenier-Martin & Rivard, 2020). Specialized educators working in this context have voiced a requirement for programs that could be implanted within their usual practices, as well as training and supervision to address behaviour and support families (Rivard et al., 2015). While the Prevent-Teach-Reinforce for Young Children model (PTR-YC; Dunlap et al., 2013) has empirical data and fits educators' needs, it has never been implemented in such a context.

Method: Our team translated the PTR-YC model and conducted a study to assess its implementation within public services when facilitated by specialized educators.

Results: This communication will present results of a mixt design approach enabling quantitative and qualitative data triangulation, to better understand the point of view of 17 educators regarding their implementation of the PTR-YC model.

Conclusions: Using Chen's (2015) program evaluation model and Dane and Schneider's (1998) dimensions of program integrity, three main themes will be discussed: 1) facilitating factors, 2) barriers to implementation and 3) fidelity.

Promoting evidence-based practice by evaluating the quality and evidence of interventions

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Background: Striving towards evidence-based practice—"*practices that are based on current best evidence that is obtained from credible sources that used reliable and valid methods and based on a clearly articulated and empirically supported theory or rationale*" (Schalock et al., 2011)—can contribute to better quality support. As evaluating the quality and effectiveness of interventions evidence is not common practice for many support providers, a system for acknowledging effective interventions has been developed in the Netherlands.

Method: A committee of experts assesses per intervention its core elements, rationale and theory underlying the intervention, and the research regarding practice and effectiveness (Veerman & van Yperen, 2007).

Results/Conclusions: In the presentation, members of the expert committee will engage with the audience in an active discussion based on their experience, and will explore directions for further development of an international system.

Building the right homes for adults with learning disabilities and autism: A multi-agency approach

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Background: There was an identified need within the Learning Disability Service for suitable housing. The project was implemented to meet the complex housing needs of this client group.

Method: Occupational Therapy and Psychology led in the design and implementation working in consultation with multi-agency colleagues. A review of published research outlining best practice for the design of accommodation for adults with autism and a learning disability was completed, taking into account internal and external physical environments. Meetings with the Learning Disability project management group were held to highlight housing needs of this particular service user group. Environmental specifications were developed to support the planning and building design of the proposed developments. These were submitted to the housing strategy manager via the project management group.

Results: Three environmental specifications were developed. Architects designed properties using these specifications. Housing projects commissioned to build these developments. The environmental specifications could also be used across Grampian for future housing projects.

Conclusions: Housing developments are currently being built that meet the needs of individuals with autism spectrum disorders and learning disabilities. We are currently chairing the project groups for two of these developments.

Lost in the literature: Trans people with intellectual disability—A narrative review

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Background: The aim was to undertake a narrative literature review seeking to examine how Trans people with intellectual disability feature in the academic literature. The positioning of Trans people with intellectual disability was explored.

Method: Ten academic databases were searched with the keywords of intellectual disability and Transgender. 472 papers were found, which were reduced to 45 for full-text reads. The number of included articles was 14. Autistic people without intellectual disability were excluded. Findings were agreed through discursive methods.

Results: Trans people with intellectual disability are an under-researched group, who are medicalised and show a lack of clear identity in the literature. The policing of behaviour of Trans people with intellectual disability is also focused upon.

Conclusions: Trans people with intellectual disability are “lost in the literature.” Further empirical research is required to elicit the lived experience of this population. Parents, caregivers and primary care staff also require support through progressive policy, informed by a psycho-social view of Trans people.

The use of online support during COVID-19

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Background: With this poster we aim to contribute to the build-up of knowledge regarding the usefulness of offering remote, online support to independently living people with ID during a time of crisis, when regular onsite services are less (or not at all) available.

Method: We explored the use of the online support service DigiContact by people with intellectual disabilities living independently during the first 20 weeks of the COVID-19 pandemic in the Netherlands. More specifically, we analyzed quantitative data on both planned and unplanned support contacts between DigiContact support staff and service users and compared this with two control periods.

Results: The results indicate that the COVID-19 outbreak and the related restrictive measures had an impact on the use of online support: the amount of unplanned support contacts (per day/per service user) was significantly higher than during both control periods.

Conclusions: Offering online support as a standard component of services for independently living people with intellectual disability enables service providers to be flexible and responsive towards fluctuations in both support needs and onsite support availability during a social crisis like COVID-19.

Experiences of support professionals with providing remote (online) support

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Background: Remote support services for people with intellectual disabilities are becoming increasingly common. A remote delivery of support is likely to have implications for (the work of) support workers. This study was part of a broader evaluation project of the Dutch online support service DigiContact. Its aim was to gain insight into: 1) the support practice of DigiContact support workers, and 2) how DigiContact support workers experience their work in an online support context.

Method: Semi-structured interviews were held with 10 DigiContact support workers. A qualitative thematic content analysis was performed on the transcripts.

Results: We identified four areas of support that reflect what the participants do to support people with intellectual disabilities remotely (e.g., creating a safe environment, identifying the request for help), and three general characteristics of their support (e.g., self-direction of people with intellectual disabilities, efficiency). We also constructed five themes that reflect what it is like for the participants to work at DigiContact (e.g., experiencing both limitations and possibilities in support).

Conclusions: The findings shed light on the specificities and complexities of the relatively new and upcoming field of work that is providing remote (online) support to people with intellectual disabilities.

A pilot randomised controlled trial of befriending by lay volunteers in people with intellectual disabilities

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Background: People with intellectual disabilities have less access to social support and networks, which may contribute to the maintenance of chronic depression. Little is known about whether befriending improves symptoms of depression and social outcomes in people with intellectual disabilities. The aim was to conduct a pilot RCT to assess the feasibility and acceptability of befriending delivered by lay volunteers compared to usual care.

Methods: Adults with mild/moderate intellectual disabilities with a score on the depression scale (GDS-LD) of 5 or above and were randomised to either the intervention arm (matched to a volunteer and were required to meet once a week for 6 months) or the usual care group. The main outcomes were recruitment (target $n = 40$) and retention rate of participants, adherence (10 meetings) and acceptability of the intervention, and changes in depressive symptoms.

Results: We only recruited 16 participants with intellectual disabilities and 10 volunteers. Six participants were matched with a volunteer but no participants dropped out (except 2 volunteers). There was good adherence (mean 11.8 meetings) and befriending was considered acceptable, but modifications were suggested.

Conclusions: There were challenges in recruitment, and therefore a large scale RCT is not feasible. Other study designs should be considered.

The impact of austerity on the lives of people with intellectual and developmental disabilities

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Background: UK austerity policies of the last decade have resulted in reductions to the amount of services, care and support available for people with intellectual and developmental disabilities, potentially impacting on their social lives. This study provides empirical evidence regarding the experiences of managers of services which support people with intellectual and developmental disabilities.

Method: Eight managers of five charitable services and one manager of a government agency in the UK took part in semi-structured interviews about how cuts in funding had affected them, their services and the social lives of people with intellectual and developmental disabilities. Responses were analysed using Interpretative Phenomenological Analysis.

Results: Many managers reported feeling unrelenting, significant and wide-ranging loss, including loss of shared understandings of care and loss of meaningful relationships with funders. Loss of equitable treatment of people with intellectual and developmental disabilities was also identified. Opportunities for social network maintenance and development were affected.

Conclusions: The sense of loss identified in this study across a range of areas and the negative impact of poor relationships with funders suggests that both people with intellectual and developmental disabilities and managers experience personal and social loss when services, care and support are cut.

Development of the compendium of intellectual disability nursing interventions

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Background: There is a lack of definitive and up-to-date handbook or compendium of effective interventions that can be carried out by intellectual disabilities (ID) nurses A scoping literature review by Mafuba et al. (2020), and a mixed method evaluation study by Mafuba et al. (2020) categorised ID nursing interventions as effectuating nursing procedures, enhancing impact of services, and enhancing quality of life. The objective of this project was to produce a compendium of ID nursing interventions.

Methods: The PRISMA-ScR process and JBI guidance were used to undertake a scoping literature review (Trico et al., 2018). Mixed methods evaluation methodology was used (Creswell and Plano-Clark, 2011) to collect qualitative and quantitative data using an online

survey questionnaire. Identified interventions undertaken by ID were compiled into a referenced compendium.

Results: 53 publications were included in the review. ID nurses ($n = 228$) from 7 countries participated in the survey and reported a wide range of interventions undertaken in a variety of settings across the lifespan.

Conclusions: We recommend that a searchable online version of the compendium of ID nursing interventions be established and regularly updated. This will provide opportunities to engage more effectively in evidence-based practice.

Assessing self-determination in adults with autism spectrum disorder: Using the AUTODDIS scale

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Background: In the Spanish context, there is a lack of instruments to measure self-determination in adults with ASD. To address this need, this study aims to make a first step to adapt and analyze the psychometric properties of the AUTODDIS scale (Verdugo et al., 2020) in adults with autism spectrum disorder. The preliminary results of the scale adaptation are presented.

Method: First, two experts on self-determination and eight caregivers of youths and adults with autism spectrum disorder assessed the clarity, importance and suitability of the scale for this population. Then, the scale was administered to families of adults with autism spectrum disorder, and psychometric properties were analyzed.

Results: Results stress the psychometric properties of the pilot version of the scale adaptation for people with autism spectrum disorder and highlight areas for improvement.

Conclusions: The results obtained in this pilot study will allow us to acquire a better knowledge about specific changes to make before the final validation.

What aspects of sport participation are related to thriving in youth with intellectual disability?

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Background: Sport participation is an important contributor to positive youth development and ultimately, thriving (Fraser-Thomas et al., 2005). Few studies, however, have examined whether different aspects of sport participation are associated with thriving among youth with intellectual disability.

Method: Data were collected from 442 caregivers of youth with intellectual disability who were between 11 and 25 years of age and registered with a Special Olympics (SO) program in Ontario (Canada). Caregivers completed surveys on their child's thriving (Lerner et al., 2005), frequency of SO sport participation, sport diversity (i.e., number of sports participated in), years of involvement, medals won, and positive SO experiences.

Results: Correlational analyses revealed that thriving was positively associated with sport frequency ($r = .14$, $p = .003$), sport diversity ($r = .23$, $p = .04$), years of involvement ($r = .12$, $p = .02$), and positive experiences ($r = .45$, $p < .001$). Thriving was not associated with child age, gender, or number of medals won (all $p > .05$). A linear regression revealed that thriving was only predicted by positive experiences ($p < .01$).

Conclusions: The results highlight the importance of positive experiences in sport programs in fostering thriving for youth with intellectual disabilities.

The perceptions of adults with intellectual disabilities on their travels and means of transport

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Background: This poster documents the perceptions of adults with an intellectual disability on their travelling habits.

Method: Preliminary results are issued from the qualitative portion of a research project evaluating a training program for the use of public transit. The participants will go through two qualitative interviews, one before and one after their participation in the program. Eight of the participants completed their first interview before the COVID-19 pandemic.

Results: Inductive analysis (Blais & Martineau, 2006) indicates that the participants like their travels to be a pleasant experience. However, they are stressed by the idea of using a new method of transport on their own. The results indicate that the people in the participants' social environment, the characteristics of the environment, and certain facilitators and obstacles also influence the means of transport used.

Conclusions: These results will address the preoccupations of people with intellectual disabilities so that they can be comfortable with using public transit if they wish to do so, after having completed a training program. By encouraging the independent use of public transit by people with intellectual disabilities, these results will contribute to their social inclusion (Bascom and Christensen, 2017) and their self-determination (Walker et al., 2011).

Stress and resilience of Japanese special needs school teachers during the COVID-19 pandemic

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Background: The stress and resilience of Japanese special needs school teachers for students with intellectual disabilities during the COVID-19 pandemic were investigated.

Methods: A questionnaire was administered to 227 teachers in Japanese special needs schools for students with intellectual disabilities. Stressors were assessed using the stressor scale for teachers of special needs schools developed in this study. Stress responses were assessed using the Public Health Research Foundation Check List Short Form (Imazu, Murakami, Kobayashi, Matsuno, Shiihara, Ishihara, Joh, Kodama, 2006), and resilience was assessed using the Bidimensional Resilience Scale (Hirano, 2010).

Results: Almost no correlation was indicated between the COVID-19-related stressors and stress responses, whereas a mid-level correlation was seen between human relationships and stress responses. Female teachers' stressors and stress responses were significantly higher than those of male teachers, whereas female teachers' resilience was significantly lower than male teachers.

Conclusions: It is suggested that the COVID-19-related stressors have caused almost no stress responses in Japanese special needs school teachers. Higher stressors and stress responses in female than male Japanese special needs school teachers indicate support needs.

Facilitators and barriers to physical activity experienced and perceived by adults with intellectual disability

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Background: Adults with intellectual disability experience disproportionately high rates of physical and mental health conditions that can be prevented, mitigated, and improved through health-promoting behaviours, such as regular physical activity. However, this population has been shown to engage in considerably lower levels of physical activity compared to adults without intellectual disability, and this can have a negative impact on their health and fitness. This study's objective was to explore the various factors that influence physical activity participation among adults with intellectual disability.

Methods: This study utilized qualitative phenomenological inquiry to explore facilitators and barriers to physical activity, with an emphasis on capturing the perspectives of adults with intellectual disability (n=13) who attended day programs that incorporated physical activities. Two focus groups were employed and were guided by a set of semi-structured interview questions. Audio recordings were transcribed verbatim, and the resulting transcripts were coded in NVivo and thematically analyzed.

Results: A total of seven over-arching themes emerged from the data. The four facilitator themes related to (1) the *individual*, (2) their *supports*, (3) the *programs* they attend, and (4) the *resources* to which they have access. The three barrier themes related to (1) *internal* influences, (2) *external* influences, and (3) *difficulty in recognizing and understanding barriers*.

Conclusions: The results suggest that adults with intellectual disability face a variety of facilitators and barriers to their physical activity, which often act in combination to influence participation. This information can be used in conjunction with previous research to inform and develop strategies, programs, organizations, and policies to improve the physical activity specific to this population, which has the potential to positively impact their fitness and overall health and well-being.

Track 2c Parenting

PRESENTATIONS IN A SYMPOSIUM

Supporting mothers with intellectual and developmental disabilities

Clinician attitudes around perinatal care of women with intellectual and developmental disabilities

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Background: This study examines clinician attitudes towards maternity care of women with intellectual and developmental disabilities from the perspectives of both clinicians and women.

Method: We conducted semi-structured individual interviews and one focus group with clinicians (n=17) and individual interviews with women with intellectual and developmental disabilities (n=16). Both datasets were analyzed separately using a content analysis approach. Then themes related to clinician attitudes from both datasets were compared and analyzed to determine larger themes and relationships.

Results: Themes of negative clinician attitudes around pregnancy in women with intellectual and developmental disabilities include: 1) inability to parent, 2) inability to make care decisions, 3) inability to understand/follow clinician instructions, 4) biased sterilization practices and provision of contraception, 5) clinician unwillingness to provide care. Positive attitudes include: 1) responsibility to accommodate, such as with extra visit time, 2) clinician advocacy on a woman's behalf, and 3) support of clinician and staff training and development of guidelines.

Conclusions: Clinician attitudes constitute a substantial barrier to appropriate perinatal care of women with intellectual and developmental disabilities. Clinician training to address attitudes, stigma, and communication as well as materials and supports accessible to women with intellectual and developmental disabilities are needed to facilitate better care experiences and improve outcomes for women with intellectual and developmental disabilities.

Child protection involvement of children of mothers with intellectual disability

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Background: To investigate child protection involvement for children born to mothers with intellectual disability.

Method: A cohort of 1,106 children born to a mother with intellectual disability and a comparison group of 9,796 children of mothers without intellectual disability were identified using linked administrative data. Cox regression analyses were conducted to investigate risk of child involvement with child protection services and care placement. The analysis was conducted stratifying by maternal Aboriginal status.

Results: Children born to a mother with intellectual disability were at higher risk of having contact with child protection services (HR: 4.35 (3.92-4.83)) and placement in out-of-home care (HR: 6.21(5. 19-7.44)). For non-Aboriginal children, the risks of child protection involvement and placement for those born to mothers with intellectual disability were 7 times and 12 times higher than those of mothers without intellectual disability, respectively. The risk was lower for Aboriginal children, at 1.7 and 1.9 times. Infants were at higher risk of child protection involvement compared to other age-groups. Maternal mental health and substance use moderated the increased risk found.

Conclusions: Intellectual disability alone is not sufficient justification for removal of children from their parents. The challenge for services is ensuring that resources and supports are adequate to meet the family's needs.

Clinician barriers to perinatal care of women with intellectual and developmental disabilities

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Background: This qualitative study examined clinician perspectives about perinatal care for pregnant women with intellectual and developmental disabilities to better understand the potential mechanisms driving perinatal health disparities and unmet needs reported by women with intellectual and developmental disabilities.

Method: We conducted semi-structured interviews and one focus group with 17 US obstetric care providers who have experience providing perinatal care to pregnant women with intellectual and developmental disabilities. Using a content analysis approach, inductive and deductive coding techniques and category development, codes were systematically applied to transcripts. Themes related to clinician-perceived barriers to care are reported.

Results: Participants reported barriers in three distinct levels: 1) individual clinicians (e.g., communication challenges, care continuity, clinician knowledge); 2) practices (e.g., lack of practice protocols, identification of intellectual disability status); 3) systems (e.g., lack of available clinician training on pregnancy and intellectual disability, lack of guidelines).

Conclusions: Clinicians experience barriers providing care to pregnant women with intellectual and developmental disabilities across individual, practice, and system levels. These findings suggest care would improve with increased clinician access to training and evidence-based guidelines for perinatal care of women with intellectual and developmental disabilities.

Perinatal mental illness among women with intellectual and developmental disabilities

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Background: To compare the risks of incident and ongoing mental illness in the perinatal period among women with and without intellectual and developmental disabilities.

Method: We conducted a population-based cohort study of 15 to 49-year-old women with intellectual and developmental disabilities ($n=2{,}227$) and those without disabilities ($n=1{,}601{,}363$) in Ontario, Canada, all with a singleton obstetrical delivery (2003-2018). We used modified Poisson regression to estimate adjusted relative risks (aRR) of health care encounters for mental illness between conception and 365 days postpartum, among women with and without a history of mental illness.

Results: Compared to women without disabilities, the risk of mental illness in the perinatal period was elevated among women with intellectual and developmental disabilities with (aRR 1.27, 95% CI 1.22-1.33) and without a history of mental illness (aRR 1.59, 95% CI 1.46-1.73). Risks were elevated for prenatal and postpartum mental illness; for mood and anxiety, psychotic disorders, substance use disorders, and self-harm/suicide; and for ambulatory and acute mental health care use.

Conclusions: Our findings demonstrate an urgent need to improve mental health supports for women with intellectual and developmental disabilities in pregnancy and across the postpartum period, with attention not only to women with a history of mental illness but also women with no prior mental illness.

ORAL PRESENTATIONS

The experiences of mothers with an intellectual disability in light of the affirmative model

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Background: Article 23 of the Convention on the Rights of Persons with Disabilities calls us to respect people with disabilities' right to

have a family. However, women with intellectual disability have long been perceived as incapable of being successful mothers. Previous studies on mothers with intellectual disability have focused on negative outcomes regarding the children's poor health and loss of custody. The aim of the study is to explore the subjective experiences of mothers with intellectual disability in light of the affirmative model of disabilities, focusing on the empowering aspects of the motherhood journey alongside the challenges.

Method: In-depth interviews were conducted with ten Israeli mothers with ID who live in the community.

Results: Qualitative content analysis produced five themes: a) Inherent desire to become a mother; b) No prior education and guidance on how to become a mother and take care of the children; c) Motherhood was perceived as a positive experience; d) the motherhood journey contributed to the women's sense of self-efficacy; e) family support was perceived as a primary resource to success.

Conclusions: Practitioners should focus on the positive side of parenting for women with intellectual disability and support their needs in a way that empowers the mothers and their families.

Discourse analysis of child welfare court reports of parents with intellectual disability

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Background: The lives of parents with intellectual disability is constrained by intersecting discourses on ableism and ideal parenting. There is scant research that has explored the discursive conditions embedded within child welfare court reports of parents with intellectual disability. The aim of this study is to explore how parents with intellectual disability are constructed and how this construction influences decision making within child welfare courts.

Methods: The overall research project utilized mixed methods on publicly available court reports of parents with intellectual disability in Quebec, Canada. A three-level critical discourse analysis was performed on 15 child welfare court reports that met the inclusion criteria.

Results: Different terms were used to describe the parents' intellectual disability, and the intellectual disability was primarily used to construct the unfit parent. Three intersecting discursive patterns emerged from the court reports: The deviant parent with intellectual disability vs. the capable alternate caregiver, Love is not enough for parents with intellectual disability, and highly scrutinized yet voiceless in court proceedings.

Conclusions: Critical documents, such as child welfare court reports, mirror the ways in which marginalized communities, such parents with intellectual disability, are regarded and treated in different facets of society. Unveiling these hidden ideological assumptions can challenge and confront unequal power relations.

Perinatal care experiences of people with intellectual and developmental disabilities in Ontario

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Background: Accessible and quality care during the perinatal period is critical for optimal maternal and neonatal health. Using the socio-ecological model, the purpose of this study was to explore barriers and facilitators that shape the perinatal care experiences of people with intellectual and developmental disabilities.

Methods: Semi-structured interviews were conducted with 10 individuals with intellectual and developmental disabilities in Ontario, Canada. Interviews focused on care experiences before, during, and after pregnancy. Data were analyzed using a directed content analysis approach, and the socio-ecological model guided analysis.

Results: Barriers at the societal (e.g., cultural norms of motherhood), policy/institutional (e.g., child protection policies and practices), interpersonal (e.g., inadequate formal and informal support), and intrapersonal levels (e.g., internalized stigma) contributed to participants having negative perinatal care experiences. Conversely, we identified facilitators on the interpersonal level (e.g., positive interactions with perinatal care providers) as positively shaping participants' perinatal care experiences.

Conclusions: Perinatal care experiences of people with intellectual and developmental disabilities are shaped by several factors that largely stem from societal-level barriers. There is a need for interventions at multiple levels including the development of policies to support diverse populations and training perinatal care providers to enact policies at the institutional and interpersonal levels.

Severe maternal morbidity among women with intellectual and developmental disabilities

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Background: We assessed differences in severe maternal morbidity (SMM) and other perinatal complications by presence and type of disability.

Method: We conducted a retrospective cohort study of deliveries in California, USA, using birth certificate data linked with hospital discharge records from 2000-2012 (n=5,787,090). Maternal disability status and type (physical, sensory, intellectual and developmental disabilities) were identified by diagnosis codes in discharge records. Our primary outcome was a composite indicator of SMM. Other perinatal complications (e.g., pre-eclampsia; perinatal mental disorders) were secondary outcomes. Logistic regression models tested the association of disability status and type with SMM and secondary outcomes while adjusting for sociodemographic, health and pregnancy characteristics.

Results: Odds of SMM were significantly elevated for women with intellectual and developmental disabilities compared to women without disabilities (adjusted odds ratio=2.42, 95% CI: 1.82, 3.21). Most secondary outcomes were also significantly more common among women with intellectual and developmental disabilities. In particular, more than one quarter of births to women with intellectual and developmental disabilities were complicated by mental health disorders in pregnancy or postpartum (26.5% vs. 1.2% for women without disabilities, $p<0.001$).

Conclusions: Women with intellectual and developmental disabilities have elevated risk of SMM and other perinatal complications. Efforts are needed to address preventable health conditions and systemic and social risk factors that may contribute to risk.

Born to challenge: Adjustment and personal growth of adults raised by a parent with mental disabilities or intellectual and developmental disabilities

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Background: The objective of this mixed method study was to explore the unique and combined contribution of intrapersonal factors, social-ecological factors, and coping strategies to the adjustment and personal growth of adults raised by a person with disabilities.

Method: A comparative analysis assessed these factors alongside a sample population of adults raised by parents without a disability. 215 adults participated in the study.

Results: Participants raised by a person with a disability presented higher levels of perceived stress and as receiving lower levels of parental care; and reported a lower perception of social support and levels of mental health. Paternal care was found to moderate the link between being raised by a person with disabilities and perceived stress. Avoidant attachment orientation and problem-focused coping were found to mediate the impact of perceived stress on mental health. Six main qualitative themes emerged (and are connected to the quantitative data).

Conclusions: The findings of this study will add nuance and depth to policy makers' engagement with the human rights of people with disabilities, specifically with regards to their capacity for parenting. The study identifies the specific needs of the children of PWD and supportive family members, and can feed into the development of appropriate programs to address the unique challenges that these families face.

The taboo of desiring to be parents of adults with intellectual disabilities living in care homes

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Background: This research focuses on the parenting desires of adults with intellectual disabilities living in care homes in France. While this desire is recognized as a fundamental right, it seems to be marginalized within this population. The objective of this study is to evaluate the reception and accompaniment offered by the support network of care homes' residents.

Method: We carried out interviews with life history method with seven family caregivers. Two focus groups using photo-expression have also been conducted with care homes' professionals. Both were analysed with a narrative analysis method.

Results: The desire of adults with intellectual disabilities to have children is taboo within families and institutions. In the day-to-day accompaniment, the support network unwittingly contributes to prohibit/cancel this type of desire. Among residents, hypersexualisation or asexualisation appear to be adaptative behaviors activated to comply with the institution's norms.

Conclusions: People with intellectual disabilities are at risk of internalising stigma surrounding their affective and intimate desires, inducing psychological distress. Highlighting the mechanisms of invisibilisation of these desires can help the support network to overcome the institutional violence originated in their preconceptions toward sexuality/parenting desires of individuals with moderate to severe intellectual disabilities.

The toolkit-promoted insights about future parenting in students with intellectual disabilities that led to My Adult Life

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Background: To present how research can inspire to further development of educational material starting with a study evaluating an intervention using the Toolkit among students with intellectual disabilities in special schools.

Method: The material was evaluated in students ($n=16$) with mild or moderate intellectual disabilities who participated in an intervention model created to provide knowledge and experiences about future parenting. The intervention included a combination of 13 weekly theoretical lessons using the Toolkit "Children—what does that involve?" (ASVZ) and a three-day caring session with the RCB simulator. Individual interviews were done after the intervention was completed. Qualitative content analysis was used.

Results: The students with intellectual disabilities reported that the intervention provided important thoughts and insights on future parenting, providing a basis for informed decisions. The ability to be responsible and have autonomy in life and in caring for a future child was described as important to the students.

Conclusions: The intervention could equip students with intellectual disabilities with insights about future parenting. The adapted Toolkit will be further developed in a new project "My Adult Life" that will benefit practice in special schools. Short information about the new project will be provided.

Severe maternal morbidity among US women: Disparities at the intersection of intellectual and developmental disabilities and race/ethnicity

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Background: This study aimed to assess severe maternal morbidity (SMM) risk at the intersection of intellectual and developmental disability and race or ethnicity.
Method: We analyzed data from the 2004-17 Healthcare Cost and Utilization Project Nationwide Inpatient Sample. We used modified Poisson regression to compare non-Hispanic White women with IDD and women with and without intellectual and developmental disability in three other race/ethnicity groups (non-Hispanic Black, Hispanic, non-Hispanic other race) to a reference group of non-Hispanic White women without intellectual and developmental disability.
Results: We found that the disparities in SMM for women with intellectual and developmental disability who were Black, Hispanic and from other race were additive, with the adjusted risk ratio (RR=2.51; 95%CI: 1.95-3.25 for Black women with intellectual and developmental disability, RR=2.42; 95%CI: 1.74-3.37 for Hispanic women with intellectual and developmental disability, and RR=2.75; 95%CI: 1.86-4.08 for other race IDD women) equal to the sum of the risk ratios for intellectual and developmental disability alone (RR=1.29; 95% CI: 1.35 - 2.06) and Black race alone (PR, 1.47; 95% CI, 1.36–1.58) and respectively, Black race alone (RR=1.41;95% CI: 1.13-1.77), Hispanic ethnicity alone (RR=1.31; 95%CI: 1.04-1.66), and other race alone (RR=0.81; 95% CI: 0.57 - 1.17).
Conclusions: Targeted efforts are needed to prevent SMM risk in women of reproductive age with intellectual and developmental disability in these minoritized racial and ethnic groups.

Israeli social workers' attitudes on parenting with an intellectual disability

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Background: Article 23 of the United Nations Convention on the Rights of Persons with Disabilities aims to ensure that persons with disabilities can create a family by providing adequate supports. Social workers are required simultaneously to support parents' rights and to secure the health and well-being of their children, a position fraught with challenges and complexities. This study aims to explore the experiences of Israeli social workers relating to parenthood of persons with disabilities.
Method: A qualitative method using semi-structured interviews with twenty-one social workers. A thematic analysis was used to identify major themes.
Results: Social workers recognized the parental desires of adults with intellectual disabilities. Furthermore, social workers acknowledge their role to support parents in exercising their right to parent their children, despite their own personal perceptions of their parental capacity.
Conclusions: Social workers often feel conflicted regarding the capability of parents with intellectual disabilities, with a conscious desire to honor their duty to support these clients. Social workers' training is critical to ensure adequate support for these parents in Israel.

Parenting with intellectual disability and structural violence: A case study approach from Iceland

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Background: This contribution is a collective re-analysis drawn from a number of projects in Iceland focused on parenting with a disability spanning a two-decade period. The core purpose of these projects is to understand why parents with intellectual disabilities encounter such difficulties with the child protection system. Our aim with this contribution is to identify, through a longitudinal and comparative framework, why these difficulties persist despite a changing disability rights environment.
Method: A case study methodology has been employed, highlighting cases from each research project that focus narrowly on the parents' struggles with the child protection system in the context of the maternity ward.
Results: The findings, framed in the concept of structural violence, indicate poor working practices on the part of healthcare and child protection, a lack of trust between parents and professionals, and that context is still ignored in favour of disability as the explanatory framework for the perceived inadequacies of the parents.
Conclusions: We contend that child protection authorities continue to remain out of step with developments in disability and human rights. The contribution concludes to make a case as to why the concept of structural violence is a useful framework for criticism and advocacy work in this area.

What are the experiences of professionals working with parents with intellectual disabilities?

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Background: It has been recommended by the IASSIDD Special Interest Research Group that social, health and other relevant professionals work collaboratively in order to support parents with intellectual disability and their children. The aim of this meta-ethnography was to review existing literature on how professionals experience working with parents with intellectual disability, in order to inform practice guidelines on how parents with intellectual disability should be supported.

Method: A systematic search took place using five databases and fifteen peer-reviewed papers were identified based on the relevant inclusion and exclusion criteria. The quality of each included paper was systematically evaluated. The method of meta-ethnography was used in order to synthesise the qualitative data from the identified studies.

Results: The synthesis offered six themes: Concerns about Knowledge and Experience, Importance of and Difficulties with Available Support, Importance of and Challenges with Liaison with and between Professionals, Differences in Power, Conflicting Priorities – parents or children? and Personal Impact on Professionals.

Conclusions: The results are discussed in the context of two theories: psychological safety and burnout. Aspects of each theme relating to these theories are discussed, and recommendations for further research and practice improvement are made.

Reproductive freedom for women with intellectual disability

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Background: The aim is to widen a social reflection on the theme of access to reproductive rights and the right to family life for women with intellectual disabilities in Polish conditions, in which the adulthood of people with intellectual disabilities is a taboo subject and the reproductive rights of women are limited.

Method: Intersectional qualitative research, 25 in-depth interviews (with mothers with intellectual disabilities and their mothers), analysed according to the procedures of Grounded Theory.

Results: The common understanding of reproductive freedom does not include the intellectual disabilities variable. Women with intellectual disabilities are discriminated in access to the above-mentioned rights, both in social practice and legal regulations. It is visible in: undermining the right to making procreative decisions; creating a social image of women with intellectual disabilities as incompetent mothers; limiting their influence on the child upbringing.

Conclusions: The area of the right to procreation is full of normative cracks. Women with intellectual disabilities, due to their gender, disability and its type, belong to various discriminated groups at the same time. This results in a specific experience of discrimination in the area of reproductive freedom, which is further strengthened by the specific context of the Central and Eastern European country.

How do fathers with intellectual disabilities who have had children removed make sense of this?

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Background: Experiences of fathers with intellectual disabilities whose children have been removed from their care are under-researched. The aim of this study was to provide insights into the experiences of these fathers and those of professionals working with them, to inform future practice and policy in this area.

Method: Template Analysis (TA) was used to make sense of data gathered via individual semi-structured interviews with five professionals. Interpretative Phenomenological Analysis (IPA) was used to analyse interviews with five fathers.

Results: The TA resulted in first-level themes: Importance of and Difficulties with Available Support, Differences in Power, Stigma of being Male and Multiple Trauma. The IPA produced the following themes: The Court as a Lion's Den, Fighting for my Role as a Father and The Personal Cost of it All.

Conclusions: The findings highlight that fathers with intellectual disabilities find the experience of their children being removed from their care overwhelmingly painful. The processes by which these decisions are made are seen as unfair by both professionals and fathers themselves. Recommendations for practice improvement and service delivery/innovation prior, during and after court involvement are offered.

Supporting parents with intellectual disabilities in child welfare: A systematic review

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Background: Parents with intellectual disabilities are overrepresented in child welfare. However, there is a lack of empirical research in the U.S. to guide interventions. This study examines: 1) What are risk factors for child welfare involvement among parents with intellectual disabilities? 2) What interventions exist to support parents with intellectual disabilities? and 3) What are research recommendations to advance the field?

Method: A systematic review was conducted on four databases: Google Scholar, ProQuest Central, PsycINFO, and ERIC using key search terms (e.g., intellectual disabilities, learning disabilities, child welfare). Inclusion criteria included articles relevant to the US, in English, and between the years 1987 to 2019. Data were analyzed using content analysis.

Results: Fifty-four articles were identified. Risk factors included parental race, poverty, housing instability, substance use, mental illness, interpersonal violence, and low levels of social support. Interventions included parent support groups, navigation services and home visiting programs. Recommendations included developing and validating intellectual disabilities assessment tools, offering targeted and intensive parenting programs, and training child welfare professionals.

Conclusions: Results demonstrate the need for child welfare system-level capacity building in order to identify parents with intellectual disabilities, provide tailored parenting programs/services, and training/support of professionals to meet the unique needs of this population.

Mothers with mild intellectual disabilities and child behavior problems: The role of maternal sensitivity, trauma and IQ

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Background: The research aim was to investigate if children of mothers with mild intellectual disabilities display higher levels of behavior problems than matched comparison children, and if problems are predicted by maternal sensitivity, maternal experiences of abuse, trauma, and maltreatment (ATM), and/or intelligence.

Method: Participants were 23 mothers with mild intellectual disabilities and their children (M age = 77 months, 58% boys), and 25 socioeconomically matched comparison mothers/children. Child behavior problems (psychosomatic, anxiety, anger, hyperactivity, total) were assessed with maternal ratings, maternal ATM, with semi-structured interviews (Granqvist et al., 2014), maternal sensitivity with structured observations (Lindberg et al., 2016), and maternal intelligence with a subtest from WAIS-III.

Results: Children of mothers with intellectual disabilities were higher in all problems but anxiety. Maternal sensitivity was associated with anger ($r = -.66$), hyperactivity ($r = -.51$) and total problems ($r = -.53$), and maternal ATM with anger ($r = .58$). Maternal intelligence was unrelated to child behavior problems, all associations remained with control for intelligence, and the association between sensitivity and anger remained with control for child hyperactivity. Robust measures (bootstrapping, 1000 samples, BCa) were used.

Conclusions: Clinical practice must take into account the impact of trauma on the capacity of mothers with intellectual disabilities to give sensitive care and their children's behavioral development.

Screening for parental intellectual disability: A first step in delivering inclusive services?

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Background: Early identification of parental intellectual disability may be key to the planning and delivery of appropriately adapted supports and services. The purpose of this study was to investigate the performance of a brief screener for parental intellectual disability.

Method: A total of 185 parents, including 91 parents in receipt of specialist intellectual disability services and 94 parents utilizing generic family support services, completed an interview/survey which incorporated candidate screening questions.

Results: The results of logistic regression and ROC curve analysis showed that a simple four-item screener performed well (accuracy 90.44%, sensitivity 92.31%, specificity 90.43%, AUC .96).

Conclusions: The potential benefits of screening have to be weighed up against the risks of potential misuse. We therefore suggest that screening be introduced in the context of continuing professional education and initiatives to build system's capacity to support parents with intellectual disability and their families.

Improving communication about “good parenting” between parents with mild intellectual disabilities and professionals

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Background: In care and support for parents with mild intellectual disabilities, tools are available to determine the safety of the child and risks. However, it remains unclear if these tools fit the needs of parents. What is helpful for parents and care professionals when communicating about (good enough) parenting in a supportive manner? This project aims to gain insight in aspects and needs in communication about (good enough) parenting between parents with mild intellectual disabilities and care professionals. This leads to prerequisites for both parents and care professionals for a (visual) tool to support communication about parenting skills.

Method: This qualitative study follows the Adapted Intervention Mapping (AIM) protocol consisting of six steps: from needs assessment, to specifying aims, selecting communication elements, leading to the development of a tool, implementation and evaluation. All stakeholders are involved: parents with mild intellectual disabilities, care professionals, social services (practice) and scientists (theoretic evidence and literature). Data of these four perspectives are gathered through literature search, qualitative interviews and focus groups with parents and care professionals.

Results: Results of analysed data, differences and matching needs in communication will be analysed.

Conclusions: The developmental process and first results on prerequisites for a visual tool will be presented at the congress.

Advice on navigating the child protection "bumpy road" by those who have travelled it

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Background: Parents with intellectual and developmental disabilities who encounter child protection systems experience differential treatment and outcomes. These parents need reliable and accessible information to enable them to assert their rights in decisions about their child's best interests. This presentation reports on an evaluation of Participatory Action Research (PAR) with a group of parents with intellectual and developmental disabilities with lived experience of the child protection system that was used to create a website for other parents.

Method: Eight parents participated in facilitated workshops over 12 months. Parents and facilitators were interviewed prior to and at the Conclusions of the project. Inductive thematic analysis was conducted.

Results: Themes demonstrate the transformative impact of PAR on project members. Parents were motivated to participate so the knowledge they had gained through their painful experience could help other parents. However, they did not anticipate that participation would enhance their interpersonal skills and confidence. Workers observed that the website became a physical manifestation of the personal growth parents had undergone during the project.

Conclusions: This project demonstrates the efficacy of PAR as a means of involving parents with IDD as experts and partners in effecting change and the sensitivity and skilled facilitation needed to achieve positive outcomes.

Love is not enough: Analyses of court reports on parents with intellectual and developmental disabilities

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Background: Parents with intellectual and developmental disabilities face disparities in the child welfare courts. However, little is known about the data contained in court reports and how it is interpreted in cases of parents with intellectual and developmental disabilities. The purpose of this study was to survey child welfare court reports of parents with intellectual and developmental disabilities to document the demographic data, decipher how judges make their decisions and based on what evidence.

Methods: 119 reports concerning one or both parents with intellectual and developmental disabilities, were found in an open-access site. These reports include 128 children of 106 different families headed by at least one parent with intellectual and developmental disabilities. A grid was developed by the authors to analyze the court files, aiming to provide descriptive statistics as well as a basis for further analysis.

Results: The parents' health and diagnosis, reason for referral, services received, history of domestic violence, substance abuse and criminal record will be presented. Parents' intellectual disability was often used to substantiate claims of parental incapacity.

Conclusions: Parents with intellectual and developmental disabilities are subject to injustice in the child welfare courts, as they experience higher rates of child removal, restricted access to their children and a lack of services to support the identified issues presented in court.

Track 2d Inclusion/Inclusive Research

WORKSHOPS

Experience experts and diversity: Contextual work with experience experts in different fields

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Description: Collaboration with experience experts in various fields and within different sectors is booming. We focus on the field of NAH (Non-congenital brain injury), poverty policy and the support of people with mild intellectual disabilities (LVG). Due to specific circumstances such as poverty, limitations in cognition and other mental conditions, these people usually have less access to the regular participation and training programs.

Contribution: We discuss how knowledge from these three sectors can reinforce each other and look for general principles that are of value for a greater diversity of experiential expertise. Extra attention will be paid to the role of the (assistance) context and strategies to prevent pitfalls and obstacles to the ownership of this diverse group with a diversity of possibilities and limitations.

Doing inclusive mental health research with people with intellectual and developmental disabilities in a Canadian mental health service

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Description: The need for inclusive research and practice to support the mental health of people with IDD is needed now, more than ever with the onset of the global pandemic. Inclusive mental health research will expand our understanding of the daily lives, needs, and abilities of this group, and has potential to generate new insights to guide mental health interventions, policies, and practices. In this workshop, presenters will discuss innovative inclusive research practices and programs currently being supported through the Azrieli Adult Neurodevelopmental Centre at the Centre for Addiction and Mental Health in Ontario, Canada. Presenters will share experiences with digital storytelling methods, as well as the development and implementation of virtual peer support programs and an inclusive research training course. The workshop will contribute to furthering our understanding of how to 1) implement inclusive mental health research practices, 2) build capacity among self-advocates, researchers and clinicians and 3) foster mental health.

Contribution: Through this workshop we will encourage sharing and discussion of successful strategies and challenges in the implementation of inclusive mental health research and education. The aim will be to build capacity amongst participants and encourage the uptake of inclusive practices in mental health service research, and evaluation.

ORAL PRESENTATIONS

We are now meeting online! Doing inclusive research during the Covid-19 pandemic

Lisa Acheson[1], Fionn Angus[1], Jonathan Angus[1], Christina Burke[1], Edurne García Iriarte[2], Brian Hogan[1], Rob Hopkins[3], Nicola Maxwell[4], Orla McMahon[1], Kathleen McMeel[1], Helen O'Regan[1], Pauline Skehan[1], Michael Sulllivan[1]
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Background: Inclusive research is about involving people with intellectual disabilities in research, rather than doing research on them. Inclusive research is supported by the Convention on the Rights of Persons with Disabilities, which calls for active participation of disabled people in all aspects important to them. Inclusive researchers learn about the lives of people with intellectual disabilities, gain confidence, research skills and new friends. Lockdown periods since March 2020 have meant that much of the work, education, social relations and research have happened online across the world. People with intellectual disabilities do not have the same access to technology as non-disabled people and they may not know how to use it. However, online meetings were the only alternative for an Inclusive Research group to continue their research during lockdown.

Methods: In this presentation, we reflect on the impact of living during Covid-19, on the challenges and opportunities that this time had in our research and in our lives. We looked at the research meetings minutes from March 2020 to March 2021 and gathered personal accounts of researchers at two focus groups.

Results/Conclusions: Using our findings, we make recommendations about doing inclusive research online and about access and use of technology.

How are individuals with intellectual disability Involved in program evaluation? A scoping review

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Background: In response to a lack of empirically informed guidance on how to conduct participatory evaluations involving persons with intellectual disabilities, we report findings from a scoping review that examined how persons with intellectual disabilities have been engaged as active participants in evaluations and applied research.

Method: Following the PRISMA method, we conducted a search for empirical studies in all relevant library databases and the major evaluation journals. After title and abstract review of 6624 sources and then a full-text review of 39 sources, we deemed a total of 34 articles met our inclusion criteria. This sample was then coded and analyzed using thematic analysis.

Results: The findings address four categories of interest: 1) philosophical underpinnings and practical justifications for using participatory approaches based on study objectives, research contexts and rationales for inclusion, 2) specific approaches for including persons with intellectual disabilities in various phases of the research cycle, 3) reflections by researchers and persons with intellectual disabilities as co-researchers regarding their relationships, the inclusion process, and mutual learning, and 4) methodological considerations and limitations.

Conclusions: Findings provide conceptual and practical guidance for evaluators and others engaged in applied research when designing participatory methodologies involving persons with intellectual disabilities.

The ambitions, motivations and experiences of co-researchers in an inclusive research project

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Background: There is a long tradition of involving people with intellectual disabilities in research. This presentation explores the ambitions, motivations and experiences of 15 co-researchers with intellectual disabilities who were part of a research team exploring social isolation and ageing.

Method: The research draws on qualitative data collected from focus groups with the co-researchers at the start and end of the project.

Results: The findings suggest that pre-project, the aspirations of the co-researchers ranged from simply "being involved" to specific aspirations such as asking interview questions, learning new skills and improving the lives of people with intellectual disabilities. The main motivations for wanting to be a co-researcher were to make new friends, sharing experiences and becoming more confident. Post-project, the co-researchers' aspirations for increasing confidence were met and they developed the skills to speak up and make decisions.

Conclusions: The research highlighted possible differing agendas between academic researchers and co-researchers with intellectual disabilities. Strategies to ensure that both agendas can be accommodated in inclusive research are discussed.

Reflections on conducting focus groups with people with intellectual disabilities

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Background: To examine the use of focus groups when undertaking research with people with intellectual disabilities. This is presented within the context of a research project to identify the most important areas of information to be included in a health communication tool.

Method: Four focus groups involving 22 participants with intellectual disabilities were held. Forty-one areas of information identified in existing tools (Northway et al, 2017) were rephrased into "Easy Read," to make them accessible to people with intellectual disabilities and transferred on to individual cards along with a relevant picture. Each group was facilitated by two members of the research team and involved discussion and prioritising the 41 areas of information.
Results: Participants were able to discuss the areas of information, to prioritise them and to provide a rationale for their prioritisation. However, challenges were experienced in relation to group dynamics particularly in ensuring that the views of people with intellectual disabilities were not influenced by their supporters who were present.
Conclusions: Focus groups can be a useful way of seeking the views of people with intellectual disabilities, but careful planning and management are required. This session will explore practical strategies that may assist others in addressing such issues.

Inclusive research on future teachers' perceptions of intellectual disability

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Background: Society's perception of people with intellectual disabilities can have a negative impact on their opportunities to exercise their own rights. For this reason, a group of people with intellectual disabilities decided to investigate the future teachers' perceptions of intellectual disability, as they will soon become professionals who might work with people with intellectual disabilities. This presentation describes the inclusive research process developed.
Method: Sixteen people with intellectual disabilities and four researchers participated in this inclusive research, which took place between 2018 and 2020, following the next steps: research objectives establishment, review of intellectual disability conceptions, exploration of personal experiences, questionnaire design, data collection, data analysis, and assessment of the research process.
Results: This research made it possible to analyse the future teachers' beliefs regarding intellectual disability. It also allowed to put forward some proposals to be considered in teacher training to promote that future teachers are able to foster the right to inclusive education.
Conclusions: The inclusive research methodology is presented as a source of learning and empowerment for people with intellectual disabilities, while helping to move forward with the exercise of their rights.

Shadowing as a research method for intellectual disability research: Opportunities & challenges

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Background: While qualitative research on intellectual disability is on the rise, researchers have frequently reported that their methods bring methodological and ethical challenges. The authors advance shadowing as an alternative method to respond to these concerns.
Method: The authors draw on their experiences with shadowing on the basis of two separate studies, respectively involving 28 and 17 people with intellectual disabilities.
Results: Four distinct advantages of shadowing are presented: it is flexible, gives unique insight in daily life experiences, can aid in giving "voice" to people with intellectual disabilities, and can aid in the pursuit of inclusive research. Three challenges of shadowing research are also identified, relating to ethical approval, privacy and role confusion.
Conclusions: Shadowing is a promising method for intellectual disability research, as it allows researchers to garner data virtually inaccessible with other methods. It is particularly useful for research questions about everyday life and interpersonal relationships.

Planning and implementing an inclusive research project: Reflections on an evolving enterprise

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Background: This paper will discuss the implementation of an inclusive research project and the steps taken to put into practice the principles of this research approach, while attending to pragmatic matters. The focus of the paper is an inclusive research project that is currently under way.
Method: The project team is comprised of myself as the lead researcher and three co-researchers, two of whom have intellectual disabilities. The main aim of the project is to create an online resource with video curriculum vitae of persons with intellectual disability to showcase their achievements and skills.
Results: I will present a reflexive analysis on the work that has been carried out so far, from designing the project, to seeking and obtaining funding through to starting the implementation of the project. The analysis will focus on putting together the research team, taking decisions collaboratively, adapting the original concept to suit potential funders' priorities without losing sight of the project aims, making selection criteria for project participants inclusive, providing support, and dealing with the difficulties brought on by the pandemic.
Conclusions: The reflection will highlight the steps taken to handle the various issues encountered while remaining true to the aims of the project and to the principles of inclusive research.

Inclusive research in Spain: Transforming our social environment

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Background: This work is part of projects coordinated by the National Research Plan and Innovation Networks for Educational and Social Inclusion, which aims to promote social justice in Spain. Specifically, this contribution discusses an 18-month project developed by a team from the University of Cantabria composed of eight young people with intellectual disabilities and two academic researchers. Our project is recognized within the inclusive research processes, a political approach that allows individuals with intellectual disabilities to research on issues that affect them and influence discourses and practices that undervalue them. The research group explores the importance of social relationships and loneliness for young people.

Method: From the methodological point of view, this project acknowledges the qualitative research paradigm and uses an ethnographic approach. Thus, relevant issues and social inequalities are analysed through image theatre, personal objects, interviews, body maps, photographs, and video and audio recordings.

Results/Conclusions: The results demonstrate that inclusive research should be a dialogical practice that addresses significant and relevant issues concerning people with IDs serving as researchers.

Implementing an inclusive Community Living Model in MINDS (Phases 1 and 2)

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Background: MINDS seeks to implement a Community Living Model in Singapore for persons with intellectual disabilities across five phases. Research was conducted in phases 1 and 2. The first phase seeks to understand the support needs for persons with intellectual disabilities to live independently. The second phase examines the enablers and barriers to implementing the Community Living Model, as well as referencing three models for comparison.

Method: Phase 1 findings were obtained from two focus groups comprising of nine employees of MINDS and four caregivers of persons with intellectual disabilities. In addition, a semi-structured interview was conducted with a MINDS community facilitator. Phase 2 findings were obtained from semi-structured interviews and focus groups with four academics and 11 caregivers.

Results: Phase 1 identified structural difficulties with housing, employment and finances, and the caregivers' doubts that persons with intellectual disabilities could resolve daily issues autonomously as the main reasons hindering PWIDs from living independently. Phase 2 results suggested that persons with intellectual disabilities had to be introduced to independent living incrementally via training and assistive technologies, and supported by volunteers, allied health professionals and the wider community.

Conclusions: This research informed the development of a hybrid model, which would be uniquely tailored for the local context of Singapore.

Inclusive research in people with profound intellectual and multiple disabilities

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Background: The aim of this study was to explore how inclusive research can be structurally and meaningfully embedded in the research practice related to people with profound intellectual and multiple disabilities by embedding the experiential expertise of different stakeholders.

Method: A brief literature review and interviews with scientists and relatives (n=7) affiliated with the Academic Collaborative Centre (ACC) on people with profound intellectual and multiple disabilities (PIMD) gained insight into practical and ethical challenges that arise around this topic. The possible answers to raised questions that could shed light on the ways in which experiential expertise could be embedded were explored in open interviews (n=6) and a focus group (n=7).

Results: The results could be arranged in four topics: defining the used concepts, the utility and aim of the involvement of stakeholders, competences needed to participate in research and how participation could be structurally embedded within the research practice of the ACC PIMD.

Conclusions: In order to find meaningful ways to structurally embed experiential expertise in the ACC PIMD, the context of a given research project and the various perspectives of stakeholders within that project should be taken into account. An ongoing dialogue between all involved is thereby essential.

Experiences of community participation identified by adults with intellectual disabilities

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Background: Community participation has increasingly become a mainstay of policies and practices focused on people with a disability. However, many studies with adults with intellectual disabilities suggest they experience disabling community interactions in places where they are not familiar and accommodated. The purpose of this research is to investigate in depth the community participation experiences of adults with intellectual disability.

Method: This study explores five case studies of adults with intellectual disabilities identifying their individual community participation. Self-photographed sites are used to prompt the telling of stories through interviews and a focus group. Their place in community is seen through their lens.

Results: These innovative methodologies elicit biography and give adults with intellectual disability the opportunity to present their understanding of community in places of their choosing.

Conclusions: Case studies contribute an individual perspective on the community participation of adults with intellectual disabilities. The depth of exploration into the experiences of participants in this study highlight the importance of creatively facilitating the voice of adults with an intellectual disability who are infrequently heard on their understandings of community participation.

Are we getting there yet?: The journey from institutions to community-based services in the EU

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Background: Over the last five decades numerous stakeholders at European and national level have been working on promoting social inclusion, combating poverty and discrimination, and making the shift from institutional to community-based care a reality for a variety of target groups in European countries including persons with intellectual disabilities.

Method: The aim of our study was to collate information about policies and plans, changes over time, strengths and areas of concerns relevant to advancement tin deinstitutionalisation in 27 EU countries and for six target groups: adults with disabilities, adults with mental health problems, children (including children with disabilities), unaccompanied or separated migrant children, homeless persons and older adults.

Results: The data reviewed showed that in all countries there are still people living in residential care, although in a few countries this is primarily small-scale and community-based.

Conclusions: In almost all countries, independent living through personal assistance is still a minority form of provision and large institutions are still used. However, there is evidence of some progress, especially for children, and in countries within the group of 12 where deinstitutionalisation was one of the priority areas for investments for 2014-2020.

An exploration of online questionnaires as a method for including autistic adults in qualitative health research

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Background: Autistic adults' perspectives and experiences in healthcare systems are not well known, necessitating an exploratory qualitative approach to research and best practice initiatives in this area. Unfortunately, individuals with verbal communication challenges or differences are often excluded from qualitative research where the dominant methods of data collection include in-person or by-phone verbal question and answer sessions. As a result, the research and knowledge base relevant to autism is largely informed by non-autistic participants, such as caregivers, professionals, and academics. Healthcare researchers have been encouraged to consider ways to better include the voices and perspectives of autistic adults. Accordingly, this presentation will examine the use of online qualitative questionnaires as a means of increasing equitable access to participation in research for this population.

Method: A comprehensive review of research to date was conducted examining the benefits and challenges of utilizing online questionnaires in comparison to traditional data collection methods in qualitative research. These findings were then analyzed through the lens of considering implications as pertinent to research with autistic participants.

Results: Research examining differences between online and in-person data collection in qualitative research have shared mixed results. Research on the use of online qualitative questionnaires with autistic participants specifically is limited but suggest that an online format may allow for better accessibility and inclusiveness of participants – especially autistic adults, who are more likely than neurotypical adults to experience barriers to in-person questioning methods.

Conclusions: This presentation should generate discussions about online questionnaires as a potential method of data collection to promote equitable access to participation in research and better inclusion of autistic perspectives in healthcare best practice initiatives.

"They just listen but not well enough"

Jenny Rosendahl[1], Jenny Wilder[1], Mara Westling Allodi[1]
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Background: The aim of this research was to increase the influence and participation in the society for young people with intellectual disabilities.

Method: Participatory action research together with young adults with intellectual disabilities as co-researchers. An action was added to try to find a method to let young people with intellectual disabilities affect and develop municipal leisure, culture and democratic activities. The co-researchers took part in two single interviews, three focus group interviews and three actions. Staff from the municipality took part in a focus group. A survey was also answered by the municipal management.

Results: The research team found adjustments for better adaptations of municipal activities. The co-researchers instructed staff from the municipality to become better at listening to young people with intellectual disabilities, and thereby staff in the municipality gained increased knowledge about treatment and inclusion of young people with intellectual disabilities. Young people with intellectual disabilities received a higher level of influence and participation in the municipality.

Conclusions: If staff in the municipality get opportunities to learn to meet and listen to young people with intellectual disabilities, young people with intellectual disabilities can contribute to the development of society in a more inclusive way. When young people with intellectual disabilities teach staff, better working methods and municipal activities for young people with intellectual disabilities materialize.

Does a dedicated training program increase nursing students' knowledge on intellectual disabilities?

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Background: The 2011 World Health and Disability Report (WHO-DR) recommends to "train all health care workers in disability issues including rights." A 30-hour program on disability issues was developed for Bachelor nursing students at the Geneva School of Health Sciences to raise nurses' knowledge on issues regarding people with intellectual disabilities. The study intends to describe students' knowledge on the issues of people with intellectual disabilities across the four years of training.

Method: The survey was conducted in 2020 with students from each year of training who had benefited from the program. The questionnaire entailed 10 questions, covering intellectual disability, rights and healthcare. A total of 496 questionnaires were collected (response rate of 53,4%). A descriptive analysis was conducted on the responses.

Results: The results point out the situational nature of the concept of intellectual disabilities as reported by the students, as well as the importance of self-determination regarding health conditions of people with intellectual disabilities.

Conclusions: The findings highlight the importance of a dedicated nursing program to raise awareness on intellectual disabilities, rights and self-determination, and healthcare for PWID. The program contributes to responding to the WHO-DR guidelines in nurses training.

An inclusive research methodology using collaborative inquiry circles

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Background: This research report draws on inclusive PhD research conducted *with*: Specific Learning Difficulties (SpLD) tutors in UK universities using Collaborative Inquiry Circles (CICs). CICs "continue dialogue with colleagues who share similar experiences and challenges" with a particular emphasis on "what it means for inclusive educators to teach for social justice" (Broderick et al., 2012: pp. 827–828). As SpLD tutors, we know we receive little to no training on theories of social justice and inclusion, despite working with learners who experience exclusion and social injustice.

Method: In the CICs, we discuss theories of social justice and critical pedagogy, including work by Ahmed, Bourdieu, Freire, Giroux, hooks and Sen. CICs enable SpLD tutors to work collaboratively together on theories and affords free dialogue, which is particularly beneficial to neurodiverse SpLD tutors. Inclusion and social justice are central to the theories discussed in the CICs and inclusion is enacted in the research methodology itself. In this project, each SpLD tutor is a research colleague, a co-researcher to be involved in all stages of the research including the data analysis.

Results/Conclusions: This is a "democratization of the research process" (Nind, 2014: p.1).

Developing meaningful accessible information for diverse communities

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Background: This paper will present outcomes from a collaboration between Women with Disabilities Australia (WWDA) and Access Easy English (AEE), culminating in 27 Easy English factsheets on WWDA's website designed by and for women and girls with disability (https://oursite.wwda.org.au/).

Method: The collaboration involved building capacity at WWDA to engage with women with intellectual disability and low literacy.

Results: Three staff attended Easy English training. The new website has 27 Easy English factsheets. Five of these factsheets translated into 15 community languages and into three Australian indigenous languages. The factsheets were used to create Auslan videos. New content in Easy English was developed by WWDA. Personal stories from women who need information in Easy English indicate the resources filled a gap in accessible information on topics vital to women's well-being, including their rights, sexuality, health and safety.

Conclusions: Having Easy English as part of the suite of publications has wide ranging benefits for women with disabilities for their health, agency to make choices and ability to advocate for their rights. It takes time for staff to learn the skills, be competent and confident Easy English developers. Now developed, WWDA can incorporate Easy English versions of content for their publications for their diverse audiences.

Learnings from co-researching: Views of assessors with intellectual disabilities

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Background: This study aims to investigate the perspectives of people with intellectual disabilities who are part of an advisory committee that has been collaborating in research for nine years on what they learnt and what the research experience means to them.

Method: The opinion of the advisory committee members has been analysed through individual interviews, focus groups, and the analysis of written and visual documents produced during the last nine years.

Results: Regardless of how long participants have been part of the advisory committee, they all report significant learning related to the research process, as well as socio-personal learning. Moreover, they state their gain of knowledge regarding their own rights. The sense of belonging to a socially valued group reported by the participants is also significant, as is their personal well-being, which they relate to the social recognition they get.

Conclusions: Beyond contributing to conduct research based on the people's needs, inclusive research brings well-being to the participants, enriches their social networks, and contributes to their recognition

Understanding the rights is the way to improve our lives: An inclusive research project

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Background: The aim of this research project is to design, in a collaborative and inclusive way with people with intellectual disabilities, a training programme on rights aimed at people with intellectual disabilities.

Method: Focus groups and co-design strategies were developed with the support of visual techniques with people with intellectual disabilities who are members of an advisory committee with experience in research on their rights.

Results: Based on their own experiences, the participants suggested and prioritised some training topics and activities regarding their rights. Then, the design of a training programme on rights addressed to people with intellectual disabilities will be obtained. Such training programme will be implemented at the university through co-lecturing, with people with intellectual disabilities participating as trainers.

Conclusions: Knowing one's own rights is crucial to fight for them and to know how to advocate for them. Therefore, accessible training on rights aimed at promoting social inclusion at all levels is essential.

POSTER PRESENTATIONS

Pre-registered student nurses' experiences and perceptions of service user involvement in their education

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Background: In the UK there has been a growing recognition of a need for the service users to be involved in the education of health care professionals (Masters et al., 2002; Keogh, 2013). Such recognition has also been acknowledged by the World Health Organisation (2005), which has emphasised the importance of collaborating with service users in improving patient safety as well as service delivery. We report on phases one and two a three-phase study which explored pre-registration intellectual disability nursing students' experiences and perceptions of the contribution of people with intellectual disabilities in their education.

Methods: The study adopted a three-phase sequential multiple method longitudinal study. Phases 1 and 2 were informed by Grounded Theory and located within the interpretivist paradigm, and data was collected through interviews. The study lasted for the three-year duration of the pre-registration BSc (Hons) Nursing programme at a university in London, with each phase occurring in each year of the programme. 11 and 25 students participated in Phases 1 and 2, respectively.

Results: Propositional attitudes, personal construct, students as stakeholders, students' framing of purpose, value judgments, role perception, partnership, and knowledge and skills emerged as the key themes of students' perceptions of public involvement in their education.

Conclusions: Involving people with intellectual disabilities in pre-registration education of healthcare professionals prompts a much-needed reflection on practice, challenges attitudes, stereotypes and prejudice. This is fundamental to the development of a workforce that is sensitive to the complex health and social care needs of people with intellectual disabilities. People with intellectual disabilities depend on others for their safety, health, and healthcare outcomes. Professional health and social care regulators need to require involvement of people with intellectual disabilities in pre-registration education.

The role of Intellectual Disabilities Acute Liaison Nurses: Documentary analysis of job descriptions

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Background: To explore what is expected of Intellectual Disabilities (ID) Acute Liaison Nurses as articulated in their job descriptions and person specifications in order to define their role in the context of role theory.

Methods: This is part of a three-stage exploratory mixed methods design study. Stage 1 used qualitative approach to research by adopting documentary analysis methodology. Job descriptions and person specifications of ID Acute Liaison Nurses in England were analysed using thematic analysis to identify patterns in how they enact their roles.

Results: Different ID Acute Liaison Nurses enact the role differently depending on their level of employment and where they work or type of setting. The role includes direct and indirect clinical activities, education and practice development activities, and strategic organisational development. Most importantly what was seen was that the ID Acute Liaison Nurses are considered as reasonable adjustment in acute healthcare to address some of the health inequalities experienced by people ID. The nurses are also seen as safeguarding

nurses for people with intellectual disabilities when accessing acute healthcare services.

Conclusions: The role of ID Acute Liaison Nurses in acute healthcare services was defined in the context of role theory. This contributed to the body of knowledge and evidence base in ID nursing. The findings will help to improve the hospital experience and safety of people with intellectual disabilities when they access acute healthcare services.

Taking steps towards the measurement of the Convention on the Rights of Persons with Disabilities

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Background: The intangible nature and the context-based expression of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) pose a challenge for its evaluation and implementation. The aim of this study is to identify conceptual frameworks and assessment instruments that have been proposed in scientific literature to monitor the implementation of the UN CRPD for people with intellectual and developmental disabilities.

Method: Following the PRISMA guidelines, a systematic review of articles published from 2008 was conducted across the Web of Science Core Collection, Current Contents Connect, MEDLINE and SciELO Citation Index.

Results: Eight studies used or proposed conceptual frameworks to monitor the implementation of the UN CRPD. All papers pointed to the individual quality of life (QoL) framework and QoL indicators that must be incorporated into comprehensive instruments to assess progress and identify needs and gaps in implementation. Five of the studies named specific measurement tools.

Conclusions: The individual QoL construct provides a promising conceptual framework to operationalize the UN CRPD, and to develop and apply reliable and valid instruments that not only allow countries to monitor the fulfillment of the rights set out in the UN CRPD in the macrosystem, but especially in the microsystem and the mesosystem.

Track 3: Health Issues

PRESENTATIONS IN A SYMPOSIUM

Primary care for people with intellectual disabilities

Context, content and concerns of out-of-hours primary care for people with intellectual disabilities

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Background: Out-of-hours primary care for people with intellectual disabilities is an vulnerable setting and little is known about the accessibility and quality of care. This presentation aims to explore its current state in terms of organisational context, medical content, and professionals' concerns.

Method: This presentation is a synthesis of three studies that complement each other: 1) Telephone survey on current out-of-hours organizational arrangements at care provider services for people with intellectual disabilities in the Netherlands; 2) Routine data from GP out-of-hours services on the risk of requesting care, level of urgency, and commonly presented health problems of people with intellectual disabilities compared with the general population; and 3) Interviews with GPs, triage nurses and daily care professionals involved in this care regarding their concerns on the context and content of this care.

Results: The findings on context, content, and concerns of the out-of-hours primary care for people with ID will be presented. Overviewing all findings shows that they are interconnected, with all findings being related to all three fields.

Conclusions: The only way to improve the accessibility and quality of out-of-hours primary care for people with intellectual disabilities is to look at it as a whole and respect its interconnectedness.

Exploring chronic disease prevalence in people with intellectual disabilities

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Background: Primary care providers require accurate evidence on chronic disease prevalence in people with intellectual disabilities in order to apply this information into practice. However, inconsistencies in the scientific literature hamper correct interpretation. To provide guidance for interpreting prevalence reports, this study aimed to identify how prevalence estimates have been established in the context of primary care.

Methods: A scoping review of peer-reviewed literature was conducted, covering 2000 to February 2020.

Results: The final sample included 19 studies. Chronic disease prevalence varied considerably between people with and without intellectual disabilities. In general, studies focusing on larger age groups reported lower diabetes and COPD prevalence, whereas a focus on older adults resulted in a higher prevalence of cardiovascular disease among people with and without intellectual disabilities. Organisation of primary care seemed to be relevant in chronic disease prevalence, as US-based studies often reported the highest chronic disease prevalence compared to other studies.

Conclusions: Primary care providers should interpret results on chronic disease prevalence among people with intellectual disabilities in light of the study characteristics. Researchers should be aware of the influence that study characteristics may have on generalisability. Prevalence rates should therefore always be interpreted in the context of methodology.

Towards a shared conceptualization of medical care for people with intellectual and developmental disabilities: A concept mapping study

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Background: Medical care for people with intellectual and developmental disabilities is organized differently internationally, resulting in ambiguity around this care. This complicates reporting on and comparing medical care research, policy and practices for people with intellectual and developmental disabilities worldwide. This study aimed to develop an internationally shared conceptualization of medical care for people with intellectual and developmental disabilities to facilitate international learning.

Method: Twenty-five experts on medical care for people with intellectual and developmental disabilities from 17 different countries participated. In phase one, participants described medical care for people with intellectual and developmental disabilities in their country in as many ways as possible. In phase two, participants sorted all generated descriptions into piles of conceptual similarity. Data was analyzed using multidimensional scaling and hierarchical cluster analysis.

Results: A concept map with 13 clusters was formed, representing the central aspects of medical care for people with intellectual and developmental disabilities. The map includes themes such as heterogeneity, access, and specific knowledge.

Conclusions: The concept map is helpful as a framework about what medical care for people with intellectual and developmental disabilities entails. It can be used to describe the context in which intellectual and developmental disabilities research on medical care services took place. This conceptualization contributes to a better understanding of medical care research, policy, and practices around the world.

Interprofessional primary care for adults with intellectual and developmental disabilities in Ontario, Canada

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Background: High-quality primary care has been identified as a pressing need for adults with intellectual and developmental disabilities. Interprofessional primary care teams have been recommended to improve care and health outcomes however, little is known about this approach to care in Canada. This research aimed to describe the current provision of interprofessional primary care for this population in the province of Ontario.

Method: Multiple case study of five primary care teams. Data collection involved document reviews, a practice report, an organizational attribute survey, patient and provider interviews. Pattern matching was the main analytic approach.

Results: Adults with intellectual and developmental disabilities were a small part of the patient population served and overall, were poorly identified in four of five teams. Organizational structures and processes that facilitate care were reported and supported by patient and provider experiences. Despite the presence of a team, there were challenges engaging interprofessional services, and there were no processes in place to measure the impact of interprofessional primary care for this population.

Conclusions: To ensure access to appropriate and equitable care, organizational structures and processes are needed to engage a team and further work is required to demonstrate the value of the approach for adults with intellectual and developmental disabilities.

COVID-19 in intellectual disability: Data, care and information exchange

Results from COVID-19 registration in long-term intellectual disabilities care in the Netherlands

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Background: People with intellectual disabilities may be at increased risk for COVID-19 infection. However, data on the incidence and development of Covid-19 among people with intellectual disabilities are scarce and it is unknown to what extent general population data applies to people with intellectual disabilities. Our registration aims to provide insight into the impact of COVID-19 on people with intellectual disabilities, in Dutch long term care facilities.

Method: As of March 24 a multicenter online registration base was made available to long term intellectual disabilities care organizations in the Netherlands. Organizations registered data of their patients with either suspected or confirmed COVID-19 infection, regarding sociodemographics, medical history and COVID-19 infection characteristics.

Results: Through the year 2020, intellectual disabilities care organizations of over 75% of clients with intellectual disabilities participated and registered 5878 patients. In 23% of the patients suspected for COVID-19, the infection was confirmed by a test. This presentation focuses on current incidence and case fatality rates, as well as characteristics of the patients with intellectual disabilities and COVID-19 infection.

Conclusions: According to our findings, people with intellectual disabilities proved to be vulnerable for COVID-19. Our findings inform policy makers and care providers on specific risks and consequences of the COVID-19 pandemic in this special population.

Differences between first and second wave COVID-19 infections in persons with intellectual disabilities in the Netherlands

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Background: This research aims to examine the differences between the first and second wave on COVID-19 infected persons with intellectual disabilities in long-term intellectual disabilities care in the Netherlands.

Method: Data were retrieved from a multicenter observational study on patients in long-term intellectual disabilities care with suspected or confirmed COVID infection and is originally initiated as a registration study. Only persons infected with COVID-19 were included in these analyses. Person-related characteristics, COVID-19 related factors and medical history were compared between the two waves. Additionally, sensitivity analyses on persons infected and deceased with COVID-19 were done.

Results: The results presented will show the differences between the two waves of COVID-19 with more than 1500 persons with intellectual disabilities who were infected. This study showed that age at COVID-19 infection was higher in the first wave compared to the second wave. For gender no differences were found. Also, a first peak will be shown for patients infected and deceased regarding the included factors.

Conclusions: Although more tests were available, this will not explain the differences found between the first and second wave. Is the virus growing milder? Findings provide insight into needs and characteristics of people with intellectual disabilities with a COVID-19 infection.

Practical implications of a COVID-19 database study in medical care to people with intellectual disabilities (ID)

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Background: The aim was to find out what medical doctors could learn from a COVID-19 database study.

Method: From the very beginning of the Corona pandemic, medical doctors, most often intellectual disabilities physicians, from over 72 service care providers for people with intellectual disabilities in the Netherlands collected data in a secure (Castor) database. For every patient with intellectual disabilities suspected of having COVID-19, they filled in a questionnaire. Information was received on age, sex, living circumstances, COVID-19 PCR test, hospital admissions, complaints, comorbidities, level of intellectual disabilities, aetiology of intellectual disabilities, deaths, etc.

Results: People with intellectual disabilities are vulnerable to COVID-19 at a younger age compared to people in the general population. Their living circumstances matter: in group home living circumstances we saw more infected people with intellectual disabilities. The aetiology of the intellectual disability, especially Down syndrome, is an unfavorable predictor. As in the general population, obesity is a very important co-morbidity in relation to COVID-19. The two alert symptoms of COVID-19 were fever together with breathing difficulty.

Conclusions: The results of this database study help physicians to make a timely diagnosis of COVID-19 and establish appropriate care.

Information exchange between research-practice in intellectual disabilities (ID) health care during the COVID-19 pandemic

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Background: The COVID-19 pandemic poses unknown challenges to healthcare for people with intellectual disabilities. Having up-to-date and accurate knowledge quickly available has proven to be of great importance. This study explores how various actors in Dutch intellectual disabilities healthcare joined forces and exchanged information.

Method: Semi-structured interviews were conducted with 25 actors affiliated with intellectual disabilities care working in scientific research, knowledge institutes, policy or intermediary organizations and end users. Interviews focused on participants experiences with information exchanges during the COVID-19 pandemic, most common used resources and interactions between knowledge users and producers. The interviews were analyzed for the purpose of creating insight in the characteristics of knowledge management in intellectual disabilities healthcare.

Results: Results focus on the characterization of roles in the infrastructure of intellectual disabilities healthcare, and provide insight into whether the information exchange is in line with the needs.

Conclusions: Knowledge about the general population does not always apply to people with intellectual disabilities and often needs a translation. To support care organizations during the COVID-19 pandemic, various actors in intellectual disabilities healthcare are at work, but often without a concrete division of roles. There is a clear need for starting points and division of roles in the knowledge infrastructure of intellectual disabilities healthcare.

Pandemic experiences: Not good, just bad and ugly

Pandemic experiences of family members supporting persons with and without epilepsy who have intellectual and developmental disabilities

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Background: To explore the global experiences of family members supporting a person with IDD during the COVID-19 pandemic with a particular focus on the impact of epilepsy.
Method: 1906 family members who took part in a large anonymous online survey in 12 countries reported on the epilepsy status of the person(s) they supported during the pandemic in August and September 2020. All questions were closed items and included two standardised scales examining mood.
Results: Individuals with intellectual disabilities who have epilepsy were more likely to be supported in services, notably community group homes and residential centres than in independent living or in the family home. No differences were observed in the support of those who had epilepsy when compared with those who did not across a range of issues including access to health care and medication, restrictions and general satisfaction levels. Differences were, however, observed in the use of casual staff to replace existing staff during the pandemic, a practice which was less likely to occur for persons with intellectual disabilities and epilepsy.
Conclusions: These preliminary data indicate similar experiences for family members supporting people with and without epilepsy during the pandemic.

Priority concerns for people with developmental disabilities during the pandemic

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Background: The aim was to provide systemised evidence-based information of the priority concerns for people with developmental disabilities regarding the pandemic.
Method: Senior representatives of major UK-based professional and service-user representative organisations with a stake in the care of people with developmental disabilities were contacted. They were asked to liaise with their membership and report the five highest ranking concerns pertaining to the COVID-19 pandemic in each of the following three domains: "mental health and challenging behaviour," "physical health and epilepsy" and "social circumstances and support." Ten statements relating to the most frequently occurring priorities were formulated for each of the domains. These priorities were then rated blindly by the authors on a scale of −10 (strongly disagree) to +10 (strongly agree). A meeting to reconcile outliers and generate a consensus statement list was held.
Results: Thirty-two organisations were contacted, of which 26 (81%) replied. From respondent's data, 30 draft consensus statements were generated. Following rating, there was initially strong consensus for seven statements (23%), increasing to 27 statements (90%) following video conferencing.
Conclusions: These recommendations (DOI: 10.1192/bjo.2020.122 – will be presented) highlight expectations of people with developmental disabilities in the current pandemic. This could support policymakers and professionals' deliver and evidence person-centred care

Seizure frequency and changes in daily life: What can we learn from the pandemic?

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Background: The response measures due to the COVID-19 pandemic have affected the daily lives of people with intellectual disabilities severely. They include various restrictions to cope with, but also provide a more transparent and predictable daily routine and therefore might reduce the risk of overstimulation. For people with intellectual disabilities and epilepsy, these response measures might indirectly result in changes in seizure frequency. The aim of this study was to provides systematic information regarding the (indirect) effects of specific response measures on the occurrence of epileptic seizures.
Method: Approximately 250 individuals with developmental disabilities and epilepsy using the residential care facilities of Kempenhaeghe in the Netherlands, are included. Alterations in patient records of seizures during the pandemic are analysed. Intra-individual comparisons are performed with a specific focus on pandemic response measures that are expected to affect daily life routines considerably.
Results: The analyses are ongoing, results are to be expected in Q1 of 2021.
Conclusions: The results contribute to a better understanding of the relationship between seizure frequency and sudden changes in daily life of people with intellectual disabilities, which can be used for evidence-based policy-making and person-centered care plans.

Cardiovascular disease in intellectual disability (ID)

(Hidden) heart conditions in older adults with intellectual disabilities

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Background: To gain more insight into the prevalence and degree of possible underdiagnosis of heart conditions in older adults with intellectual disabilities and possible explanations for missed diagnoses in clinical practice.
Method: Cross-sectional cohort study in older adults (≥60 years) with intellectual disabilities as part of the HA-ID study. We will review medical files and perform electrocardiograms to examine the prevalence of cardiac arrhythmias, second- and third-degree heart block, left bundle branch block, old myocardial infarctions, and other

clinically relevant conditions that require treatment based on electrocardiogram findings. The results of the electrocardiograms will be used as a reference standard to investigate the presence of underdiagnosis in the medical files. If the electrocardiogram indicates a heart condition that is not reported in the medical file, interviews will take place with a random sample of involved physicians to explore explanations for missed diagnoses.

Results: As the data collection is still ongoing in July 2021, preliminary results of approximately 40 to 50 participants will be presented.

Conclusions: This study can provide new insights into the prevalence and degree of possible underdiagnosis in clinical practice and can contribute to screening and diagnostic protocols to improve cardiovascular health of adults with intellectual disabilities.

Effects of resistance training on cardiovascular risk in adults with intellectual disabilities

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Background: Cardiovascular risk factors (CVRF) such as, diabetes, hypertension, hypercholesterolemia, obesity and metabolic syndrome, are highly prevalent in adults with intellectual disabilities. Progressive resistance training (PRET) reduces CVRF in the general population. We aim to briefly summarize the effects of PRET in the general population, and second present the study protocol of our study, investigating the effects of PRET on CVRF in adults with intellectual disabilities.

Method: We will use a before-after design. Adults with mild to moderate intellectual disabilities and having at least two CVRF will be followed over a one-year period consisting of a three-month baseline period, six-month intervention period, and a three-month follow-up period. Blood pressure, cholesterol, diabetes, and obesity will be measured repeatedly. Results will be analysed with a hierarchical multilevel regression model accounting for repeated measures and trainer delivering the program. Recruitment of participants starts in January 2021.

Results: Results are expected in spring 2022.

Conclusions: PRET is promising to reduce CVRF. However, the effects of PRET in adults with intellectual disabilities has not been investigated yet. If PRET has an effect, it can be used as an intervention to reduce CVRF in adults with intellectual disabilities.

Prevalence of cardiovascular and other chronic diseases in Dutch inhabitants with and without ID

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Background: Cardiovascular disease (CVD) and other chronic diseases are of high impact, but perhaps even higher for people with intellectual disabilities. Adequate information on the prevalence of these health conditions is therefore important. The aim is to compare prevalence of CVD and related comorbidities between people with and without intellectual disabilities in primary care settings in the Netherlands.

Method: Cross-sectional population-based observational study, in which population data form Statistics Netherlands is used to identify intellectual disabilities and Nivel Primary Care Database to identify medical diagnoses (by ICPC-codes).

Results: CVD prevalence differs between people with and without intellectual disabilities. In addition, age and sex seem to be important interacting factors in prevalence rates of chronic diseases. The prevalence of chronic comorbidities in CVD is different among people with intellectual disabilities compared to people without intellectual disabilities, while the nature of comorbidities is largely similar between people with and without intellectual disabilities.

Conclusions: CVD prevalence and prevalence of comorbidities vary between people with and without intellectual disabilities. Age and sex differences need to be acknowledged. When providing primary care to people with intellectual disabilities, general practitioners should be considerate of such differences. More research into chronic disease prevalence is needed to establish optimally tailored chronic care.

Cardiovascular-related mortality among people with intellectual disabilities

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Background: Earlier studies showed that in case of acute cardiovascular complications, people with intellectual disabilities may visit the hospital less often than people without with intellectual disabilities. This study investigated if this has implications for cardiovascular diseases (CVD) being reported as cause of death among adults with and without with intellectual disabilities.

Method: A population-based cohort study in the Netherlands with five-year follow-up and a 1.45% with intellectual disabilities prevalence.

Results: Overall mortality was higher among people with intellectual disabilities, and they died on average 15 years younger than people without with intellectual disabilities. CVD were the primary cause of death among people with intellectual disabilities, with heart failure being reported most frequently. At all ages, people with intellectual disabilities had a higher risk for CVD-related mortality than their comparator groups without intellectual disabilities, and was labelled as potentially avoidable up to four times as often. The highest proportion of avoidable CVD-related deaths were among people with a mild with intellectual disabilities.

Conclusions: Despite an underrepresentation of acute cardiovascular complications in routine healthcare, CVD are a prominent cause of death for people with intellectual disabilities. With relatively many avoidable CVD-related deaths, our results suggest that urgent cardiovascular problems among people with intellectual disabilities may not be recognized and treated adequately.

Accessible technology and innovation

Integrated framework for developing, implementing and evaluating eHealth for people with intellectual disabilities

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Background: The use of eHealth by people with intellectual disabilities is increasing. Despite the promising eHealth applications that are being introduced, their implementation is challenging and often cannot be maintained over time. This could be explained by the fact that eHealth is often developed without the involvement of key stakeholders, such as the target group, their caretaker and supervisors and organizations that have to work with the eHealth applications. A better fit between the users, the eHealth technology and context can be made by creating a framework for organizing development and implementation together.

Method: The CeHRes Roadmap and the NASSS framework are integrated to guide development, implementation and evaluation of eHealth for people with intellectual disabilities. By applying inclusive research, all stakeholders can contribute throughout the whole process of creating an appropriate eHealth application.

Results: This presentation shows how different frameworks for the creation of eHealth can be integrated and whether it enhance the chance of eHealth for people with intellectual disabilities succeeding in practice.

Conclusions: eHealth presents a wide range of applications people with intellectual disabilities can benefit from. By providing guidelines for development, implementation and evaluation, eHealth can be made more accessible for people with intellectual disabilities.

The value of inclusive design in eHealth development for people with intellectual disabilities

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Background: The accessibility to and use of eHealth technology for people with disabilities is challenging due to the variety of needs. Despite general recommendations for eHealth users with intellectual disabilities, it is important to include users with intellectual disabilities in the (re-)design, implementation and evaluation of eHealth applications. This study examined the value of inclusive research for the re-design of the research web application “Crowdience” (in Dutch: “Ik onderzoek mee”), which is used for crowdsourcing health-related experiences and knowledge.

Method: An interdisciplinary team of researchers, designers and individuals with intellectual disabilities re-designed the intellectual disabilities-friendly web application. The study included a literature review and followed a participatory-action model conducting inclusive research. A mixed methods design was used to collect quantitative and qualitative data on the re-design and implementation process of the application among fifteen participants with intellectual disabilities.

Results: An iterative process with multiple feedback loops is necessary during design and implementation phase. Among the identified design elements were visually and linguistically simplified layout, navigation paths and step by step instructions.

Conclusions: It is discouraged to develop eHealth technology based on literature recommendations and evaluate only after implementation, because individuals with intellectual disabilities provide detailed crucial feedback during the entire design and implementation process.

Online survey on mental health of illiterates and people with mild intellectual disabilities during the COVID-19 pandemic

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Background: Illiterates and people with mild intellectual disabilities are at greater risk of developing mental diseases as they have small social networks, depend on daily activities for daily structure and are in a vulnerable position on the labor market (Foundation for People with Learning Disabilities, 2001; Hastings et al., 2004). The COVID-19 pandemic has an impact on these factors and is therefore expected to substantially affect mental health of this group. This research aims to measure the impact of COVID-19 on mental health of illiterates and people with mild intellectual disabilities during the COVID-19 pandemic in the Netherlands, and to determine which subgroups are hit hardest.

Method: In collaboration with the target group, a survey that suits their needs in terms of languages level, relevancy of topics and suitable examples was developed and tested. Over 400 participants completed the online questionnaire via a special developed platform named Crowdience.

Results: The results give an overview of the survey outcomes, showing the impact of COVID-19 on different factors such as change in daily structure, social network and mental health.

Conclusions: Results will be shared and discussed with healthcare professionals and policymakers to improve policy and support for illiterates and people with mild intellectual disabilities.

Inclusive science communication for people with intellectual disabilities: Co-designing accessible Easy Read material

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Background: Scientific processes and output are not always accessible to people with intellectual disabilities. Inclusive design and technology play an important role in the development and dissemination of accessible information and research results. In inclusive science communication it is important that the target group is involved in all stages of the research process. The aim of this presentation is to give practical tips, applications and more insight into the process of inclusive science communication for people with intellectual disabilities.

Method: Two ways to achieve inclusive science communication for people with intellectual disabilities will be discussed as well as how to include them during the research process.

Results: There are several examples of inclusive science communication, such as co-designing an easy read poster or a website as well as establishing and discussing research results in consultative groups including co-researchers and experts with intellectual disabilities.

Conclusions: Co-designing accessible easy read material supports the dissemination of research findings and their practical implications. This increases access to information among people with intellectual disabilities. In addition, the collaboration between the target group, researchers and communication professionals raises awareness about the perception of people with intellectual disabilities. This awareness in of itself creates a more inclusive society for people with intellectual disabilities.

Supporting a healthy lifestyle of people with intellectual disability

A program for direct support professionals to promote a healthy lifestyle

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Background: A healthy lifestyle is not obvious for people with moderate, severe and profound intellectual disabilities. Direct support professionals (DSPs) can provide support but need knowledge and skills to support healthy living. Therefore, the aim was to develop a theory-based intervention for DSPs to promote a healthy lifestyle for people with moderate, severe and profound intellectual disabilities and evaluate the implementation process.

Method: Intervention Mapping was used to develop the program, then a mixed method design was used to evaluate the implementation process and to show preliminary results. In this implementation study, 32 DSPs and 24 people with moderate, severe and profound intellectual disabilities from four care provider organizations participated.

Results: First results show some barriers in the implementation of the program in daily practice, such as alignment of mutual expectations. The preliminary results show the attitude of DSPs improves after three months. The final results will be shared at the IASSIDD conference.

Conclusions: Although the implementation in daily practice faced some barriers, the first results of the evaluation indicate the intervention is promising for supporting DSPs to promote a healthy lifestyle for people with moderate, severe and profound intellectual disabilities.

Improving health-promoting capacities in care settings for people with intellectual disabilities

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Background: To live healthily, people with intellectual disabilities are largely dependent on their environment. Intellectual disabilities support organizations play a vital role to create a health-promoting environment. An environmental asset mapping tool for intellectual disabilities support settings has been developed. This study aims to provide insight into whether or not the tool can provide a comprehensive view on assets in the system and actionable knowledge to improve health-promoting capacities in intellectual disabilities support settings.

Methods: Fifty-seven users from four settings participated and completed the tool on availability, user satisfaction, and dreams regarding social, physical, organizational, and financial assets.

Results: The findings provide an overview of available assets, user satisfaction and dreams for improvements for the four locations. Combining this information provides actionable knowledge for improving the health-promoting capacities of the settings, including: 1) how use of available assets can be improved, 2) the type of assets that should be enriched, and 3) the assets that can be added to the system.

Conclusions: The asset mapping tool provides a comprehensive view on assets in the system and actionable knowledge to improve health-promoting capacities in intellectual disabilities support settings. Intellectual disabilities support organizations can use this actionable bottom-up knowledge for priority setting and implementing interventions to improve their health-promoting capacities.

Supporting healthy lifestyle of people with intellectual disabilities – The next step

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Background: Professionals supporting people with intellectual disabilities face difficulties in supporting them in having a healthy lifestyle. The aim of this study is to design, implement, and evaluate an Integral Lifestyle Approach for professionals to support people with intellectual disabilities, and their environment, in achieving and maintaining a healthy lifestyle, with a focus on physical activity and nutrition.

Method: An integral Healthy Lifestyle Approach for people with intellectual disabilities (HLA-ID) will be composed consisting of a tool to support professionals in choosing the most suitable lifestyle approach. The approach can be individually tailored to the wishes of the person with intellectual disabilities and his/her environment, and digital tools will be integrated to support professionals with implementation. Feasibility for both professionals and people with intellectual disabilities will be evaluated. Implementation process will be examined using a Plan-Do-Check-Act cycle. Effectiveness of the HLA-ID will be determined regarding healthy lifestyle outcomes, i.e., physical activity levels, healthy nutrition, and achievement of personal goals.

Results: The design of this proposed next step and its intended goals will be discussed during this presentation.

Conclusions: The intended goal of the HLA-ID is to support people with intellectual disabilities, and their professional, social, and physical environment in achieving a healthier lifestyle.

From big data to small data and back

Differences in primary care use and chronic disease management between people with and without intellectual disabilities

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Background: To explore the value of a multi-regional primary care-database in examining management of chronic diseases in people with intellectual disabilities as compared to people without intellectual disabilities in the Netherlands.

Method: Cross-sectional population-based observational study, in which population data from Statistics Netherlands were linked to the Nivel Primary Care Database. People with and without intellectual disabilities who have chronic diseases were compared in primary care use regarding their chronic diseases.

Results: Out of the 1.2 million people in the Nivel Primary Care Database, 30,000 individuals were identified with intellectual disabilities, of whom 18,000 had one or more chronic diseases in 2018. Most common were cardiovascular diseases, diabetes, and chronic obstructive pulmonary disease, but prevalence varied between people with and without intellectual disabilities. The database provides insight in other medical diagnoses, use of primary care, and management of chronic diseases.

Conclusions: Linking several population-based datasets resulted in a large dataset containing valuable information on primary care use of people with intellectual disabilities. By comparing people with and without intellectual disabilities, this study provides insight in potential disparities between both groups. Moreover, this study identifies opportunities to optimize chronic care for people with intellectual disabilities.

From outpatient care for persons with intellectual disabilities to outpatient health data results: A promising initiative

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Background: When specialised medical care is needed for persons with intellectual disabilities who live in the community, the general practitioner in the Netherlands can refer to an intellectual disabilities (ID) physician. By using electronic health records (EHR) from these outpatient intellectual disabilities clinics for scientific research, essential aspects of patient care can be investigated. This study describes the procedures required for using EHR of persons with intellectual disabilities in the outpatient clinic for scientific research.

Method: The process of using EHR for research and setup of data extraction according to legal and scientific rules is described. The outpatient clinic started in 2013 and covers >400 EHR. Explorative results from the first data extraction will be presented.

Results: Procedures for access, permission and sharing of EHR are essential in obtaining health care data. We will explain how procedures complied with legal frameworks, but at the same time remained understandable for persons with intellectual disabilities. The most prevalent health problems treated at the outpatient clinic will be shown.

Conclusions: Future researchers will benefit from our clear overview of the procedures for working with EHR data from outpatient intellectual disabilities clinics. This initiative will also give insight into different aspects of patient care in the outpatient intellectual disabilities clinic.

Big data: An inclusive science platform to improve health and health care

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Background: Routine (medical) care data has tremendous potential to improve the health of people with an intellectual disability using state-of-the-art analytic techniques. This study presents the first steps in the inclusive development and possible applications of a data platform.

Methods: A platform with routine health data from multiple Dutch intellectual disabilities care institutions is being developed, via our academic collaborative "Stronger on your own feet" with Dutch care organizations.

Results: Privacy and security are important topics in the development of the platform, as we deal with data from a vulnerable population. We will show possible applications for the platform to improve the health and health care of people with an intellectual disability without compromising privacy and security. In the future, the platform should answer research questions coming from care providers, managers, clients and their representatives by means of machine learning approaches.

Conclusions: With the help of state-of-the-art techniques, we can transform routine data into information that should eventually lead to more knowledge about people with intellectual disabilities and their health. Although most data has initially not been collected for research purposes, current analysis techniques support the development of a structural monitoring platform.

Using administrative population data to identify people with intellectual disabilities and study mortality

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Background: The aim was to estimate the prevalence of intellectual disabilities in Dutch population datasets and to pilot-test this identification method with an analysis of mortality data.

Method: National datasets on chronic care and social support were linked with the population register to identify individuals with intellectual disabilities. The identification method was then applied to the mortality register to study overall mortality, avoidable mortality, and excess mortality patterns.

Results: Linking national databases resulted in a 1.45% intellectual disabilities prevalence. People with intellectual disabilities receiving residential care were better identifiable than those supported through other systems. Intellectual disability-related causes of mortality appeared almost exclusively in people who were previously identified with intellectual disabilities, confirming correct classification of people with intellectual disabilities. Overall mortality among people with intellectual disabilities was higher, and so was avoidable mortality. During an identified influenza epidemic, excess deaths among people with intellectual disabilities were three times higher than among people without intellectual disabilities, with a broader range of underlying causes.

Conclusions: The intellectual disabilities prevalence based on population-based administrative datasets in the Netherlands aligned with international estimates. Analysis of mortality data showed the identification method was useful and can be applied to other (national) data as well.

WORKSHOPS

VGN Academy, a co-creative collaboration on e-learning for healthcare professionals in intellectual disabilities care

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Description: Learning on the job supported by e-learning is a proven method for making knowledge from research and experience accessible to healthcare workers. The VGN Academy develops innovative e-learning on the basis of evidence-based knowledge and healthcare practice. Behavioral experts from different organisations meet in editorial boards to assess knowledge and research results. In close collaboration with educationalists, this leads to the embedding of that knowledge in online practice-oriented learning content. The healthcare institutions then make the e-learning accessible via their own learning environment. About 200 experts in 15 editorial boards have now converted knowledge into practical learning tools. The e-learning is available to 120.000 healthcare professionals in the care of people with intellectual disabilities.

Contribution: In the workshop we demonstrate our method for embedding evidence-based knowledge in e-learning and how to use it in the workplace. We will show an example of a quality guide on person-centered care, which is embedded in an e-learning for clients with severe intellectual disabilities. The participants will get to know the method, the learning content and are challenged to get started with it themselves.

Adapting HealthMatters Program intervention for new contexts: A US and Swedish experience

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Description: This workshop will present and discuss Swedish experiences of translating, performing content, and cultural adaptations, updating and implementing HealthMatters Program, an evidence-based training for staff and a 12-week health promotion program for people with intellectual and developmental disabilities. We will discuss core and discretionary components, drift, fidelity, program theory, reinvention, reapplication, transcreation, scale-out, scale-up, social validity, and capacity building of the HealthMatters Program and provide global adaptation guidance. In addition, the development of a web-based version in Sweden will be discussed. The HealthMatters™ Program was founded in 2008 as one of the first community-translated research-to-practice health promotion programs for people with intellectual and developmental disabilities and their support staff. Since then, the Program has reached over 10,000 people with intellectual and developmental disabilities and certified 2,650 instructors in 210 community-based organizations in seven countries and resulted in significant improvements in health status and organizational support.

Contribution: Workshop participants will use Intervention Mapping Adapt 6-step process and workshop recommendations to plan an implementation of the HealthMatters Program to the setting and population of their choice. People with intellectual and developmental disabilities in Sweden and the US experience considerable health inequalities relative to the general population, such as, poor nutrition, low physical activity, obesity and diabetes. Having access to health promotion programs in community settings is imperative. In Sweden, similar to the US, support staff have an opportunity to be role models, provide social support, and to create a health promoting environment for people with intellectual and developmental disabilities. However, studies have shown that staff are often insufficiently trained regarding health and health promotion, often have poor health-related behaviors, and can benefit from health promotion education. The aim of this international collaboration is to extend the scale-up research initiatives from the US internationally.

HealthIDea: Connect, share and learn about health and medical care for people with intellectual and developmental disabilities worldwide

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Description: The organization of healthcare and medical care for people with intellectual and developmental disabilities varies worldwide. This complicates reporting on and publishing research results and the ability to understand and compare medical care policy, practice and research from different contexts. With HealthIDea (www.HealthIDea.nl) we aim to create an international online platform to share, learn, connect and crowdsource beyond scientific journals and conferences. This workshop will present the first version of the platform and the first pilot project on international COVID-19 responses and the impact on people with intellectual and developmental disabilities. Furthermore, we will collaboratively reflect on the positioning of HealthIDea in the field of comparable platforms (for example LTCcovid). The workshop aims to create a network of HealthIDea correspondents interested in connecting and contributing to the platform. We will discuss opportunities for shared projects, funding applications and increasing visibility. Participants can actively contribute to the project and network.

Contribution: This workshop aims to achieve: 1) Starting an international HealthIDea network, 2) Share experiences about the organization of health and medical care worldwide, 3) Reflect on the positioning on HealthIDea in the field of comparable platforms, 4) Discuss opportunities for connecting and collaborating, 5) Discuss relevant topics to share with regard to healthcare and medical care

Building capacity to participate in bike riding using virtual reality

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Description: People living with intellectual disability are often less active than others and experience the negative consequences around reduced mental health, physical well-being, fitness and life satisfaction. Evidence shows that participation rates of engagement in bike riding are reduced for individuals living with intellectual disability and a significant barrier is the lack of capacity to ride a bike safely in the community. Research reports that learning to ride a bike is considered by significant others as a risk, and therefore opportunities to ride a bike and learn road safety are often limited.

Contribution: This workshop will outline a project that aims to increase capacity to safely learn to ride a bike and access community bike riding to increase fitness and well-being as well as life satisfaction and independence. Using indoor cycling technology that allows participants to use their actual bike to learn and practice along with virtual reality 3D movie technology to gain confidence, orientation and practice on the bike trails and road in their local context; this project is developing shareable resources and how to information to be implemented more broadly. This workshop will present early results and engage attendees in discussion that could see outcomes shared internationally.

ORAL PRESENTATIONS

Sleep problems in people with intellectual disability: Diagnosis and treatment

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Background: People with intellectual disabilities are prone to sleep problems. Our aim was to elucidate the prevalence, diagnoses and feasibility of treatment of those sleep problems.

Method: Questionnaires, clinical interviews, actigraphy and polysomnography (PSG) were performed in 143 patients. Insomnia was defined as a sleep complaint of the patient and or caregiver. Other sleep disorders were diagnosed and treated according to international guidelines. Effect of the treatment was evaluated by clinical interviews, actigraphy and/ or PSG.

Results: The most frequent reasons for referral were sleep maintenance difficulties, 58% of the patients had more than one reason. 94% of the patients underwent actigraphy successfully, 90% eligible for polysomnography underwent PSG successfully. 64% of the patients had insomnia and 32% sleep disordered breathing (SDB). Insomnia was comorbid in all patients with other sleep disorders. Insomnia was successfully treated in 68% of the patients, SDB treatment was up to 42% successful. When insomnia was co-treated in SDB, the success rate went up to 80%. Crucial determinant for success for both diagnostic and therapeutic procedures was the matching to the patients level of emotional functioning.

Conclusions: Insomnia and SDB are common in people with intellectual disabilities. Diagnostic procedures and treatment are feasible when personalized.

Digi-ID: Accessible digital skills education to enhance health and inclusion of adults with intellectual disabilities

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Background: This paper is based on our EIT Health-funded project "Digi-ID: Digital skills education to support health and social inclusion for adults with intellectual disabilities."

Our two large national longitudinal studies (IDS-TILDA and HA-ID), paucity of digital access and use to support health and social inclusion is recognised. To address the issue of very low usage of technology amongst people with intellectual disabilities, we are co-creating accessible digital skills education programme via an accessible solution. We aim to empower people with intellectual disabilities the knowledge skills and confidence to manage their health and wellbeing digitally. Ethical approval sought from institutions' Ethics Committees.

Methods: Digi-ID adopts a citizen co-creation methodology; focus groups with people with intellectual disabilities in Ireland, the Netherlands, Sweden and France (n-240). Engagement with our collaborator intellectual disability services and advisory panel with paid co-researchers with intellectual disabilities will shape the digital skills education content and digital learning activities.

Results: We will present preliminary results from first round of focus groups cocreating content for core digital skills module development work.

Conclusions: Co-creating with people with intellectual disabilities will highlight precise skills knowledge and gaps to ensure core topics for digital skills education development, barriers and facilitators to enhance digital access and engagement.

A longitudinal exploration of the foot health status of older adults with intellectual disability

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Background: This study aimed to explore the factors impacting on foot health in this group in order to maintain pain-free independent mobilisation and continued social participation.

Methods: Data on foot health was extracted over a 10-year period from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing. Overall, 753 adults >40yrs were included. Retention rates remained high over the 10 years. Full ethical approval was granted by service providers and the university.

Results: 14.3% consistently reported fair/poor foot health. There was a statistically significant association between foot pain and female gender ($p=0.025$) and one tenth of the sample experienced hidden/unreported pain. Good foot health was significantly associated with good overall health ($p>0.001$) and better functional ability ($p>0.001$). Poor foot health was significantly associated with arthritis($p=0.012$). Foot health deteriorated with age and those with a severe/profound intellectual disabilities had poorer foot health, as did those living in residential settings.

Conclusions: Despite a 76% attendance at chiropody, poor foot health remained static, 14.3% over 10-year period. Hidden pain and higher prevalence of female foot pain was noted, supporting the need for robust screening and foot health promotion.

Hospital admission rates among children and young people with intellectual disabilities in Scotland

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Background: We investigated hospital admissions for children and young people with, versus without, intellectual disabilities across Scotland.

Methods: We used record-linkage between Scotland's Pupil Census, 2008-2013 (to identify intellectual disabilities) and acute hospital admissions from the Scottish Morbidity Records, up to 2015. Cox proportional-hazards models investigated admission risk for pupils with, versus without, intellectual disabilities.

Results: 18,278 pupils with intellectual disabilities and 777,912 controls were identified. 5,089 (28%) pupils with intellectual disabilities had 17,051 admissions, compared to 157,565 (20%) controls with 277,012 admissions. Pupils with intellectual disabilities had increased risk of planned hospital admission (adjusted HR=2.21 {95% CI 2.14, 2.29}) and emergency admission (aHR=1.61, {95% CI 1.55, 1.67}), sex interaction p<0.001). Emergency and planned admissions were higher for pupils with intellectual disabilities across all ICD-10 chapters, except "pregnancy, childbirth, and puerperium". Female pupils with intellectual disabilities had additional admission risk (p<0.001). Planned admissions (IRR=3.98, {95% CI 3.62, 4.37}), and emergency admissions (IRR=2.73 {95% CI 2.53, 2.94}) were longer for pupils with intellectual disabilities. Most common emergency admissions were due to seizures and respiratory infections.

Conclusions: Admissions are more common and longer for pupils with intellectual disabilities. This may reflect routine health-care management they receive but requires further investigation.

Ambulatory-care-sensitive conditions among children/youth with intellectual disabilities in Scotland

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Background: We investigated the prevalence of ambulatory-care-sensitive conditions and hospital admission rates for children/young people with, versus without, intellectual disabilities across Scotland.

Method: We used record-linkage between Scotland's Pupil Census, 2008-2013 (to identify intellectual disabilities) and prescribing information to report prevalence of epilepsy, asthma, diabetes and depression, 2009-2013. Hospital admissions were extracted from the Scottish Morbidity Records, up to 2015. Cox models were used to investigate prospective admission risk for pupils with, versus without, intellectual disabilities.

Results: There were 18,278 pupils with intellectual disabilities, and 777,912 controls. Prevalence was higher among the intellectual disabilities group for epilepsy; 8.8% versus 0.8% and asthma; 8.9% versus 6.9% (p<0.001). No differences were detected for diabetes or depression; 0.5% versus 3.0%, (p=0.841), and 3.8% versus 2.3% (p=0.717), respectively. Admission risk for epilepsy was 2.24 times higher for pupils with epilepsy and intellectual disabilities versus epilepsy alone (adjusted HR=2.24 (95% CI 1.97, 2.55). Length of stay also increased (IRR=2.21 (95% CI 1.82, 2.68). Acute admission risks for the other conditions were not significant.

Conclusions: Pupils with epilepsy and intellectual disabilities had a higher risk of epilepsy-related hospital admission and longer stays versus pupils with epilepsy alone. Management outside an acute-care setting should be further investigated.

Support a healthy lifestyle for people with moderate to profound intellectual disabilities with behaviour change techniques

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Background: Direct Support Professionals (DSPs) provide important lifestyle behaviour support for people with intellectual disabilities. They can use behaviour change techniques (BCTs) to do this. We aimed to evaluate which BCTs are used for supporting healthy lifestyle behaviour of people with moderate to profound ID by DSPs.

Method: 18 DSPs were observed in their daily work with audio-visual recordings. The Coventry Aberdeen London Refined (CALO-RE-NL) taxonomy was used for coding BCTs. Differences in the characteristics of people with intellectual disabilities and DSPs in relation to the BCTs used were evaluated.

Results: Most of the coded BCTs were used by DSPs (33 BCTs out of 42), but they rely heavily on nine of them. DSPs mostly used "feedback on performance," "instructions on how to perform the behaviour" and "doing together." No statistical differences were found for the characteristics of people with intellectual disabilities or DSPs for the top nine BCTs used.

Conclusions: DSPs mostly rely on nine BCTs. Although no statistical differences were found, DSPs use more BCTs for people with more severe intellectual disabilities. DSPs who support people with severe or profound intellectual disabilities are more aware of demonstrating, setting graded tasks and encouraging people with intellectual disabilities to practice healthy lifestyles.

Life expectancy and severe health needs in people with and without intellectual disabilities

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Background: To quantify and compare life expectancy of people with and without intellectual disabilities by presence of severe health needs.

Method: An electronic health record study of linked primary and secondary care data on 1.4 million individuals (~35,000 with intellectual disabilities) from 2000–2019. Life expectancy from age 10 years was estimated using Chiang's and flexible parametric approaches using age as the time scale. Severe health needs were modelled as presence of ≥2 specific health conditions (epilepsy, incontinence, percutaneous endoscopic gastrostomy, severe visual loss, severe hearing impairment, cerebral palsy, severe mobility difficulties) at baseline or during follow up.

Results: People with intellectual disabilities and severe health needs had substantially worse life expectancy than those without intellectual

disabilities. For example, in 2010–2019, proportions of life years lost due to severe health needs were 36.7% and 32.7% for males and females with ID compared to 24.0% and 21.3% for those without. For those without severe health needs, proportion of life years lost due to intellectual disabilities was 9.2% and 7.8% for males and females respectively.

Conclusions: Mortality disparities between people with and without intellectual disabilities can only partially be explained by increased prevalence of severe health needs.

Examining the sedentary behaviour levels among older adults with intellectual disability

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Background: To determine the prevalence of sedentary behaviour in older adults with an intellectual disability.

Method: Sedentary behaviour, for this study, is defined as "low physical activity as identified by MET or step levels or as measured by RAPA or IPAQ or sitting for more than three hours per day." A search was conducted across four databases and grey literature sources. PRISMA-P was applied to article selection. All articles were quality assessed and independently reviewed by two reviewers, a third adjudicated disputes. 1729 articles were identified. Using inclusion criteria, 49 full text articles were selected, extracted and summarised using a tabular format. GRADE was used to assess the quality of the evidence. Due to variability in measurement overall prevalence was not determined. Final data selected were thematically analysed.

Results: Sedentary behaviour was linked to adverse health conditions, increased cardio-metabolic risks, increased obesity and mortality in both men and women. Older adults with an intellectual disability have higher rates of obesity, inactivity and multi-morbidity than their non-disabled counterparts.

Conclusions: Sedentary behaviour is prevalent among those with intellectual disability, however, it is not well defined. This systematic review provides a critical insight into how sedentary behaviour could have health implications.

Prevalence of dementia in people with intellectual disabilities without Down syndrome in Japan

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Background: There are few large-scale studies of the prevalence of dementia in people with intellectual disabilities who do not have Down syndrome, although Down syndrome is well known to be related with Alzheimer's disease.

Method: We investigated 1831 adults with intellectual disabilities but without Down syndrome who were residents of a facility for people with intellectual disabilities in Japan. The caregivers answered a questionnaire, and physicians directly examined the participants suspected of cognitive decline.

Results: Of the 1831 patients, 118 were diagnosed with dementia and 51 with mild cognitive impairment (MCI). The prevalence of dementia was 5.6% for the 55 to 64 age group, 13.2% for the 65 to 74 age group, 22.2% for the 75 to 84 age group, and 42.3% for the 85 to 94 age group. The prevalence of MCI was 2.1% for the 55 to 64 age group, 7.4% for the 65 to 74 age group, and 11.5% for the 85 to 94 age group. Sixty-five patients (55.1%) had not been diagnosed with dementia before the survey.

Conclusions: People with intellectual disabilities without Down syndrome may develop dementia at an earlier age than those without intellectual disabilities. Our nationwide survey suggested there are many undiagnosed dementia patients in the community of people with intellectual disabilities.

Developing a biopsychosocial model of cognitive decline in people aging with intellectual disability

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Background: The aim of the study is to develop an initial biopsychosocial (BPS) model to longitudinally investigate the relative impact of various BPS constructs on cognitive decline in people ageing with intellectual disability.

Method: Data gathered from the four waves of IDS-TILDA will be used for the longitudinal analysis. IDS-TILDA is an Irish nationally representative longitudinal study that collects information on a variety of biological, psychological and social indicators in people ageing with intellectual disability. Structural equation modelling will be used to analyse the complex causal pathways of how BPS constructs may influence cognitive decline over time. Prior ethical approval by Trinity College, Dublin was granted for the IDS-TILDA study data gathering.

Results: An exploratory SEM model will be proposed to show the complex and bi-directional relationships between factors in the BPS model, including the potentially mediating effects of subjective wellbeing.

Conclusions: Findings from this exploratory modelling will provide an initial framework to assess the relative influence of various biological, psychological and social indicators on subsequent cognitive decline in people ageing with intellectual disability. Building such an evidence-based framework will support targeted interventions to improve the cognitive health of those with intellectual disability across the life span.

Detecting sleep apnea in adults with Down syndrome using the WatchPAT: A feasibility study

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Background: In daily practice, sleep apnea is underdiagnosed in people with Down syndrome. The WatchPAT, a finger-probe watch that detects apnea indirectly by measuring sympathetic arousal, can diagnose sleep apnea in an accessible way. This research aims to study feasibility of the WatchPAT for diagnosing sleep apnea in persons with Down syndrome.

Method: Thirty clients (aged 18+) with Down syndrome were included. Sleep apnea was assessed by the Stop-Bang sleep apnea questionnaire (current practice) and compared to results after one night wearing the WatchPAT. Two medical doctors independently draw a diagnosis based on the report that is generated by the WatchPAT. Experiences of clients and caregivers involved were studied as well by using questionnaires and semi-structured interviews.

Results: Data collection is ongoing. We will present feasibility results of WatchPAT in this population. In addition, results of the apnea diagnosis obtained with the WatchPAT will be compared with result of the Stop-Bang questionnaire, incl. interrater reliability. Furthermore, promoting and hampering factors influencing the acceptance of the WatchPAT by adults with Down syndrome will be presented.

Conclusions: This study will show to what extent the WatchPAT can be used for apnea diagnostics in people with Down syndrome.

Asthma and COPD in people with intellectual disabilities and corresponding levels of integrated care

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Background: The aim of the study was to assess the prevalence of asthma and COPD in primary care patients with and without intellectual disabilities, and to examine potential differences in the delivery of corresponding integrated care.

Method: In a 10-year retrospective cohort, we collected medical record information on diagnosis of asthma/COPD, consultation patterns, use of asthma/COPD control questionnaires, pulmonology referrals, spirometry measurement and prescribed medication.

Results: The prevalence of asthma appeared significantly higher in patients with intellectual disabilities, whereas the prevalence of COPD was relatively even. Patients with intellectual disabilities and asthma or COPD received more GP-consultations. People with intellectual disabilities and asthma received more pulmonology referrals and antibiotics prescriptions. People with intellectual disabilities and COPD were referred less often to a pulmonologist and received the COPD Control Questionnaire less frequently.

Conclusions: We conclude that asthma is more prevalent in people with intellectual disabilities and that there are quantitative differences in the care provided for asthma and COPD in this patient group compared to controls. This warrants further research into the causes of these differences and whether they also infer differences in quality or effectiveness of care for people with intellectual disabilities. Some concern for proper access to asthma and COPD care and adequate disease management and control is in place.

Umbrella systematic review on comorbid physical conditions in people with autism spectrum disorder

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Background: Comorbid physical conditions may be more common in people with autism spectrum disorder (ASD) than other people. We aimed to systematically review evidence in this area.

Method: PROSPERO registration: CRD42015020896. We undertook an umbrella systematic review of systematic reviews and meta-analyses on comorbid physical conditions in people with autism spectrum disorder. Five databases were searched.

Results: 24/5552 retrieved articles were included, 15 on children, one on adults, and eight on children and adults. Although the quality of included reviews was good, most reported several limitations in the studies they included and considerable heterogeneity. Comorbid physical conditions are common, and some are more prevalent than in the general population: sleep problems, epilepsy, sensory impairments, atopy, autoimmune disorders and obesity. Asthma is not. However, there are substantial gaps in the evidence base. Fewer studies have been undertaken on other conditions, and some findings are inconsistent.

Conclusions: Comorbid physical conditions occur more commonly in people with autism spectrum disorders, but the evidence base is slim, and more research is needed. Some comorbidities compound care if clinicians are unaware, for example sensory impairments, given the communication needs of people with autism spectrum disorders. Others, such as obesity, can lead to an array of other conditions, disadvantages and early mortality.

The use of Timed up and Go: Identifying mobility issues among adults with intellectual disability

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Background: To examine the relationship between the Timed up and Go (TUG) test and difficulties in mobility in adults with intellectual disabilities.

Method: Data for this study was drawn from Wave 2 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing. Overall, 708 participants data were included, with seven questions on activities assessed. Mobility was objectively measured using the TUG test. The ability to carry out these activities was compared to the length of time participants took to complete the TUG.

Results: A significant relationship was demonstrated between TUG and level of intellectual disability ($p=0.0001$), and place of residence ($p=0.05$). The participants aged between 50-64 years old were also found to have the highest proportion (49.9%) of poor performers in TUG, suggesting that this group has the most mobility limitations. However, there was no significant association between the activities impacted by mobility and TUG.

Conclusions: There is a need to better understand the validity of TUG in predicting mobility difficulties in adults with intellectual disabilities, and future research should strive to identify appropriate tools that can be used to assess the risk for mobility limitations in this population.

Evaluating the impact of health promotion screenings for people with intellectual disability

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Background: People with intellectual disability often experience a higher prevalence of chronic health conditions and less access to health promotion screenings. The aim of the present study was to understand if Special Olympics (SO) health screenings promote better health outcomes for people with intellectual disability, over time.

Method: Between 2015 and 2018, SO conducted nearly 53,000 health promotion screenings for individuals with I intellectual disability, worldwide. We examined the prevalence of high blood pressure (BP) and body mass index (BMI), and whether individuals with intellectual disability who attended two or more yearly screenings exhibited health improvements at follow-up.

Results: Roughly 14% of screenings indicated high BP and 39% indicated overweight or obese BMI (18% and 21%, respectively). Among individuals with intellectual disability with high BP or BMI at their first screening, 60% no longer had high BP and 15% showed less severe BMI status (e.g., overweight to normal) at their follow-up screening. Additional differences by global region were observed.

Conclusions: Findings indicate that SO health promotion screenings may contribute to improvements in health for individuals with intellectual disability, and have implications for the importance of regular health promotion programming and screenings.

Medication load and frailty in older adults with intellectual disability: An observational study

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Background: Recently, efforts have been made to quantify frailty among older adults with intellectual disability. Little research has been performed on the association between medication exposure and frailty among older adults with intellectual disability, despite a known association among older adults without intellectual disability. The aim of this study was to examine the association between frailty and medication exposure, specifically polypharmacy, anticholinergic and sedative medication exposure.

Method: Data was drawn from Wave 2 (2013/2014) of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA). A modified Fried's frailty phenotype was constructed and analysed for associations with four measures of medication load: polypharmacy, Drug Burden Index (DBI), Anticholinergic Cognitive Burden (ACB) and Sedative Load model using multinomial logistic regression.

Results: Frailty status was significantly associated with excessive polypharmacy, but not with DBI, ACB or Sedative Load score.

Conclusions: This is the first study to examine the association of frailty with anticholinergic and sedative load among older adults with intellectual disability. Polypharmacy may be an important factor involved in frailty in this population. Further research is required to investigate the trajectory of frailty and frailty as measured by other models in relation to medication load.

An exploration of lifestyle/obesity programmes for adults with intellectual disabilities through a realist lens: Impact of a "context, mechanism and outcome" evaluation

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Background: Obesity is higher in people with intellectual disabilities. There are two aims of this explorative paper. Firstly, using a realist lens, to go beyond "what works" and examine the "context, mechanisms and outcomes" (CMO) of lifestyle/obesity programmes for this population. Second, using a logic model framework to inform how these programmes could be implemented within practice.

Method: We explored six review papers and the individual lifestyle/obesity programmes that these papers reviewed using the CMO framework.

Results: There were few theoretically underpinned, multi-component programmes that were effective in the short to long-term and many failed to explore the "context and mechanisms." We developed a logic

model and engaged in two co-production workshops to refine this model.

Conclusions: Using a realist approach, programmes need to be underpinned by both individual and systems change theories, be multi-component, have a closer understanding of the interplay of the "context and mechanisms," and co-designed using a logic model framework.

Providing a scaffold of support: Exploring the role of the CNSp acute hospital liaison nurse

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Background: An Acute Hospital Liaison Nurse has been shown to improve hospital experiences for people with intellectual disabilities. This is an emerging role in Ireland.

Method: Research was undertaken with a descriptive qualitative design to explore the impact and breadth of Clinical Nurse Specialist Acute Hospital Liaison Nurse in an intellectual disability community organisation, from the perspective of support staff. Purposive sampling was used to source focus groups from different staff support levels, and data were analysed using thematic content analysis.

Results: Participants identified significant past challenges with supporting people with intellectual disabilities in hospital, including accessing and understanding information, anxieties related to attending hospitals, and not being prepared for supporting transitions.

Conclusions: The role is seen as a very positive step, with findings demonstrating its provision of support for staff including experiences of improved information sharing, being better prepared for hospital and alleviating anxieties when supporting someone in hospital. The findings identify that the role has considerable benefits to support staff and can positively impact experiences in hospitals. This is the first known Irish study in this area and contributes to previous studies but there is a need to examine it from the perspective of people with intellectual disabilities and of staff in hospitals.

Healthy Community Special Olympics program in the Czech Republic

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Background: The Czech Special Olympics Program (CZ SO) has been active in SOI fitness and health policy since the year 2003. Due to experience with several SOEE grants, CZ SO was included in a three-year SOI project (2016-2019) supported by the Golisano Foundation. The survey of the goals, management, approaches of the Czech Special Olympics are described.

Method: During this period 520 SO athletes (male and female) were assessed – 65 items for each participant (e.g., spectrum 12 to 62.) Items assessed were relevant to standardized requests of Special Olympics Healthy Community project: BMI assessment, heart rate, blood pressure; questioning (and observing) personal age, gender, health status and living environment; and measurement of basic health fitness variables. The items were classified and processed according to gender, age, medical care, health status, type of accommodation and environment. The content was oriented on fitness screening, motivation for applying healthy lifestyle in CZ SO, family and community inclusion, education of all participants, involvement of trained volunteers from universities.

Results/Conclusions: Recent findings show appropriate follow-up health care, education impacts, differences in healthy lifestyle of athletes living in families, sheltered or residential environment, and active lifestyle of elderly athletes.

Utilizing a population health intervention to improve preventing health screening rates in people with intellectual and developmental disabilities

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Background: Regular and timely preventive health screenings are critical for detecting cancers early and identifying risk for stroke, cardiovascular disease and other conditions such as osteoporosis or diabetes. Early detection improves treatment and disease management options. However, research shows that people with intellectual and developmental disabilities are at a deficit when it comes to obtaining preventive health screenings. This population experiences substantial disparities in receipt of screenings compared to adults in the general population despite strong evidence that adults with intellectual and developmental disabilities have higher risks of developing many of these diseases. The aim of this research was to improve preventive screening rates in people with intellectual and developmental disabilities through targeted strategies.

Methods: The Center for Developmental Disabilities Evaluation and Research (CDDER) partnered with a U.S. state disability system to analyze health data in support of interventions to improve screening rates. This included analysis of data regarding mortality, individual health care records, and a review of general population data.

Results: Authors will present evidence of disparities including mortality rates which show higher rates of death from preventable cancers in the population of state IDD service recipients. Access to health care visits and screening receipt data will also be presented for use in targeting interventions along with a discussion of possible barriers to obtaining preventive health screenings.

Conclusions: The state designed targets to decrease variation of preventive health at annual physicals. This was accomplished by developing tools to improve knowledge of preventive screenings recommendations and encourage advocacy by staff and providers. Additional strategies will be presented including efforts to modernize advocacy tools in alignment with modern screening technologies and to enhance the utility of the tools for self-advocates and family members. Tools will also be enhanced to include strategies for overcoming screening barriers and best practices from provider agencies who are successful in this area.

Reasonable equitable accessible care for health (REACH): Application to a health passport framework

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Background: The UN Convention on the Rights of Persons with Disabilities, provincial accessibility acts and consent laws require health care professionals to provide equitable access to care and respect the autonomy of persons with disabilities. Provision of health care services to individuals with intellectual or developmental disabilities can be difficult when they may not communicate or behave in expected ways, putting them at risk of being deemed incapable of making decisions when they may be capable with the appropriate support. Furthermore, the health care environment is limited in time resources, professional training in the support of adults with intellectual and developmental disabilities, and access to experts skilled in supporting this population, which can hinder health care professionals in their fiduciary duties. Resources and guidelines to support adults with intellectual and developmental disabilities are available however, quick, easily readable, and accessible tools that can be used by adults with intellectual and developmental disabilities to assist health care providers to maximize comfort, lower stress, and enhance communication are limited. A health passport tool incorporating REACH principles could meet this need.

Method: Based on the results of a recent MHSc-Bioethics capstone project, REACH principles and a health passport tool designed for use with adults with intellectual and developmental disabilities will be presented. Literature review, preliminary framework design and community and stakeholder consultation results will be shared.

Results: Participants will gain knowledge of REACH principles and will be aware of a novel health passport framework to support health care interactions with adults with intellectual and developmental disabilities.

Conclusions: REACH principles applied to a health passport tool can support respect for persons, enable autonomous decision making and facilitate just procedures during health care services with adults with intellectual and developmental disabilities. The framework can support health care professionals and their organizations to recognize and accommodate sensory, motor and communication needs, and to remove systemic, attitudinal and communicative barriers.

Comprehensive health checkup for patients with intellectual and/or multiple disabilities in Japan

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Background: Comprehensive health checkups are provided to most healthy workers and family in Japan to facilitate early detection of diseases and reduce overall medical costs. Access to the checkup for intellectual and/or multiple disabilities patients, including those with profound intellectual and multiple disabilities, can be difficult, especially for those who stay at home. Delayed detection causes late detection of diseases and poor prognosis. We started a comprehensive health checkup for patients with disabilities to provide a fair opportunity compared to the healthy population, and will report early results and issues.

Method: We have an outpatient clinic specifically for patients with disabilities, and collaborated with Jyunpukai Checkup Clinic to provide the checkup. It included a complete outpatient checkup with medical interview, examination, blood testing and optional tumor marker, helicobacter pylori antibody, which is a known risk factor for gastric cancer. We added otorhinolaryngology, orthopedics and dental examination, which are not included in the healthy population checkup, considering the specific health concerns of patients with disabilities. Basic cost was 20.000 JPY plus additional cost for optional exams, thus the total cost ranged from 200 to 300 US dollars. There is no public support. We evaluated the result of examination and referred hospitals for further medical care for positive results.

Results: So far eight patients have had the checkup. There were borderline results in these patients for hypertension (4) and diabetes mellitus (4), with a recommended course of observation. Five patients had a positive test for the helicobacter pylori antibody, and were instructed to have gastrointestinal endoscopy and H. pylori eradication.

Conclusions: Early results of comprehensive health checkup for patients with intellectual and/or multiple disabilities, including profound intellectual and multiple disabilities, are encouraging, but there is hesitation from patients because of the cost, since there is no public financial support. We continue to improve the optimal program for patients with disabilities, and lobby with the government to acquire financial support.

Barriers to practice leadership by frontline managers in England

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Background: Frontline managers in English services have a complex role, including supporting staff practice, for example, through observing them working and providing feedback, that is, practice leadership. They also face many administrative demands. The balance between administration and practice has favoured administration, despite the research evidence demonstrating the positive impact of practice leadership.

Method: Fourteen frontline managers in England were interviewed using a semi-structured guide to understand their "lived experience" of the expectations and demands placed upon them. The participants managed services supporting autistic individuals, living in group or individual homes in the community. Interviews were transcribed and subject to thematic analysis.

Results: The thematic structure had three major themes: difficulties in recruitment and retention of staff, supporting staff to work with people who may show behaviour regarded as challenging, and administration and paperwork. Sub-themes arose in each theme, and some were specific to managing staff working with people living in individual settings.

Conclusions: The findings support research demonstrating the complexity of the frontline manager's role. Administrative paperwork may dominate frontline managers' daily experiences, compromising their ability to provide practice leadership. Individual settings may make it harder to provide practice leadership that is, not having a base or frequent "presence" in the service.

Developing the ID-Frailty Index Short Form to assess frailty in adults with intellectual disability

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Background: To develop a shortened version of the Intellectual Disability Frailty Index (ID-FI Short Form) for more practical and feasible assessment of frailty in adults with intellectual disability.

Method: The ID-FI Short Form was based on the 51-item ID-Frailty Index (ID-FI, validated in the HA-ID study). Stepwise forward linear regression was used for statistical item reduction until included items explained ≥90% of the full ID-FI. Experts combined or replaced items to achieve consensus on the ID-FI Short Form, based on the clinical applicability of items and statistical item reduction. We investigated internal consistency, agreement in frailty categories between full and shortened ID-FI, and association with survival.

Results: The ID-FI Short Form consists of 17 items, explaining 90.3% of the variance of the full ID-FI, with good internal consistency (Cronbach's α=0.75). The Pearson correlation between indices was 0.94 ($p<0.001$) and agreement was good when dividing participants by frailty categories (κ=0.63). The ID-FI Short Form was associated with five-year survival with a Hazard Ratio of 1.07 ($p<0.001$) with each 1/100 increase in frailty-score.

Conclusions: The ID-FI Short Form is developed for use in clinical practice, has good internal consistency, strong agreement with the full ID-FI, and predicts survival among adults with intellectual disability.

Small steps in fitness can lead to major leaps in health

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Background: Cut-off values are available for the minimum physical fitness levels required to generate health benefits as decreased morbidity and longer survival. However, these cut-off values may be impossible to reach for extremely unfit populations, such as older adults with intellectual disabilities. We want to propose a novel hypothesis that even among very unfit, older adults with intellectual disabilities, small changes in fitness can lead to major leaps in health.

Methods: Data collected in the Healthy Ageing and Intellectual Disabilities (HA-ID) study was used to support this hypothesis. Physical fitness (cardiorespiratory fitness, gait speed, grip strength) was measured in 900 older adults with intellectual disabilities (50 years and older). Mortality was collected 5 years after baseline. The relationships between fitness and survival were analysed with multiple linear regression models and Cox proportional hazard models.

Results: Looking at cardiorespiratory fitness, 100% of the older adults with intellectual disabilities scored below the average reference range of the general population. For gait speed this was 43% of the men and 54% of the women, and for grip strength 77% of the men and 67% of the women scored below the average reference range of the general population. Within these extremely low fitness levels, better baseline fitness was still associated with better survival (cardiorespiratory fitness HR = 0.997 [0.995–0.999], comfortable gait speed HR = 0.65 [0.54–0.78], grip strength HR = 0.97 [0.94–0.99]).

Conclusions: Our study is the first to support our hypothesis that even small differences at the lower end of the physical fitness spectrum are associated with health benefits. Improving physical fitness is important to improve outcomes even in extremely unfit populations scoring well under the cut-off values for the general population. This supports a stronger focus on improving fitness amongst these unfit adults with intellectual disabilities.

Prevalence and patterns of healthcare utilisation for children with intellectual disability admitted to a tertiary paediatric healthcare organisation

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Background: Children with intellectual disability have a poor care experiences and a heightened risk of harm every time they access tertiary healthcare. However, reliable methods to identify children with intellectual disabilities when they access hospital care are

lacking both in the Australian context and internationally, impeding the opportunity to improve the quality of care experience for these children. This study sought to quantify the prevalence of the paediatric intellectual disabilities population, describe the demographics, health utilisation and reported clinical incidents of the paediatric intellectual disability population with subgroup analysis for different socioeconomic, geographical and cultural backgrounds.

Method: A retrospective chart review of 1021 randomly selected patients admitted at least once for greater than 23 hours to one of the two tertiary children's hospitals in Sydney, Australia, in 2017. Each record was manually interrogated to identify which children had documented evidence of intellectual disability or developmental delay. Data including patient demographics, length of stay, number of admissions, cultural background, language and reported clinical incidents for each patient were also extracted.

Results: Initial analysis has found approximately 9% of children admitted during the study period had an intellectual disability. A further 4% were identified as having developmental delay (pre-school children yet to be formally assessed). No intellectual/developmental disability were identified in the remaining children. Other findings to be presented will be differences across the three groups in terms of demographics, length of stay, patterns of admission and medical specialty. Analysis of the differences in reported rates and types of clinical incidents across the three groups will also be discussed. Subgroup analysis of children from diverse cultural backgrounds will be included.

Conclusions: Without knowing the prevalence, health utilisation and deficits in care quality for children with intellectual disabilities in hospital, health services cannot adequately adapt to meet their care needs, and drive improvements in care delivery.

"Know your bugs": Enabling adults with intellectual disabilities to manage good health

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Background: This research aimed to understand the health education experiences of adults with intellectual disabilities and, consequently, to identify the components of an effective community learning model.

Methods: Beginning with a scoping review of "what works," this research involved observation of the learning context in two locations, and semi-structured interviews with 18 course participants to explore health knowledge and behaviour change in the short, medium and longer term. Data were analysed iteratively according to the realist concept of context/mechanism/outcome configurations.

Results: Participants had a positive learning experience and gained knowledge about microbes, hand hygiene, self-care and antibiotic use. Some participants reported behaviour change regarding handwashing and self-care. The contexts that influenced learning were personal, social, physical and external. Important mechanisms included: accessible teaching methods, visual and interactive resources, relaxed and effective participant interactions, facilitation of independent thinking and planning, appropriate involvement of supporters, and an inclusive and engaging educator style.

Conclusions: In the context of this study, an effective learning environment comprises changing combinations of contexts and mechanisms that generate different outcomes for different individuals. The research suggests a model that can guide effective community provision of a course such as this.

Don't forget about me: Neurocognitive aging in adults with intellectual disability and epilepsy—A study protocol

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Background: Early cognitive and adaptive decline is a major clinical concern in adults with intellectual disability and epilepsy. It is thought to occur in the context of a "chronic accumulation model": the effects of seizures, medication and aging on an already vulnerable brain. However, incidence, symptomatology and determinants of a decline in functioning are unknown, as this vulnerable population is under-researched.

Methods: Neuropsychological assessment and analysis of serum biomarkers for dementia will be performed. Based on power analysis at least 85 people with intellectual disabilities and epilepsy of various genetic origins, who received neuropsychological examination in a previous study, will be included. Furthermore, we aim to include 200 adults with one of four genetic neurodevelopmental disorders: Fragile X Syndrome, Tuberous Sclerosis Complex, Angelman Syndrome and Dravet syndrome, particularly those with SCN1A mutations.

Results: Results will be presented on primary outcomes, including the difference in current adaptive functioning compared with previous results and associations with biomarker serum levels. Secondary outcomes include the associations between adaptive functioning changes and clinical characteristics.

Conclusions: More insights in the course and determinants of cognitive trajectories will contribute to a better quality of care through improving preventative screening and diagnostics and providing treatment targets.

The impact of COVID-19 on older people with an intellectual disability in Ireland

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Background: This study examined the impact of COVID-19 social restrictions and service closures on the health and well-being of older adults with intellectual disability in Ireland.

Method: Data was drawn from a supplemental COVID-19 survey added to Wave 4 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) (n=710). Measures of COVID-19 symptoms, testing, outcomes and procedures for case management were analysed alongside demographic and health-related data.

Results: Most participants had health conditions associated with adverse COVID-19 outcomes, including over half with cardiovascular disease and overweight/obesity. Two-thirds (62.4%) were tested for COVID-19, with a 2.5% infection rate; and 10% reported COVID-19-like symptoms. Residential care participants had the highest rates of testing (84.8%) and positive tests (4.6%). Some participants (7.8%) moved home, most commonly to follow isolation procedures. Over three-quarters (78.7%) had plans to manage self-isolation according to guidelines. Most were able to comply with guidelines, but one-third were unable.

Conclusions: The demographic and health profile of older adults with intellectual disability places them at high-risk for contracting COVID-19 and for poor outcomes. Widespread testing with good service planning and procedures may have mitigated the worst effects of the first COVID-19 wave for this vulnerable population.

The implementation of a pro-active health assessment instrument for people with intellectual disabilities

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Background: People with intellectual disabilities have more health problems and die more often of treatable diseases than people in the general population. Therefore, Philadelphia Care Foundation started a pilot to implement the pro-active health assessment instrument (PROSPER-ID) for people with intellectual disabilities. In this presentation we will share and discuss the findings of this pilot implementation study that explored the experiences of the involved general practitioners, professionals, patients, or their representatives.

Method: Semi-structured interviews were held with general practitioners, other professionals and the patients with intellectual disabilities or their representatives who were involved in this pilot. A deductive approach was used to analyze this qualitative data.

Results: The preliminary results of the implementation of the PROSPER-ID and the facilitators and impediments will be presented.

Conclusions: Our findings shed light on the implementation of the PROSPER- intellectual disabilities, a necessary health assessment screening instrument for people with intellectual disabilities. Recommendations for future studies and stakeholders will be presented.

Dental experiences of adults with learning disabilities: A record linkage study of n=17,220

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Background: The aim was to investigate dental health experiences of adults with intellectual disabilities who rely on carer support and medications with increased dental risks.

Method: Record linkage study of administrative datasets (dental, medication, primary care long-term conditions), in adults with intellectual disabilities compared with age-sex-neighbourhood deprivation-matched general population controls.

Results: Group differences in dental experiences: attendance 68.1% with people with intellectual disabilities and 60.1% without intellectual disabilities, odds ratio (OR)=1.42 [1.32-1.53]; restorations 31.6% people with intellectual disabilities vs. 40.5% without intellectual disabilities OR=0.68 [0.63-0.73]; and extractions 13.2% with intellectual disabilities vs 15.9% without intellectual disabilities: OR=0.80 [0.73-0.89]. Treatment differences were greatest between groups in older ages, whilst attendance differed more in younger ages. Adults with intellectual disabilities were more likely to be prescribed anticholinergics (57.9% vs. 48.3%: OR=1.49 [1.39-1.59]), and sugar-containing liquids (38.1% vs. 17.9%: OR=2.89 [2.67-3.12]). Prevalence of long-term conditions varied. Adults with intellectual disabilities were less likely to have coronary heart disease and chronic obstructive pulmonary disorder, but more likely to have type 2 diabetes.

Conclusions: Accessed dental data show no association between extractions and medications or long-term conditions for the adults with intellectual disabilities. Carers support dental appointments, but dentists may be less likely to restore teeth, possibly extracting multiple teeth at individual appointments instead.

Psychometric properties of the Zuidwester Balance Scale, a measuring instrument for people with intellectual disabilities

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Background: Frequent falls and associated injuries are a common health problem in people with intellectual disabilities. The Zuidwester Balance Scale (ZBS) was developed to measure balance in people with intellectual disabilities. The aim of this study was to determine the feasibility and reliability of the ZBS.

Method: The ZBS consists of three subscales (sitting, standing, walking) with a total of 15 items. A total of 84 adults with intellectual disabilities (moderate ID=64, severe ID=20; mean age 55,7 ± 9,7) performed the ZBS twice. Two physiotherapists scored these attempts independently.
Results: At least 63.4% of the participants were able to perform the ZBS according to protocol. Individual test items of the ZBS showed a feasibility of 68,3-97,6%. Feasibility was lower for participants with severe intellectual disabilities than participants with moderate intellectual disabilities. The ZBS as a whole had an inter-rater and intra-rater reliability of 0,996 (ICC). Reliability was comparable for both levels of intellectual disabilities.
Conclusions: The ZBS has good to excellent feasibility in people with moderate intellectual disabilities, and moderate to excellent feasibility in people with severe intellectual disabilities. Reliability of the ZBS for people with moderate and severe intellectual disabilities was classified as good. The ZBS is a promising tool to assess balance in people with intellectual disabilities.

Reliability of community health workers on mHealth developmental screening for vulnerable children

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Background: This study evaluated the reliability of mHealth developmental screening conducted by community health workers (CHWs) compared to speech-language pathologists (SLPs).
Method: A cross-sectional, within-subject, comparative research design was employed. The study was conducted in low-income communities. Data was collected at various ECD centers and through home visits. Caregivers with children between the ages of 36 and 83 months participated in the study. Non-probability purposive sampling was used to select ten CHWs to participate by conducting developmental screening using the mHealth PEDS tools.
Results: CHWs and SLPs screened 279 children using the mHealth PEDS tools. Inter-rater reliability between screening conducted by CHWs and SLPs across various age cohorts varied from slight ($k=.184$; $p<0.03$) to perfect agreement ($k=1.00$; $p<0.001$). CHW and SLP referral rates were similar (86.0% and 87.1% respectively). The high prevalence rate may, in part, be ascribed to the vulnerability of the sample included in the study.
Conclusions: CHWs were recognized as key role players in entry-level developmental screening and showed moderate to perfect inter-rater agreement to SLPs when conducting developmental screening services.

Sex! What's the big deal?: Promoting sexual health, romance, relationships and rights!

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Background: Individuals with intellectual and developmental disabilities experience stigma, lack of opportunities for sexual expression, and a lack of sexual knowledge and access to sexual education, resources and support. This research project aimed to understand self-advocates' experiences of learning about sexual health, and identify what self-advocates understand as important for promoting their rights to romance and relationships.
Method: Descriptive qualitative methods were used. Face to face interviews were conducted with 19 self-advocates, and content analysis was used to identify key findings. The key findings were used to co-develop and co-create scenes of importance to self-advocates through theatre in an effort to promote the rights of individuals with intellectual and developmental disabilities to romance and relationships. Four performances were delivered in spring 2019 to over 1000 diverse audience members.
Results: Self-advocates repeatedly underscored that relationships are important to them. That said, individuals reported that sexual health education emphasized information about biology, sexual health and consent, but often excluded information about relationships and pleasure in sexual relationships, and further excluded information about sexual and gender diversity. They also described that support people in their lives (e.g., parents, support workers) were uncomfortable having conversations with them about sexuality and relationships.
Conclusions: Romance and relationships are important rights for self-advocates! More attention to supporting self-advocates' access to information and knowledge about their sexual health and their rights to participate in relationships is needed. Devised/social theatre that engages self-advocates in the co-creation of content is a powerful medium for knowledge translation and knowledge mobilization.

Inclusion of stakeholders in the development of a national intellectual disability memory service

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Background: To include the voices of key stakeholders, including people with an intellectual disability, family members and service providers in developing key performance indicators for the newly established National Intellectual Disability Memory Service in Ireland.
Method: A series of semi-structured interviews using accessible guides and prompts were completed with individuals with an intellectual disability to gain input on the development of strategic short- and long-term activities with the National Intellectual Disability Memory Service. This process was also completed with family members and staff from intellectual disabilities service providers. The information was used to inform the development of key performance indicators for the service.
Results: Important aspects identified related to service user experience, supports offered and outputs of the service. The resulting

indicators were structured using the Donabedian model for examining quality in health services under three components: Structures, Processes and Outcomes.

Conclusions: The National Intellectual Disability Memory service addresses the inequity in service provision for people with an intellectual disability through providing specialist memory assessment, dementia diagnosis and post diagnostic support. The involvement of people with intellectual disabilities, their families and service providers in developing indicators was key to developing a service based on the principles of person-centredness.

Identifying components of autism-friendly healthcare: A modified Delphi study

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Background: Individuals with autism spectrum disorders are more likely to report lower healthcare satisfaction. Currently, there is no set of "best practice" standards in caring for patients with autism spectrum disorders. We aim to identify what makes a healthcare practice "autism friendly" according to key stakeholders (i.e., professionals, individuals with autism spectrum disorders, family members) using a modified three-round Delphi study.

Method: A list of statements about possible components of an "autism friendly" healthcare practice was compiled from a hospital-wide, multidisciplinary steering committee of the Autism Friendly Initiative at Boston Medical Center. In the first two rounds, participants scored 37 statements from 1-9 in terms of importance. Statements with low scores (i.e., bottom 50%) across all stakeholder groups were eliminated. In the third round, participants ranked statements from most important to least important. To date, 38 participants (26 professionals; 12 individuals with autism spectrum disorder and family members) responded to the final round of the survey, which consists of 16 statements.

Results/Conclusions: Themes that emerged from highly ranked statements include environmental/operational modifications and autism spectrum disorders-focused staff training. More research is needed to explore implementation of the findings of this study, as well as discordance between professionals and families/individuals with autism spectrum disorders about what makes a healthcare practice "autism friendly."

Smoking cessation in people with mild intellectual disabilities: A motivational approach

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Background: Smoking rates in people with mild intellectual disabilities are high, estimates of 74 percent have been found. However, little evidence-based interventions to promote smoking cessation among people with mild intellectual disabilities have been found. The aim of the current study was to develop and pilot test an intervention to increase motivation to stop smoking in people with mild intellectual disabilities.

Method: Alongside a staff training in Motivational Interviewing (MI), in cooperation with a certified MI-trainer, staff and people with mild intellectual disabilities, a motivational intervention was developed. The intervention was pilot tested with eleven clients with mild intellectual disabilities. Both qualitative and quantitative information regarding smoking rates and motivation to stop smoking was collected.

Results: Questionnaire results showed that clients increased in their perceived importance attached to stopping smoking. Furthermore, three clients stopped smoking and three clients decreased smoking. Interview results coloured the stories behind the quantitative results, highlighting clients perceived barriers to stopping smoking, such as negative life events and continuous high stress levels.

Conclusions: The current study shows that effective interventions for smoking cessation in people with mild intellectual disabilities must consist of multiple elements, following the client path and life. From stress reduction to motivation, to actual smoking behavior, ending with a flexible follow-up.

Determining frailty in people with intellectual disabilities during the COVID-19 pandemic

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Background: During the COVID-19 pandemic, the Clinical Frailty Scale (CFS) is used in guidelines for triaging in crisis situations. The CFS identifies frail individuals mainly based on performance of daily tasks. Individuals with intellectual disabilities experience lifelong dependence to varying degrees. Using the CFS for triage could potentially unjustifiably classify them as too frail and exclude them from Intensive Care treatment. We compared the classification of individuals with intellectual disabilities into different frailty categories based on the CFS and the well-investigated ID-Frailty Index, to determine suitability for evaluation during the COVID-19 pandemic.

Method: Participants with intellectual disabilities ($n=982$, ≥ 50 years) from the HA-ID study were classified into frailty categories according to the CFS and the ID-Frailty Index.

Results: Based on the CFS, 63.7% would be classified as moderately frail, while 92% were not moderately frail according to the ID-Frailty Index. Additionally, 20.3% would be classified as at least severely frail with CFS, while 74.9% were not severely frail according to the ID-Frailty Index. Overall, 730/982 (74.9%) would be incorrectly classified as too frail by the CFS.

Conclusions: The CFS is not suitable to evaluate frailty in individuals with intellectual disabilities, with potential dramatic consequences for triage and decision-making during the COVID-19 pandemic.

Recognition of mild intellectual disability in primary care

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Background: In the Netherlands, 1.1 million people have a mild form of intellectual disability. The prevalence of problems with health and well-being is higher in this group compared to the general population; in addition, they consult their general practitioner (GP) more often. To support them appropriately, it's important to recognize the presence of signals of mild intellectual disability. The aim of our research was to study whether GPs recognize and assess signals of mild intellectual disability.

Method: Using an existing panel of Dutch GPs, a sample of 281 GPs was recruited. Data were gathered by online self-report questionnaires. The study was conducted by Kantar, a well-known Dutch consulting company.

Results: GP's underestimate the proportion of people with mild intellectual disability in their own practice (4.4% vs. 6.4% mean estimated proportion in the Netherlands). Four out of ten GPs find it (very) difficult to recognize (signals of) mild intellectual disability. Screenings instruments for the assessment of mild intellectual disability are used by 4% of the GPs.

Conclusions: A mild intellectual disability is not always recognized in primary care. This might result in people with a mild form of intellectual disability not receiving appropriate care.

Cancer prevalence and treatment in Dutch individuals with and without intellectual disabilities

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Background: Individuals with intellectual disabilities are often diagnosed with cancer at a more advanced stage than the general population, and there are uncertainties about the true incidence of cancer among people with intellectual disabilities. Insight into cancer characteristics at diagnosis and subsequent cancer treatment in people with intellectual disabilities on a population level is lacking. Therefore, the aim of this study is to explore this knowledge gap in individuals with moderate or severe intellectual disabilities, compared to individuals without intellectual disabilities in the Netherlands.

Methods: Individuals with moderate/severe intellectual disabilities were identified in the Dutch chronic care database and linked with the National Cancer Registry to retrieve data on cancer and treatment, if any. A matched control group was generated from the general population.

Results: We present the diagnosed cancers and chosen treatment in adults with ID between 2015 and 2019. We specified by cancer type, sex and age group. We present statistically significant differences between individuals with and without intellectual disabilities.

Conclusions: This study is one of the first to provide an overview of cancer and treatment in individuals with and without intellectual disabilities based on national data. It provides the basis for further research to address potential disparities and to improve cancer care for people with intellectual disabilities.

Barriers to and facilitators of physical activity for adolescents with intellectual disabilities

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Background: Using the capability, opportunity, motivation, behaviour (COM-B) model (Michie et al., 2011), the aim is to develop a comprehensive understanding of the barriers to, and facilitators of physical activity (PA) for adolescents with intellectual disabilities.

Method: Purposive sampling recruited participants from three stakeholder groups: 1) adolescents with intellectual disabilities ($n = 6$), 2) parents/carers ($n = 12$), and 3) teachers ($n = 9$) in one UK region. A qualitative research design was implemented through focus group methodology. Topic guides were developed through COM-B constructs. Data was analysed using Braun and Clarkes' six phases of thematic analysis (2013). Generated themes were then deductively mapped across to the COM-B constructs.

Results: Participants placed importance upon PA for the development of physical, psychological, and social well-being during adolescence. However, various barriers to, and facilitators of PA were identified across all COM-B constructs.

Conclusions: This was the first study conducted using the COM-B model to investigate PA behaviour amongst adolescents with intellectual disabilities. The model provided a systematic method for the identification of a range of individual, interpersonal and environmental factors influencing PA. Subsequently, researchers can provide consideration for these barriers and facilitators when attempting to develop tailored, effective, and sustainable PA programmes within this population.

The impact of COVID-19 on the health of adults with intellectual impairment in the UK

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Background: People with intellectual impairment experience high levels of inequalities. We investigated the impact of COVID-19 on the health of people with intellectual impairment, controlling for demographic risk, socio-economic circumstances and pre-pandemic health levels.

Method: Data were drawn from two UK birth cohorts that surveyed their participants on the impact of COVID-19 in May 2020: the Millennium Cohort Study (20-year-old participants) and the British Cohort Survey (50-year-old participants). Health outcomes (COVID-19 infection, COVID-19 symptoms, self-reported physical health, mental health, health service use and impact on health behaviours) were compared between people with and without intellectual impairment, adjusting for gender and ethnicity. Those that differed were further adjusted for self-reported health pre-pandemic and socio-economic circumstances.

Results: Controlling for gender and ethnicity, poor health was reported less often by younger adults (RR: 0.44 95% CI 0.23, 0.86) and more often by older adults (RR: 1.99 95% CI 1.45, 2.73) with intellectual impairment compared to peers. Older adults were more likely to report fever and loss of taste/smell. Adjusting for pre-pandemic health and socio-economic circumstances, eliminated differences in the older cohort, but not in the younger one.

Conclusions: Findings largely suggest a socio-economic and age gradient of COVID-19 impacts on the health in intellectual impairment.

A tool for oral health data among people with intellectual disabilities: Valid, simple, feasible

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Background: Oral disease is pervasive across people with intellectual disabilities. A lack of robust data about oral health contributes to health disparities that people with intellectual disabilities face. This problem stems from routine exclusion from dental epidemiological research and the many barriers preventing oral data collection from being included in disability-centred research. Examples include cost, equipment, lack of inclusively trained dental researchers and acceptable non-invasive indices.

Method: In this presentation we share a new tool called the Oral Status Survey Tool (OSST) that we developed to enable oral data collection in Trinity College Dublin as part of the Intellectual Disability Supplement to The Irish Study on Ageing (IDS TILDA). The OSST can record a range of clinical oral features including tooth count; denture wear; occluding pairs of teeth and functional dentition; oral cleanliness; gum condition; cavities and oral pain.

Results/Conclusions: We share an overview of the tool's development, properties, training module and attributes, so attendees will be able to consider this tool for use in their own data collection protocols, whether that is for health surveys, local oral health needs assessment, or national dental service planning for people with intellectual disabilities.

Hypertension prevalence and control in adults with an intellectual disability: A systematic review

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Background: The aim of this study was to determine the prevalence and control of hypertension among adults with an intellectual disability.

Method: A systematic search of CINAHL, MEDLINE and PsycINFO databases was performed using the search strings for "Hypertension," "Intellectual disability," "Prevalence" and "Control." Two reviewers independently screened all titles and abstracts for relevance, while the third resolved conflicts. Subsequently, two reviewers conducted full-text screening, quality assessment and data extraction. Extracted data will be analysed using RevMan where data from included studies are homogenous. Other data will be summarised narratively. The complete search process is documented as per PRISMA guidelines.

Results: Of 2769 studies identified, 2, 412 were screened for title and abstract, with 55 subject to full-text review. Included studies will be presented in tabular format, including how hypertension was diagnosed in addition to prevalence and control of hypertension. Forest plots will be used as appropriate.

Conclusions: As a first in the field of intellectual disabilities, this systematic review provides a unique insight into prevalence and control of hypertension in adults with intellectual disabilities. This review has the potential to inform the planning and policy response to the global health concern of hypertension.

Anti-epileptics, psychotropic drugs and seizures in adults with epilepsy and intellectual disability

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Background: To explore the characteristics of participants with epilepsy and intellectual disability and the patterns of their medication use. To examine the association between seizure frequency and co-prescribed psychotropic medication with the potential to lower the seizure threshold.

Method: Data were drawn from Wave 3 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA). Psychotropic drugs were categorised for potential seizure threshold-lowering risk (low, moderate, high). Binary logistic regression was performed to identify factors associated with seizure frequency. Ethics approval was acquired from the Faculty of Health Sciences, Ethics Committee at Trinity College Dublin and all 138 service providers.

Results: Epilepsy prevalence was 35.8% (n=196), of which 57.7% reported a mental health condition. 59.5% of participants reported no seizure in the last year. Participants with seizure data classified as taking at least one moderate/high risk medication, were significantly less likely to experience a seizure compared to participants taking no potential seizure threshold-lowering medication. 76.2% of those taking 2+ potentially seizure threshold-lowering psychotropic medications reported no seizures in the last year.

Conclusions: Psychotropic medication recommended to be avoided or used with caution did not provoke increased seizure frequency in this cohort.

POSTER PRESENTATIONS

TRAIN-ID: A training programme on intellectual disability and health in Zambia and the Netherlands

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Background: Difficulties in accessing services and unmet healthcare needs for people with intellectual disabilities remains an inequity matter globally. Fieldworkers and care personnel without any medical background indicate their lack of knowledge to signal health needs and improve the health and well-being of people with intellectual disabilities. This study (TRAIN-ID) aims to reduce health inequity through the provision of a context-based training programme on healthcare needs and stigma for fieldworkers and care personnel in Zambia and the Netherlands.

Method: First, the content and structure of the training programme is developed based on literature, expert opinion, and local focus group discussions in Zambia and the Netherlands. Second, two pilot groups per country receive two separate training weeks with a six-month interval. The outcomes of the training programme will be studied using face-to-face interviews and surveys with a longitudinal aspect. Behavioral change of stakeholders will also be assessed using intervention mapping methodology throughout the study.

Results/Conclusions: The context, barriers and organisation of healthcare for people with intellectual disabilities varies in every country. With this study, TRAIN-ID aims to develop a model training programme that can be adapted to and implemented in different countries (low-, medium- and high-resource), systems, and settings.

Exploring the impact of intellectual and developmental disability on the stage of colorectal cancer at diagnosis among adults in Ontario

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Background: Stage is the most important predictor of cancer survival. However, there is no published research on the stage of colorectal cancer at diagnosis in adults with intellectual and developmental disability. The aim of this study is to explore the association between intellectual and developmental disability and the stage of colorectal cancer at diagnosis among adults in Ontario.

Method: This study will use Ontario health administrative databases linked to the Ontario Cancer Registry (OCR). The study will include adults aged 18 years and older in Ontario with a new diagnosis of colorectal cancer between 2007 and 2019. People with intellectual and developmental disability will be identified using an Ontario-specific algorithm based on health service use.

Results: The study is in progress. However, it is hypothesized that a larger proportion of adults with intellectual and developmental disability will be diagnosed with an advanced stage (IV) of colorectal cancer compared to adults without intellectual and developmental disability, and that women with intellectual and developmental disability will have a greater risk of an advanced stage at diagnosis relative to the general population, compared to men with intellectual and developmental disability.

Conclusions: This study will provide important information on the impact of intellectual and developmental disability on the stage of colorectal cancer at diagnosis, which can be used to direct public health interventions.

Impact of healthy ageing interventions for elders with intellectual and developmental disabilities

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Background: For the Decade of the Healthy Ageing, we conducted the first systematic review focused on the efficacy of healthy ageing interventions (e.g., cognitive, mental, and physical health) and their impact on the health status of older adults with intellectual and developmental disabilities.

Method: Searches carried out in the databases Web of Science, Scielo and PsycINFO retrieved 23 papers including prospective "healthy ageing" interventions designed for adults with intellectual and developmental disabilities. The papers were organised in thematic areas: 1) Physical activity and health nutrition (n=10), 2) Health education and health screening (n=6), 3) Social inclusion and community participation (n=3) and 4) Multi-components (n=4).

Results: Participants were 2,398 men and women with intellectual and developmental disabilities (age range between 18 and 86 years [mean age: 44.3 yrs.]). Most interventions led to increased physical activity and health knowledge in terms of healthy lifestyle behaviours and health screening, and improved nutrition and social inclusion.

However, the number of healthy ageing programs and participants was small and limited to developed countries, and these interventions were rarely replicated.

Conclusions: We recommend that more attention needs to be given to active health promotion with people with intellectual and developmental disabilities as a program practice among organizations and as a focal public policy among governments.

Longitudinal psychotropic medication patterns among former residents with intellectual disability in Ontario

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Background: In 2009, the final three institutions in Ontario were closed. Following these closures, the Facilities Initiative (FI) studies were conducted to evaluate health and mental health outcomes for individuals with intellectual and developmental disability (IDD; Condillac, Frijters, & Martin, 2012).

Method: This study was completed as a follow-up to the FI studies, and evaluated psychotropic medications following deinstitutionalization. The purpose of this study was to examine psychotropic medication changes over time in the community and to identify predictors associated with psychotropic medication usage. Participants were former residents with intellectual and developmental disabilities who had relocated from the final three institutions in Ontario ($N = 120$). Data was gathered across three points in time (F1 = last facility; C1 = 1st community; C2 = 2nd community). Proxy measures were collected (e.g., demographic variables, adaptive functioning, psychotropic medications, challenging behaviour, health status, and mental health status). A multilevel model was conducted to determine the changes in psychotropic medications over time and to identify predictors of psychotropic medication usage.

Result: Psychotropic medications decreased as individuals relocated to the community (Facility to community change = −0.389*; Within community change = −.261*). Improved cognitive performance was associated with more psychotropic medications (Estimate = −.132*). Worse health, pain, and the number of psychiatric diagnoses positively predicted psychotropic medications (Estimates = 0.639*; 0.512*, and 0.271*, respectively). The influence of the worse health variable changed as individuals relocated, as individuals with worse health received fewer medications in the community (Estimate = −.765*).

Conclusions: Health and mental health variables were the primary predictors of psychotropic medication usage, which emphasizes the importance of incorporating the biopsychosocial model when assessing and treating individuals with intellectual and developmental disorders. These results could be used to inform prescribing guidelines for individuals with intellectual and developmental disorders. Lastly, the decrease in psychotropic medications following relocation contributes to the research supporting the deinstitutionalization of individuals with intellectual and developmental disorders.

COVID-19 Predictors and course in people with intellectual and developmental disorders

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Background: The aim was to understand who among the service-connected adults with intellectual and developmental disorders in Pennsylvania was most likely to test positive with COVID-19, what characteristics were most associated with positivity, and what was the course of COVID-19 infection.

Method: Claims data over a 10-month period for health and health care utilization and all services utilization for service-connected adults with intellectual and developmental disorders in Pennsylvania were utilized to examine the experience of COVID-19.

Results: As compared to populations without identified with intellectual and developmental disorders, when COVID-19 infection was established findings confirmed both similarities and differences in age of onset and prior health characteristics of people with intellectual and developmental disorders.

Conclusions: As has been seen with other chronic conditions such as dementia, onset of COVID-19 was influenced by different risk factors and by earlier ages.

Diagnostic test set for osteoarthritis in people with an intellectual disability

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Background: Osteoarthritis is difficult to diagnose in people with intellectual disabilities. They have difficulties reporting pain, which is an important criterion for osteoarthritis. Aim of this study was to develop a diagnostic test set to diagnose osteoarthritis of the hip and knee in people with intellectual disabilities, based on tests used in the general population.

Method: Tests were based on the American College of Rheumatology criteria for osteoarthritis. A panel consisting of an osteoarthritis expert, a physician specialized in intellectual disabilities care, a movement scientist, and two physiotherapists discussed and proposed adaptations for use in people with intellectual disabilities.

Results: The proposed tests consist of 1) Physical examination; 2) Structural pain observation, including the Rotterdam Elderly Pain Observation Score and a self-report Faces Pain Scale; 3) Questionnaires to assess limitations in daily life: the Knee and Osteoarthritis Outcome Score (KOOS and HOOS) and the Animated Activity Questionnaire; (4) X-rays of both knees and hips.

Conclusions: We present the tests we composed to identify clinical and radiological aspects of osteoarthritis in people with intellectual disabilities. Next steps include feasibility and reliability assessment to provide clinicians with advice on how to diagnose hip and knee osteoarthritis in people with intellectual disabilities.

General health of young people with autism over time and its relationship to family circumstances

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Background: We aimed to quantify the extent to which personal characteristics, parental relationship and household income are associated with general health status in youth with autism with/without intellectual disabilities.

Method: We conducted random-effects ordered logistic regressions to determine the odds ratios (OR) with 95% confidence intervals (CI) of wave, age, sex, ethnicity, additional intellectual disabilities, parental/guardian relationship status and household income being associated with general health status in youth with autism, drawn from the National Longitudinal Transitions Study-2, with a follow-up period of 10 years and five waves of data.

Results: Across waves, only between 74.3%-69.9% had excellent/very good health (71.7%-58.8% in those with additional intellectual disabilities), but wave was not associated with general health status. Associations were for age OR=1.18 (1.04, 1.33), additional intellectual disabilities OR=1.56 (1.00, 2.44) and household income OR=0.61 (0.40, 0.94) at \$30,001-\$50,000, OR=0.44 (0.27, 0.72) at \$50,001-\$70,000, and OR=0.34 (0.20, 0.56) at \$70,001+. Sex, ethnicity and parental/guardian relationship status were not associated with general health status.

Conclusions: There was little change in general health status longitudinally across the transitional period. Youth with autism need health planning across this period given the low proportion with excellent/very good health, including consideration of their household circumstances.

Self-determination among people with mild intellectual disability and epilepsy

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Background: Self-determination is essential for subjective well-being and quality of life. Currently, there is a lack of knowledge with respect to the impact of epilepsy on self-determination in the lives of people with mild intellectual disability and epilepsy. Therefore, the aim of this study was to provide insight into the experiences of this population with respect to self-determination, and to explore the role of the environment in these experiences.

Method: Eight people with epilepsy and mild intellectual disability were interviewed using a semi-structured interview guide. This guide was used to explore the meaning of self-determination from the perspective of the participants and the impact of epilepsy on self-determination, operationalized by the three basic psychological needs of the self-determination theory: autonomy, relatedness and competence. The interviews were analyzed using a thematic analysis.

Results: The results of the interviews are currently being analyzed. The results and conclusions will be presented at the congress.

Conclusions: With this research, it is our goal to take a step towards a better understanding on self-determination among people with mild intellectual disability and epilepsy and provide information that might be valuable for the development of interventions and practices that enhance the wellbeing of this population.

General health in youth with intellectual disabilities and its relationship to family circumstances

Ewelina Rydzewska[1], Michael Fleming[1], Daniel Mackay[1], Genevieve Young-Southward[1], Jan Blacher[2], Yasamin Bolourian[2], Keith Widaman[2], Sally-Ann Cooper[1]

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Background: We aimed to quantify the extent to which personal characteristics, parental relationship and household income are associated with general health status in youth with intellectual disabilities with/without Down syndrome.

Method: We conducted random-effects ordered logistic regressions to determine the odds ratios (OR) with 95% confidence intervals (CI) of wave, age, sex, ethnicity, Down syndrome, parental/guardian relationship status and household income being associated with general health status in youth with intellectual disabilities, drawn from the National Longitudinal Transitions Study-2, with a follow-up period of 10 years and five waves of data.

Results: Contrary to our expectations, general health did not decline over the transitional period and did not differ between youth with and without Down syndrome. Higher income was associated with better health, significantly so over \$50 001 OR=0.559 (0.366–0.854). Poorer health was experienced by youth with Hispanic, Latino or Spanish ethnicity OR=1.790 (1.051–3.048). Female sex and parental relationship status were not associated with health status.

Conclusions: Young people with intellectual disabilities have bad health, and require support across all ages, including transition. Schools, teachers and staff in transitional services should be aware of the association between health and ethnicity and the stressful effects of low household income.

A literature review on the impact of nutrition on sleep in people with intellectual disabilities

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Background: People with intellectual disabilities are more likely to have sleep problems than people who do not have intellectual disabilities. Poor sleep can have negative impacts on an individual's physical and mental health, their quality of life, and poor sleep also negatively impacts their family or carers. Evidence from studies conducted in the general population has found that nutrients such as vitamin D, polyphenols, antioxidants and melatonin-rich foods may be beneficial for sleep. However, limited rigorous research is available on the impact of nutritional interventions to improve sleep in people with intellectual disabilities.

Method: An integrative systematic literature review was conducted on the impact of nutrition on sleep in people with intellectual disabilities. Literature was primarily sourced from searching the following databases; CINAHL, PsycINFO and SCOPUS. Following screening of papers (n=289), fourteen papers met the inclusion criteria.

Results: Themes related to nutrition and improved overall wellbeing, links to health comorbidities, use of nutritional supplements, specific foods and food fussiness.

Conclusions: Therefore, dietary patterns may be an important factor to improving the quality and quantity of sleep. However, the current literature does not allow valid and reliable conclusions regarding the benefit of improved nutrition on sleep in people with an intellectual disability.

Diet quality among people with intellectual disability and borderline intellectual functioning

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Background: Our aim was to assess diet quality among people with intellectual disability or borderline intellectual functioning who reside in residential facilities or receive day care.

Method: Diet quality, assessed with the Dutch Healthy Diet Food Frequency Questionnaire (DHD), was compared between participants and controls, using multiple regression analyses adjusted for age, sex, and body mass index (BMI). Potential correlates of diet quality were explored within the intellectual disability/borderline intellectual functioning group.

Results: A total of 151 people with intellectual disability/borderline intellectual functioning (35.1% women) with a mean age of 23.2 years ($SD = 7.9$) years and 169 controls completed the DHD. Mean diet quality was lower in people with intellectual disability/borderline intellectual functioning ($M = 80.9$) than in controls ($M = 111.2$) (mean adjusted difference -28.4; 95% CI: -32.3; -24.5; $p < 0.001$). Within the intellectual disability/borderline intellectual functioning group, participants with borderline intellectual functioning and those with mild intellectual disability had a lower diet quality and higher BMI than individuals with severe to profound intellectual disability. Being female was a predictor of better diet quality.

Conclusions: Overall, we found that diet quality was low in the sample of people with intellectual disability/borderline intellectual functioning. The main concern is excessive consumption of unhealthy products.

Implementing health assessments for adults with intellectual and developmental disabilities: A systematic review

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Background: Adults with intellectual and developmental disabilities experience health disparities, many of which are preventable by the provision of comprehensive primary care. Health assessments, in which a primary care provider systematically screens a patient for several health conditions, increases disease detection, health promotion, and preventive care in adults with intellectual and developmental disabilities, and can reduce the disparities experienced by this group. However, the uptake of health assessments remains low across countries, in spite of these benefits. This systematic review aims to describe barriers common across different settings, and identify areas for health professional education and/or health policy changes.

Method: We are conducting a systematic search of quantitative and qualitative studies identifying facilitators and barriers to implementation of health assessments for adults with intellectual and developmental disabilities. We are then inductively extracting the barriers and facilitators reported in each study. We then categorize each factor according to the constructs of existing implementation models: Consolidated Framework for implementation Research (CFIR), COM-B theory (capability, opportunity, and motivation – behaviour), and Theoretical Domains Framework (TDF).

Results: We are determining whether these barriers and facilitators are related to the individual (i.e., health professional) or system-wide factors. Individual factors could be addressed through continuing professional education for health professionals, and system-wide factors could be addressed through health policy changes at multiple health system levels.

Conclusions: By better understanding the barriers and facilitators to implementing annual health assessments across multiple countries, we can determine whether health professional education, policy change at the health system level, or some combination of interventions would be effective in increasing uptake of these assessments. The longer-term objective is to reduce the health disparities faced by

adults with intellectual and developmental disabilities through timely diagnosis and treatment of health conditions.

Exploring collaboration within the continuum of effectiveness research in people with intellectual disabilities

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Background: A strong evidence base for the effectiveness of interventions may reduce the health inequity seen in people with intellectual disabilities. However, evidence synthesis in this field has some challenges. For example, randomized controlled trials (RCTs) remain uncommon, and observational studies in which interventions are allocated during the course of usual treatment decisions are vulnerable for confounding and selection bias. Furthermore, RCTs that include heterogeneous samples of participants are of limited use to inform treatment decisions when effects vary across clinical subgroups. Individual participant data meta-analysis (IPD-MA) has the ability to reduce biases and allows exploration how participant-level covariates, such as aetiology or level of intellectual disability, modify intervention effects. This offers advantages over meta-analysis based on aggregated data. IPD-MAs are time consuming and require a team in which trialists and systematic reviewers collaborate. Luckily, recent innovations in online collaboration, crowd sourcing and automation of evidence synthesis offer potential to ensure timely and up to date answers to clinical questions. The research aim is to explore possibilities for collaboration between trialists, systematic reviewers, and methodologists to build, and maintain, an online platform for up to date IPD-MA in people with intellectual disabilities.

Methods: First, a working group will be tasked to identify trialists and systematic reviewers that are involved in intervention research in people with intellectual disabilities. Second, we will invite trialists, systematic reviewers, and methodologists to discuss possibilities for collaboration. Third, we will design an online platform and conduct an IPD-MA to test the functionality of the platform.

Conclusions: This initiative recognizes that RCTs, observational studies of interventions, and evidence synthesis are part of the same continuum of effectiveness research. Trialists and systematic reviewers need to collaborate to build a strong evidence base to inform daily treatment decisions that impact on the health of people with intellectual disabilities.

Screening instrument for dysphagia in intellectual disabilities: Development and first validation

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Background: People with intellectual disabilities (ID) are at high risk for dysphagia. Early screening for dysphagia is of essence to prevent severe health problems, like choking or pneumonia, and can contribute to improve quality of life. Therefore, we developed the Screening instrument for Dysphagia in ID (SD-ID) as easy and quick tool for daily caregivers to signal a risk for dysphagia.

Method: Development of SD-ID was based on currently used screening lists, literature and clinical experiences. The SD-ID is completed by caregivers. First validation was performed among 42 people with intellectual disabilities. SD-ID was compared to outcomes of examination by speech therapist using the Dysphagia Disorder Survey (DDS). Next, the SD-ID was used in an institutional setting for 1064 people with intellectual disabilities.

Results: Compared to the DDS, sensitivity and specificity of SD-ID was promising (>75% with cut-off score 3). Positive predictive value and negative predictive value were promising as well. More severe level of intellectual disabilities resulted in higher total scores on SD-VB. Results on item level guided optimization of the SD-ID. Conclusions SD-ID is a valid and straight forward screening tool for caregivers to screen for dysphagia in people with intellectual disabilities. This contributes to increased awareness and preventing dysphagia-related health problems.

Insight from electronic health records in the intellectual disabilities outpatient clinic

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Background: The Netherlands is the only country worldwide with a medical doctor specialized in intellectual disabilities: the ID-physician. This ID physician runs an outpatient clinic to which the general practitioner (GP) can refer patients with intellectual disabilities. Despite of increasing research on the medical care provided by ID physicians in care organizations and GP practices, the care provided by ID physicians in outpatient clinics has never been investigated at the patient level. This study is the first to provide more insight in the reasons why an ID physician is contacted by the GP, the diagnoses made, and additional diagnostics used in ID clinics.

Method: Every medical practice is obliged to use an electronic health record system. The system used in our ID outpatient clinic is developed to also extract data for use in scientific research. In this paper we consider referral reasons together with diagnostic codes (ICPC and ICD-10).

Results: We will provide a first insight in the extracted data, which consists of referral reasons and diagnoses made by the ID physician.

Conclusions: We expect that these analyses will enable us to improve medical care for people with intellectual disabilities and that they will allow us to improve the electronic health record input.

How does health professionals' communication with patients with intellectual disability impact health outcomes? A scoping review of reviews

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Background: Communicatively-vulnerable individuals, including people with intellectual disability, are individuals with inherent or circumstantial factors that create a decreased capacity to communicate verbally, nonverbally, or in writing. This study focuses on communication between health providers and such communicatively-vulnerable patients. The first aim is to map the existing research and list defined challenges to effective communication with vulnerable groups. A second aim is to identify strategies for accommodating differences in these patients' communication abilities, to improve health outcomes (e.g., survival or cure) or intermediate outcomes (e.g., access to care).

Method: Our team is completing a scoping review of reviews on patient-provider communication, with no limits on patient characteristics. Our literature search initially identified 8350 articles, and 5846 articles once removing duplicates. After title, abstract, and full-text screening, 238 reviews remained. This set was further refined by selecting reviews that examined patient-provider communication with at least one communicatively vulnerable group.

Results: We identified 92 reviews that examined communication between healthcare providers and a communicatively vulnerable group. While we found few articles specific to individuals with intellectual disability, challenges faced by other communicatively vulnerable groups are relevant. We will list the defined challenges and strategies for accommodating differences, with commentary regarding their application for individuals with intellectual disability.

Conclusions: By mapping existing research and identifying strategies for patient-provider communication, we hope to improve health outcomes for vulnerable patient groups, including those with intellectual disability. Our findings will identify areas for further research and contribute to reducing health disparities experienced by these groups.

Early recognition of swallowing difficulties in adults with intellectual disabilities: Development of a prediction model

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Background: To examine which clinical factors found in the regular care process predict swallowing difficulties in adults with intellectual disability.

Method: Participants were recruited among the population of adults with intellectual disability living in a large care organisation in the Netherlands. A random selection was made among people with diagnosed intellectual disability, aged over 18 years, and receiving medical care. People who were registered with the care organisation for less than two years were excluded. Data were collected retrospectively from patient files. In addition, a digital questionnaire was sent to the primary caregiver. Data were collected immediately after inclusion (T1) and after two years (T2). After T1, linear regression was performed to analyse which variables were associated with the outcome swallowing difficulties. Associated variables were analysed by multiple regression.

Results: At the conference, we will present initial results of the T1 analysis and analytical issues will be discussed.

Conclusions: Results of this study constitutes a first step in developing a validated multivariable prediction model of swallowing difficulties for adults with intellectual disabilities. In practice, this model will increase the attention to swallowing difficulties and therefore improve identifying early warning symptoms.

Environment scan on approaches to education of healthcare professionals in care of persons with intellectual and developmental disabilities

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Background: The aim was to identify approaches to educating healthcare professionals in care of persons with intellectual and developmental disabilities, as part of a grant for workforce improvement, the Partnering with Persons with Intellectual and Developmental Disabilities to Improve Health Outcomes (PATH-PWIDD) Program (Administration for Community Living).

Method: We are conducting an environmental scan, a systematic process to identify and categorize information from diverse sources and viewpoints on issues based upon judgments as well as facts to identify existing approaches to education of healthcare professionals about care of persons with intellectual and developmental disabilities. The scan includes two components: 1) analyzing existing healthcare literature (including curricula, guidelines, protocols, reports, competencies, etc.) focused on the healthcare professionals' interactions with and treatment of persons with intellectual and developmental disabilities; and 2) identifying and categorizing what key stakeholders: persons with intellectual and developmental disabilities; their family members; and healthcare professionals, educators and researchers in the field, view as critical elements in respecting the self-determination of persons with intellectual and developmental disabilities, competencies of healthcare professionals, improving education of healthcare professionals, improving care, and reducing health disparities. Data will be collected through a scoping review of literature and other sources, and outreach with key informants.

Results/Conclusions: We will present initial results on identified approaches to education of healthcare professionals with recommendations for improvement.

Correlates of physical activity in children and adolescents: A systematic review

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Background: The aim was to systematically review correlates of physical activity in children and adolescents with intellectual disabilities.
Method: The review was conducted in accordance with the PRISMA guidelines. Ovid Medline, Ovid Embase, Web of Science, ERIC, CINAHL and PsycINFO were searched between 1st January 1990 and 29th February 2020 to identify English-language studies which examined correlates of free-living physical activity in children (0–19 years) with intellectual disabilities. Study quality was assessed. Correlates were analysed using a narrative synthesis and classified using the socio-ecological model as intrapersonal, interpersonal, organisational, or environmental.
Results: Fifteen studies published between 2010 and 2019 met the inclusion criteria and were included in the review. Forty-eight individual correlates were identified. Studies were predominantly focused on intrapersonal level correlates. Of those correlates investigated in more than one study (n=6), having better motor development was positively associated with physical activity. Inconsistent results were found for age and cardiorespiratory fitness. Sex, percentage body fat and BMI were not correlated. No interpersonal, organisational or environmental level correlates were included in more than one study.
Conclusions: Further studies are necessary to unravel correlates and determinants, across all domains of the socioecological model, to improve health by increasing physical activity levels.

Prevalence rates of risk factors for chronic health conditions among Special Olympics athletes

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Background: Individuals with intellectual disabilities often experience high rates of risk factors for chronic health conditions. This purpose of this study was to determine the current prevalence of risk factors among Special Olympics (SO) athletes with intellectual disabilities who attended a Health Promotion screening in 2018 and 2019.
Method: In 2018 and 2019, over 33,000 Health Promotion screenings occurred globally for SO athletes. The rate of risk factors was assessed for bone mineral density (BMD), body mass index (BMI), blood pressure (BP), use of tobacco products, and exposure to second-hand smoke. Comparisons to the general population were also examined.
Results: Health Promotion data show high rates of risk factors, including 35% low bone density, 51% overweight or obese, 58% elevated or hypertensive BP reading, 6% use of tobacco products, and 35% exposure to second-hand smoke. Comparisons to the general population showed higher rates for these risk factors in the ID population.
Conclusions: High rates of risk factors for chronic health conditions may increase the chance for comorbidity. Findings indicate the need for improved access to health education and nutrition among this population and highlight the importance of regular health promotion programming.

Co-trainers with intellectual disabilities: Assessing nursing students' satisfaction

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Background: Active participation of people with intellectual disabilities as co-trainers is meant to improve healthcare students' knowledge and attitudes towards this vulnerable population. A resourceful group of people with intellectual disabilities was included as co-trainers for the initial training of nurses at the Geneva School of Health Sciences. People with intellectual disabilities were enrolled in lectures, workshops, seminars and practise teaching. The objective of the study was to assess students' satisfaction in their learning asking them if they were satisfied with the participation of people with intellectual disabilities and asking about their satisfaction level with this teaching method.
Method: Students' opinions were collected by means of paper-and-pencil satisfaction questionnaires distributed after the teaching sessions involving people with intellectual disabilities.
Results: The sample consisted in 63 senior BSc students. Among them, 93.6% considered the participation of co-trainers with disabilities to be excellent and very good; 6.4% consider it satisfying.
Conclusions: Active participation of people with intellectual disabilities in training shows satisfaction among senior nursing students. Further analyses would be required to assess the benefits of the program on students' knowledge and attitudes on care delivered to people with intellectual disabilities.

More evidence of difference: Easy English - Easy Read

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Background: This paper is a further analysis of Easy English and Easy Read from Australia and the UK in 2020. Are these differences and similarities the same as an earlier analysis from 2015-2016 presented at IASSIDD 2019?

Method: Two sets of publicly available documents were analysed from Australia (Easy English and Easy Read) and the UK (Easy Read) The content was on: 1) COVID-19, published from March - August 2020 and 2) other published content from 2020.

Results: Results replicate the findings from the earlier analysis. There appear to be identifiable, measurable and replicable differences between Easy English and Easy Read, including: Word count; Number of different words in a document; Length of sentence; Syllable length and Passive and active sentence count. There are also visual differences regarding formatting and image selection.

Conclusions: This paper reinforces the earlier, smaller study identifying many of the differences and some similarities between Easy English and Easy Read. Writers and end users need to know of and be aware of these differences. Researchers and policy writers need to also be aware that there is further evidence of this difference, and the impact on future development and research questions on Easy English and Easy Read.

Cancer treatment and treatment decision making in individuals with intellectual disabilities: Findings from a review

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Background: Current data shows that cancer in people with intellectual disabilities is often a common cause of death, rather than a (curable) disease. Cancer treatment experience in people with intellectual disabilities is limited, obstructing healthcare professionals to easily find experience or guidance in treatment decision making (TDM). This review aims to explore what is reported about cancer treatment and TDM in people with intellectual disabilities and cancer.

Methods: A scoping review of literature was conducted searching PubMed and EMBASE. Included literature was dually screened on title/abstract and full-text. Studies were included if they provided information on people with intellectual disabilities, cancer and subsequent treatment. Studies were textually coded for cancer characteristics, types of treatment, considerations and adaptations in treatment and TDM.

Results: Preliminary findings present 90 included articles (77 case studies/series). A genetic focus (n=30) and articles describing syndromic people with intellectual disabilities (n=64) were most predominant. Most mentioned cancer types were hematological (n=18), testicular (n=10) and other genito-urological (n=10). Thirteen articles discussed TDM, relating to legal (in)capacity (n=10). 28 articles mentioned treatment adaptation, of which 18 performed treatment reduction.

Conclusions: Cancer and its treatment in people with intellectual disabilities is a topic lacking specific and comprehensive research within scientific literature. There is little evidence available for clinicians involved in treating cancer in people with intellectual disabilities.

Comparing access to interventions between people with intellectual disabilities and the general population with COVID-19

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Background: People with intellectual disabilities may be disproportionally negatively impacted by COVID-19. A key concern is resource allocation, including admission to an intensive care unit (ICU). Factors in clinical decision-making include functional status and "overall look of a patient." This has implications for those with intellectual disabilities who may have lower baseline functional abilities, together with the risk of bias or discrimination influencing decisions.

Method: A sample of 506 patients with intellectual disabilities were matched on a 1:3 ratio with controls using data from the ISARIC4C ongoing prospective cohort study on patients admitted with COVID-19.

Results: People with intellectual disabilities were less likely to have "classic" COVID-19 symptoms but more likely to show altered consciousness/confusion. Significantly more people in the intellectual disabilities group required oxygen therapy at admission. Both groups experienced similar complications, but those with intellectual disabilities were more likely to experience seizures. Despite this people with intellectual disabilities were 50% less likely to be admitted to ICU and 40% less likely to receive ventilation.

Conclusions: People with intellectual disabilities may have greater symptom severity at admission. Access to interventions such as ICU and ventilation were less common in people with intellectual disabilities. The possible role of diagnostic overshadowing, discrimination and poor awareness of alternative symptom presentation could be contributing.

Track 3b: Mental Health/Challenging Behaviour Issues

PRESENTATIONS IN A SYMPOSIUM

Mental health in primary care

Mental healthcare for adults with intellectual disabilities: A scoping review in primary care publications

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Background: General practitioners (GPs) are increasingly confronted with patients with intellectual disabilities and mental health problems. Although, the mental healthcare provided to these patients in general is

considered to be insufficient, little is known about the mental healthcare provided by the GP. The aim of this scoping reviews is to provide an up-to-date literature overview on the care provided by GPs to patients with intellectual disabilities and mental health problems and to identify knowledge gaps and inform research, practice and policy about opportunities to improve care.

Method: PubMed, PsychINFO, Embase and grey literature were searched for publications concerning adults with intellectual disabilities, mental health problems and primary care. Selected publications were analysed both descriptively and thematically.

Results: One hundred publications met the inclusion criteria. Thematic analysis resulted in five overarching and relevant themes: roles of the GP, knowledge and experience, roles of caregivers, collaboration, and standardized approach.

Conclusions: GPs have an essential role in the care for patients with intellectual disabilities and mental health problems. Investments in education, evidenced-based knowledge and supportive tools are essential. Enhancing intellectual disability identification and development of interprofessional care models in close collaborations with policy makers and organizational managers can improve the quality of care for this patient group.

Mental healthcare for adults with intellectual disabilities: A retrospective cohort study in primary care data

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Background: Patients with mild intellectual disability suffer more mental health problems compared to patients without intellectual disability and often do not receive appropriate mental healthcare. The General Practitioner (GP) plays a pivotal role in this care. However, to date, there is limited fundamental research in primary care on the prevalence of mental health problems and the actual care provided by the GP to these patients and how this deviates from patients with no intellectual disability. The aim of this study is to fill this knowledge gap.

Method: A retrospective cohort study will be performed in a Dutch primary care database, covering 1.8 million listed patients and 4 years of care provision. In this database 11,887 patients with mild intellectual disability are identified by linking an administrative database of social services data.

Results: The results presented will focus on prevalence and nature of mental health problems in primary care, and the care provided in terms of consultations and medication prescriptions to patients with and without mild intellectual disabilities.

Conclusions: This study will give insight into the mental healthcare provided to patients with mild intellectual disabilities in primary care, and is a first step towards improving mental healthcare for patients with intellectual disabilities in general.

Mental healthcare for adults with intellectual disabilities: A detailed description of healthcare provided in primary care

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Background: Mental health problems are more common among people with intellectual disability (ID) but mental health care for this vulnerable group is insufficient. General Practitioners (GPs) are increasingly confronted with this patient group and experience various challenges in providing health care to them. In order to improve this, this study will describe the provided care for adults with intellectual disabilities consulting their GP for mental health problems compared with patients without intellectual disabilities.

Method: A retrospective cohort study using data of nine general practices with high data quality standards. Provided care included consultations, reasons for encounter, lab results, medication and referrals. All care is specifically linked with the mental health problem and therefore detailed information on given care is available.

Results: The most prevalent mental health problems and the total group will be described, and the care provided by the GPs of patients with intellectual disabilities will be compared to matched controls without intellectual disabilities.

Conclusions: This study will provide insight into the care provided by the GP linked with mental health problems and highlights the specific needs in health care for patients with intellectual disabilities and mental health problems. Detailed information highlights the specific needs in mental health care provided by the GP.

Mental healthcare for adults with intellectual disabilities: Urgent care within out-of-hours GP services

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Background: Patients with mild intellectual disabilities and mental health problems are more likely to request out-of-hours primary care than the general population. However, mental healthcare is insufficiently available for patients who require urgent but not acute psychosocial care. Incorporating a mental health nurse practitioner (MHNP) in out-of-hours general practitioner (GP) services may offer a solution to this problem. This research aims to identify common mental health problems presented to the MHNP and to evaluate this innovative care.

Method: Medical records of the MHNP consultations are collected and analyzed, during a nine-month pilot evaluation in three out-of-hours GP services throughout the Netherlands. Additionally, interviews with patients, GPs, triage nurses, and MHNPs experienced with this type of care provision are conducted.

Results: The results presented will focus on the nature of mental health problems and characteristics of the patients consulting the MHNP in GP services. Also, patients' and professionals' experiences regarding this healthcare provision will be discussed.

Conclusions: Findings provide insight into the needs and characteristics of people requesting out-of-hours primary mental healthcare. They will contribute to the realisation of adequate out-of-hours care for people with mental health problems, whether or not affected by the presence of an intellectual disability.

Mental Health and Intellectual Disability Initiative

Mental Health and Intellectual Disability Initiative in Youth (MHIDI-Y): A program evaluation

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Background: To assess service outcome of MHIDI-Y, an innovative specialist mental health service for young people who have intellectual disability and mental illness, embedded within a metropolitan mainstream tertiary area mental health service in Melbourne Australia.

Method: Individuals diagnosed with intellectual disability (Age: 12-23 years; male=73%, female=27%; *N*=67) were referred to MHIDI-Y with serious mental health difficulties or significant behavioural challenges for diagnostic assessment, intervention, and treatment through a multidisciplinary episode of care. Health of the Nation Outcome Scale for Adults (HoNOS) and the HoNOS for Child and Adolescents (HoNOS-CA) were utilised as outcome measures and completed at admission and discharge.

Results: Individuals admitted for an episode of care to MHIDI-Y demonstrated a 20% reduction in their HoNOS/HoNOS-CA scores from admission to discharge. Paired samples t-tests will be presented comparing means of the HoNOS outcome measures. Descriptive data (incl. clinical diagnoses) will also be presented.

Conclusions: Individuals who received services through MHIDI-Y showed improvement in their mental health status and reduced severity of symptoms at discharge. The provision of a specialist multidisciplinary mental health service to addresses the unique mental health needs of people with intellectual disability is an important step toward achieving more equitable healthcare for all clients.

Mental Health and Intellectual Disability Initiative in Adults (MHIDI-A) in Melbourne, Australia

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Background: To examine outcomes of innovative models of care within mainstream tertiary mental health services in Melbourne Australia, to improve mental health outcomes in adults with intellectual disability and thereby inform best-practice implementation of these specialist services.

Method: Individuals diagnosed with intellectual disability were referred to a specialist mental health service MHIDI-A (Age range: 16-74; male=65%, female=35%; *N*=110) with established or suspected mental illness for diagnostic clarification, allied health intervention, medication review, and/or capacity building. The Health of the Nation Outcome Scale for adults (HoNOS) and HoNOS for people with learning disabilities (HoNOS-LD) were completed at initial assessment and discharge for all clients to measure outcome of service provision. Outcomes will be compared with national HoNOS data.

Results: Outcome measures revealed that individuals who received services and support through MHIDI-A had a 40% reduction on scores from admission to discharge. Paired samples t-tests will be completed to compare means at initial assessment and discharge.

Conclusions: Individuals who were admitted to MHIDI-A for an episode of care demonstrated improvements over time, indicating a reduction in severity of symptoms. These clinical outcomes highlight the benefit of having a specialist multidisciplinary intellectual disability mental health service embedded within mainstream mental health programs.

Mental Health Intellectual Disability Initiatives (MHIDI) in Victoria, Australia: Models of care

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Background: To describe and compare the models of care of two innovative multidisciplinary services specialist intellectual disability mental health services: MHIDI-Youth (MHIDI-Y) and MHIDI-Adult (MHIDI-A) -each embedded within a major metropolitan mainstream mental health service (MHS).

Method: 1) Overview of public mental health service framework and paradigm of mainstream health care for people with intellectual disabilities in the state of Victoria, 2) Description of catchment populations and service characteristics of each host MHS, 3) Description of MHIDI models of care.

Results: Population of Victoria 6.4 million 1) Catchment Population/ Area: MHIDI-Y~ 385 000/102 km^2, MHIDI-A~970 000/2032 km^2; Area: MHIDIY~102 km^2 A~2031 km^2, 2) Multidisciplinary Teams: Psychiatrist, Psychiatry Registrar, Clinical Psychologist, Psychiatric Nurse, Occupational Therapist, Speech Pathologist, Social Worker, 3) Multiple and tailored service pathways, 4) Clients: Age Range: MHIDI-Y 12-25 years, MHIDI-A 16 years + 5.

Conclusions: The MHIDI services are a paradigm shift in the provision of specialist intellectual disabilities health/mental health services in

Victoria. The services have the same basic design and funding. Based on catchment population alone, MHIDI-Y receives 2.8 times more funding. Each MHIDI has developed service and clinical pathways based on the client population, the catchment demographics and geography, and resources.

Mental Health Intellectual Disability Initiative – Adult (MHIDI-A) in Australia: Clinical outcomes

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Background: To describe the clinical outcomes of Mental Health in Intellectual Disability Initiative – Adult (MHIDI-A), an innovative specialist intellectual disability mental health services within a major metropolitan mainstream tertiary mental health service in Melbourne Australia.

Method: Individuals diagnosed with intellectual disabilities referred to MHIDI-A (N=110 Age range: 16-74; male=65%, female=35%) with established or suspected mental illness for multidisciplinary psychiatric assessment and episode of care. The findings of a service audit will be described, including source of referral and demographics of participants, neurodevelopmental and psychiatric diagnoses, and services provided.

Results: 1) Referrals: External referrals 68%, Internal referrals: Inpatient 40% Community Mental Health 20%, Consultation Liaison 7%, Emergency 5%. 2) Psychiatric diagnoses at time of admission/discharge: No diagnosis (31%/16%), depressive disorder (17%/11%), bipolar disorder (10%/28%), antidepressant induced/exacerbated manic episode (0/40%), psychotic disorder (23%/29%); anxiety disorder (26%/19%), personality disorder (8%/9%), post-traumatic stress disorder (PTSD) (1%/5%) and catatonia 0%/5%.

Conclusions: Mental illnesses in people with intellectual disabilities are often not recognised or diagnosed, or are misdiagnosed, in both primary care and mainstream mental health services. In particular, mania is framed as a behaviour and/or anxiety disorder. Manic switch/exacerbation secondary to antidepressant treatment is common and unrecognised. PTSD and catatonia are underdiagnosed.

Evaluating specialized care

Evaluation of contextual support as a means to address challenging behavior

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Background: To gather information about contextual/environmental factors underlying challenging behavior that can be influenced, to optimize the Quality of Life of people with intellectual disability and severe challenging behavior residing in intensive care facilities.

Method: For four years we have followed 225 clients who receive intensive treatment and support in several care facilities in the Netherlands. We gathered information about the development (adaptive and cognitive functioning), medication and the provided professional support and treatment (through interviews). We have also repeatedly measured the Quality of Life (SMS).

Results: Through systematic evaluation, we have gathered a bulk of information on clients and their environment. We distinguished groups that show progress, stabilization and deterioration, and have gained insight into underlying personal factors. Age, presence of autism and adaptive functioning have the highest predictive value for progress. With regard to contextual factors, we found aspects of physical environment and stability in care providers to be the most important factors.

Conclusions: Through systematic evaluation of personal and contextual factors we gain more insight in what factors influence (challenging) behavior and quality of life of clients. We provide a model to continuously monitor relevant diagnostic and contextual information, to be able to determine changeable factors.

The influence of cognitive and adaptive skills on challenging behavior

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Background: The intensity of support for individuals with intellectual disability is related to the need for regulation of problematic, or challenging behavior. We have examined the influence of age, adaptive behavior and developmental age on severe and persistent challenging behavior. Outcomes should provide insight on where the focus of treatment should be.

Method: We have gathered information using different measures for intellectual functioning (WISC/WAIS, SON-R, BSID), the Vineland Adaptive Behavior Scales and DBC to gather information about the clients of five organisations that provide care for the group with the most intensive support needs in the Netherlands (Ipse de Bruggen, Hartekamp Groep, Ons Tweede Thuis and Cordaan). Through regression analyses, we have gained insight in the predictive value of these factors.

Results: There is a strong relation between challenging behavior and adaptive functioning and no relation between developmental age and challenging behavior. Three subdomains show significant relations, e.g., self-absorbed behavior (adaptive functioning and age), social relating (adaptive functioning), communication/anxiety (age). Different subdomains of the Vineland provide not more information than the total adaptive behavior score.

Conclusions: Severe and persistent challenging behavior seems to have a strong relationship with general adaptive functioning and not with cognitive functioning.

Unlimited Surroundings: A scoping review on supportive architecture and care-homes

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Background: A scoping review was carried out to systematically map the available literature on the impact of the physical environment on health, behavior and quality of life in people with disabilities in long-term care.

Method: Twelve scientific databases were searched by keyword combinations, supplemented by a field consultation. After systematic screening of 3095 documents according to PRISMA, 276 documents were included and analysed. The analysis followed a factor matrix which distinguished the categories: document types, disabilities, design components and outcomes.

Results: Forty-two literature reviews, 176 studies, 10 dissertations, 37 descriptive documents and 11 books/chapters were found. Most documents concern people with psychogeriatric disorders. There is limited research on people with somatic, physical, sensory or intellectual disabilities or mental disorder. In total, 26 design components and 19 outcome clusters concerning health, behavior and quality of life could be identified. The largest number of studies focus on housing concepts. Design components are mostly investigated in groups of people with psychogeriatric disorders.

Conclusions: In long-term care, the knowledge of Evidence Based Design criteria is limited. More empirical and longitudinal research on people with intellectual and mental disabilities is needed to effectively contribute to design and planning of future long-term care homes.

Deprescribing and overuse of psychotropics

Challenges to de-prescribe psychotropics in people with intellectual disability: The medical view

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Background: A significant proportion of adults with intellectual disability are prescribed off-licence antipsychotics in the absence of a psychiatric illness. The National Health Service in England launched an initiative in 2016, “Stopping over-medication of people with an intellectual disability, autism or both” (STOMP), to address this major public health concern.

Methods: An online questionnaire was sent to all UK psychiatrists working in the field of intellectual disability (estimated 225) to gain feedback on their experiences of STOMP.

Results: Half of the 88 respondents stated they started withdrawing antipsychotics over five years ago. 52.3% said they are less likely to initiate an antipsychotic since the STOMP launch. However, since then, 46.6% are prescribing other classes of psychotropic medication instead of antipsychotics for challenging behaviours, most frequently antidepressants. Complete antipsychotic discontinuation in over 50% patients was achieved by only 4.5% of respondents; 11.4% reported deterioration in challenging behaviours in over 50% of patients on withdrawal and 11.4% reported no deterioration. Family and paid carers' concern, lack of multi-agency and multidisciplinary input and unavailability of non-medical psychosocial intervention are key reported factors hampering the withdrawal attempt implications.

Conclusions: There is an urgent need to develop international guidelines for systematic psychotropic drug reviews and withdrawal.

Psychotropic and side effects of individuals with intellectual and developmental disabilities

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Background: Aim of the current study was to examine rates of medication side effects among individuals with intellectual and developmental disabilities staying in a specialized respite centre due to behavioural health crises.

Methods: Psychotropic side effects of 71 adults with disabilities identified by nurses who administered the Matson Evaluation of Drug Side Effects (MEDS) screen to crisis admits, a psychometrically established psychotropic medication side effects screen developed for use with people with disabilities. Data reviewed were routinely gathered, deidentified.

Results: Average age was 28 years, and 56% male. All individuals were taking at least one psychotropic, while 79% used three or more. The average number of psychotropics used was 3.94. Antipsychotics were the most commonly prescribed for 85%; 49% of whom were not reported to have psychosis. Though the overall number of psychotropics did not correlate with MEDS scores, the average scale scores for all participants was high in contrast to prior studies of people with disabilities not taking psychotropics. Central nervous system side effects were the most commonly reported.

Conclusions: In the present study, data for individuals experiencing a crisis were reviewed and indicated high rates of psychotropic polypharmacy and side effects rates. Future systematic prospective study of this topic is needed.

Optimising psychotropic prescribing by enhancing stakeholder collaboration: Theory to practice

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Background: Achieving the best use of psychotropic medications requires collaboration between multiple different stakeholders. There is a need to further embed patient and carer experience and views into shaping clinical care.
Methods: 1) Qualitative data were collected in focus groups (14 psychiatrists) and individual semi-structured interviews (38 people with intellectual disability, paid carers, and family carers) and analysed with thematic analysis to identify influences on achieving collaborative medication decisions; 2) 79 people with intellectual disability receiving care from community psychiatry teams were recruited to a feasibility study of a structured medication review tool designed to enhance the patient and carer voice in medication discussions and decisions.
Results: 1) Relationships between different stakeholders and the dynamics within a medical consultation emerged as key influences on the quality of medication decision-making; 2) A structured form of medication review, delivered in the context of routine clinic appointments, is feasible in UK settings and has potential to address some of the relational barriers to collaboration and enhance medication-related communication between stakeholders.
Conclusions: Understanding the positioning and perspectives of different stakeholders in medication discussions and decisions can help in the design and delivery of interventions to enhance collaboration and achieve true medication optimisation.

Treatment resistance and psychiatric diagnoses of patients presenting with challenging behaviour

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Background: Diagnostic confusion has been noted in usual clinical care settings for people with intellectual and developmental disabilities and significant behavioural and emotional challenges. We examined this in patients for whom current treatment was ineffective who were also treated with large numbers of psychotropics.
Method: A retrospective review of findings for 50 individuals seen in a specialized multidisciplinary evaluation clinic was conducted. Diagnoses at referral were contrasted with those arrived at by the full comprehensive multidisciplinary evaluations.
Results: The multidisciplinary team evaluation yielded more than two times the rate of anxiety disorders, more Post Traumatic Stress Disorder (PTSD) and less bipolar disorder, as well as a lower rate of psychotic disorders. Individuals received high rates of polypharmacy (averaging five medications per person) and had multiple medical comorbidities.
Conclusions: More prospective investigations of the role of diagnostic confusion in treatment failures and in polypharmacy are needed.

Aggressive behaviour in developmental disorders

Physical environmental effects on aggression in children with and without developmental disorders

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Background: Our research aims to explore the associations between physical environmental aspects and aggression in children with and without neurodevelopmental disorders.
Method: We have conducted a systematic review, adhering to PRISMA guidelines (Moher et al., 2009) that examines physical environmental influences on childhood aggression (ages 0 to 18). We included observational, psychometrically validated, and self-report measures of aggression as our primary outcome(s). We included environmental measures that assessed singular aspects of the child's immediate physical environment. From a total 170 retrieved studies for full text screening, 54 were included in this review.
Results: The results of our review provide evidence for the aggression-reducing influence of greenspace exposure, rurality, music and interior design features. Inversely, environmental stimuli which were associated with increased aggression included elevated concentrations of air pollution, humidity, traffic noise, spatial density and urbanicity.
Conclusions: Elucidating the associations between physical environmental aspects and childhood aggression, provides critical information to help identify and disentangle the complex relationship between environment and aggressive behaviour. The identification of these environmental features has far reaching implications and will be of interest to a wide range of stakeholders, including city planners, communities, public health professions, clinicians, primary caregivers and special education policy makers.

The minimal clinically important difference of the Aberrant Behaviour Checklist–Irritability

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Background: We estimated the minimal clinically important difference (MCID) for the Aberrant Behaviour Checklist–Irritability (ABC-I).
Method: We conducted a literature search to identify randomised clinical trials in the field of intellectual disabilities that have used the ABC-I subscale. For the distribution-based approach, relevant data from the clinical trials were extracted for meta-analyses. The anchor-based approach involved conducting three online workshops with stakeholders to review case studies based on scores of the ABC-I subscale that have been collected as part of a large clinical trial. Findings from the literature data extraction and stakeholder workshops were synthesised.

Results: Various values were calculated for the MCID on the ABC-I subscale. Having applied the distribution-based approach onto the data extracted from the literature, the MCID values were between 0.49 and 4.44. However, the stakeholders reported a much larger MCID, between 6.6 and 16.6.

Conclusions: The findings from this research study are significant as this is the first time the MCID has been estimated for the ABC-I subscale. The MCID values estimated can be used by trial investigators to base the sample sizes of future clinical trials and are able to identify the smallest important change for people with learning disabilities presenting irritability and aggression.

Complex interventions: What works, for whom, and in what circumstances? A rapid realist review

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Background: Aggression in adults with learning disability is common and while some current interventions demonstrate efficacy, none have managed to reduce aggression while improving quality of life in adults with learning disability in routine care. This review aims to determine why, for whom, and in what circumstances, complex interventions work for aggression in individuals with mental health difficulties.

Methods: This review follows established realist standards. We developed search terms and searched for information across six databases. We identified records for inclusion based on eligibility criteria. We extracted data, which we are presenting as context-mechanism-outcome configurations and initial programme theories. These will be refined through discussions with stakeholders, culminating in a final programme theory which will be reported at the Congress.

Results: 59 records were selected for review (this may change due to the iterative nature of realist methodology). Samples include individuals across the age range in inpatient and community settings with conditions like autism spectrum disorders, dementia and learning disability. Examples of emerging initial theories include altering physical/social environments, engaging service users/staff and adapting interventions based on individuals' needs.

Conclusions: The final programme theory will inform the development of a personalised intervention for adults with LD who display aggression. Prospero registration: CRD42020203055.

An overview of mental health interventions for people with intellectual disabilities in Singapore

Adult neurodevelopmental services: A clinical profile at a Singapore psychiatric hospital

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Background: The Adult Neurodevelopmental Service (ANDS) in Singapore is the first service in South-East Asia for adults with intellectual disabilities and/or autism spectrum disorder. This study compared the sociodemographic characteristics and clinical needs of this population.

Method: Initial assessments conducted from 2015 to 2016 were retrospectively reviewed for this descriptive study. A total of 272 patients were included in the study.

Results: Adults with intellectual disabilities comprised the largest percentage, followed by those with autism spectrum disorder, and then those with co-occurring autism spectrum disorder and intellectual disabilities. The autism spectrum disorder subgroup had the highest proportion of individuals with employment, postsecondary school education, functional capabilities, and a psychiatric disorder. In comparison, adults with only intellectual disabilities and adults with co-occurring autism spectrum disorder and intellectual disabilities shared similar lower levels of education and employment, and had a higher proportion of individuals with epilepsy and aggressive behavior.

Conclusions: Adults with autism spectrum disorder in Singapore have a unique social profile with different clinical needs compared to adults with only intellectual disabilities or to adults with co-occurring autism spectrum disorder and intellectual disabilities. Adults with only intellectual disabilities and those with co-occurring autism spectrum disorder share many same social characteristics and high clinical needs. The analysis of these profiles will be useful in developing services that better meet the needs of this population.

Integration of care for adults with intellectual disability in Singapore

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Background: A specialized Mental Health Service for adult persons with intellectual disability was started by the Institute of Mental Health in Singapore in 2012 to better cater for the needs in this population. It expanded beyond the usual outpatient and inpatient services to various outreach initiatives in recent years.

Method: Collaborative work with social sector agencies (SSAs) was an integral part of the care process, and joint initiatives with the Ministry of Social and Family Development, as well as key SSAs such as the Tsao Foundation, were rolled out subsequently to enhance the capabilities for the whole sector.

Results/Conclusions: This presentation aims to detail the work that has been done in this area, with improvements noted in both clinical and training outcomes through the joint efforts.

Exploring the experiences of stakeholders of the Adult Neurodevelopmental Service in Singapore

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Background: Mental health problems of people with intellectual disabilities can negatively affect the willingness of healthcare professionals to work with them and their family carers to support them.
Method: Five studies used a qualitative approach to explore the experiences of mental health professionals (MHPs) working with this population as well as the experiences of family carers and service users about the specialist mental health service and their mental health experiences in Singapore.
Results: Mainstream MHPs reported feelings of uncertainty working with people with intellectual disabilities and required additional training to increase their confidence to manage their mental health needs. Specialist MHPs reported initial fears when starting out and became more confidence working with this population over time. Family carers found it challenging to manage the mental health problems of their relatives and were satisfied with the specialist mental health service. Both outpatient and inpatient service users desired increased choice and autonomy over their lives.
Conclusions: These findings provide an increased understanding of the lived experiences of different stakeholders and the impact of the culture of Singapore on the provision of mental health services and outcomes of people with intellectual disabilities. Recommendations are made for service delivery, improving clinical practice and staff competency.

Peer influence and social cognition

A serious game design model and the social validity of the serious game "You & I" for adults with mild to or borderline intellectual disabilities

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Background: Persons with mild to borderline intellectual disabilities have reduced mentalizing abilities, which leads to difficulties in stress regulation. A promising method to improve abstract skills like mentalizing abilities can be serious gaming. However, developing a serious game for people with mild to borderline intellectual disabilities is also challenging, because of their wishes and needs. The aim is to present a model for the development of such a serious game and examine the social validity of the game "You & I."
Method: For the model a literature search was conducted, and the co-creation process was analyzed. The social validity of "You & I" was examined using the Social Validity Scale ($N=159$; age 19 to 67).
Results: Key elements were found relevant for developing a serious game for people with mild intellectual disabilities or borderline intellectual functioning. The social validity was high especially on the scales of usefulness and pleasantness.
Conclusions: The high social validity of the serious game "You & I" indicates that the game matches largely with the expectations of persons with mild intellectual disabilities or borderline intellectual functioning. Co-creation probably contributes to this high social validity. The key elements translated in a game design model can be used during the co-creation process of future serious games aiming at teaching abstract skills in this population.

Susceptibility to peer influence in adolescents with a mild-to-borderline intellectual disability

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Background: Adolescents with a mild-to-borderline intellectual disability may show more risk taking under peer influence than typically developing adolescents. The current study aimed to explain *why* adolescents with mild-to-borderline intellectual disability are particularly susceptible to peer influence, and therefore examined three potential factors: inhibition, Theory of Mind (ToM) and a negative interpretation bias. *Method* We assessed 163 adolescents (111 with a mild-to-borderline intellectual disability, 52 typically developing; 14–19 years; 63.0% boys) on all constructs using a multi-method approach with experimental tasks, self- and/or teacher-reports.
Results: Group comparisons revealed that adolescents with and without mild-to-borderline intellectual disability were highly similar: they did not differ in their susceptibility to peer influence, inhibition and negative interpretations, regardless of measurement method. On two of the four ToM instruments, adolescents with mild-to-borderline intellectual disability had weaker ToM than typically developing adolescents. They also reported less risk-taking than typically developing adolescents. A structural equation model within adolescents with mild-to-borderline intellectual disability showed that inhibition, ToM and negative interpretation bias were not related to susceptibility to peer influence.
Conclusions: Adolescents with mild-to-borderline intellectual disability are susceptible to peer influence, but not more so than typically developing adolescents. Their susceptibility is not related to inhibition, ToM and negative interpretation bias. We discuss this conclusion in light of earlier research as well as implications.

Improving resistance to influence in adolescents with mild intellectual disability: Adaptation of the PEER-DM curriculum

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Background: Adolescents with mild intellectual disability or borderline intellectual functioning are highly susceptible to peer influence. Khemka and Hickson (2013) developed the PEER-DM curriculum to help adolescents with developmental disabilities improve their social decision-making and resistance to negative peer influence. We will present our translated and adapted version of the PEER-DM.

Method: In collaboration with Khemka & Hickson, we translated and adapted the PEER-DM curriculum for the Dutch context. We asked focus groups of adolescents and school psychologists to help us create relevant vignettes to practice with.

Results: Based on the focus groups we developed new vignettes relevant to the Dutch context. Based on recent literature, we included video vignettes and two additional sessions to the curriculum thereby decreasing the distance between training and real-world situations. In addition, we included role-plays with the trainers and a training actor and focus on further consolidating the newly learned skills further by asking the group to create a video blog about their experience during the curriculum.

Conclusions: In this project we created an updated version of the PEER-DM curriculum that is suitable to the Dutch context, and which will be tested in an upcoming pilot study at a practical vocational school.

Is boys' and girls' autistic behavior development influenced by their preferred peers?

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Background: Students with autism spectrum disorder may experience less peer influence due to their difficulties in theory of mind. We examined the extent to which the level of autistic behavior among the preferred peers in special needs schools influences the development of students' individual autistic behavior.

Method: Longitudinal data of 330 students with high levels of autistic behavior and low levels of adaptive skills attending special needs schools were analyzed. Teachers reported on the social networks and autistic behavior of all students within school at the beginning and end of a school year. Future individual autistic behavior (T2) was predicted by T1-mean autistic behavior among those peers who were highly liked by the students of interest, controlling for their T1-individual autistic behavior (Kindermann, 2016).

Results: Multilevel analyses indicated no significant effect of preferred peers' levels of autistic behavior on individual future autistic behavior. However, interaction effects showed that girls were more susceptible to peer influence than boys.

Conclusions: Implications for understanding autistic behavior development and the role of theory of mind and gender in peer influence will be discussed. Potential ways to support individuals with ASD in their peer context will be proposed.

WORKSHOPS

Stress detection in people with intellectual disabilities

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Description: Challenging behavior and related stress in people with intellectual disabilities is a persistent problem. It has negative consequences for the quality of life, and it increases drop-out of care professionals. Early notification of stress via smart wearables enables caregivers to better respond to client needs, thereby reducing the number of incidents against significant cost savings. The workshop demonstrates real-time stress detection with the HUME, the emotion artificial intelligence platform of Mentech. HUME converts physiological features measured with wearables, such as skin conductance and heart rate, into stress levels via trained artificial intelligence models. We will explain the methodology of stress detection and how we train models with labelled physiological data from a control group of healthy subjects, performed in a reference setting in which emotions are prompted.

Contribution: During the demonstration, we expose participants to Virtual Reality content to prompt stress reactions. The induced stress levels are visualized via a dashboard. The demonstration provides insight in the potential of stress detection with wearables. It will show that HUME is an accurate instrument to notify caregivers about stress development. It will also demonstrate the potential to use HUME to measure the effect of interventions, for instance, to taper off the need for medication (psychopharmaceuticals).

ORAL PRESENTATIONS

Autistic adults and adults with intellectual disabilities who set fires: A systematic review

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Background: The purpose of this review was to systematically examine and synthesise existing research to determine what is known about autistic adults and adults with intellectual disabilities who set fires.

Method: PsychINFO, PsychARTICLES, Medline, CINAHL Plus with Full Text, Criminal Justice Abstracts, SCOPUS, Open Grey and the University of Kent arson library were searched for articles. Ancestry searches were conducted. The methodological quality of studies was assessed using the Mixed Methods Appraisal Tool.

Results: Searches resulted in 100 articles that met the specific inclusion criteria. Findings indicated that autistic adults and adults with intellectual disabilities share some characteristics with other adults who set fires (e.g., demographic features, aggression, impulsivity, maladaptive coping strategies). They also face additional challenges (e.g., communication difficulties, a lack of support, lower self-esteem).
Conclusions: Evidence suggests fire-setting is an issue for a minority of autistic adults and adults with intellectual disabilities. However, current research is generally of poor methodological quality, limiting our ability to understand the unique characteristics and treatment needs of this population. Nevertheless, there is tentative evidence that they face additional challenges, which has implications for assessment, formulation and treatment, inclusive of risk assessment.

Informant-reported cognitive decline, dementia and depression in adults with intellectual disability

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Background: The IQCODE (informant questionnaire on cognitive decline in the elderly) is an informant questionnaire that assesses changes in functional ability in different domains. The current study aims to examine if the IQCODE is associated with diagnosis of dementia, as well as depressive symptoms and limitations in activities of daily living (ADL's), in a longitudinal study of adults with intellectual disability.
Method: Data from Wave 3 and Wave 4 of IDS-TILDA (Intellectual Disability supplement to the Irish Longitudinal Study on Ageing) will be analysed. Depressive symptoms were assessed using the Glasgow depression scale. A representative sample of participants aged 40 years and over were assessed at Waves 3 and 4. Data were excluded where informants had known participants for less than two years. This analysis was pre-registered (https://osf.io/n8gbh/).
Results: Hypotheses tested are: 1) IQCODE scores will have comparable cut-off scores for dementia as in the general population, 2) IQCODE scores at Wave 4 will be significantly associated with depressive symptoms at Wave 3, and 3) IQCODE scores will be significantly associated with ADL limitations.
Conclusions: This research adds to understanding the utility of the IQCODE in tracking cognitive and functional decline over time in people with intellectual disability.

Staff training in positive behaviour support in the Netherlands: A cluster controlled trial

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Background: Positive Behaviour Support (PBS) is effective in reducing challenging behaviours in adults with intellectual disabilities. Currently, however, PBS is not offered to individuals with intellectual disabilities and challenging behaviours in the Netherlands. With this study, we examined the effectiveness of a newly developed Dutch PBS training for staff for reducing challenging behaviours of adults with intellectual disabilities.
Method: We used a multi-centre cluster control design and included 26 residential group homes which were allocated to the intervention condition (n = 14) or treatment as usual (n = 12). The primary outcome measure was the Irritability subscale of the Aberrant Behavior Checklist. Data will be analysed using longitudinal, multilevel analyses.
Results: After a long and difficult period of data collection, we collected data from 174 staff members and 123 adults with intellectual disabilities and challenging behaviours, including individuals with mild (n = 22), moderate (n = 43), severe (n = 28) and profound (n = 30) levels of intellectual disability. Results regarding the effectiveness of the intervention will be presented at the conference.
Conclusions: We will present the clinical implications of our study and offer suggestions for future studies.

The firesetting offence chain for adults with intellectual and other developmental disabilities

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Background: The aims of the research are to: 1) validate Barnoux et al.'s (2015) and Tyler et al.'s (2014) micro-level theories of adult firesetting with a sample of adults with intellectual and developmental disabilities who have set fires; and 2) to offer a unified descriptive model of the offence chain for adults with intellectual and other developmental disabilities who set fires.
Method: Thirteen adults in England with intellectual and other developmental disabilities were interviewed about the affective, cognitive, behavioural, and contextual factors leading up to and surrounding a recorded firesetting incident. Offence account interviews were analysed using a Grounded Theory approach.
Results: The resulting model consists of four main phases: 1) background, 2) early adulthood, 3) pre-offence period, and 4) offence, and post-offence period. The model accounts for unique precursors to firesetting within this population, including mental health deterioration, poor problem solving and new motivations for firesetting.
Conclusions: The theoretical model seeks to explain the contributing factors leading to a single incident of firesetting for adults with intellectual and other developmental disabilities. The findings provide

researchers and practitioners with a useful resource to inform assessment and treatment practice, as well as a theoretical grounding in which to base future research.

Assessment and treatment of PTSD in people with severe to moderate intellectual and developmental disabilities: Two pilot studies

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Background: People with intellectual and developmental disabilities are at an increased risk for developing Post-Traumatic Stress Syndrome (PTSD.) However, little is known about its manifestation and treatment in people with severe to moderate intellectual and developmental disabilities. As in children with a similar developmental level (<6 years), PTSD is expected to manifest mainly in (challenging) behaviour. This is often the main reason for seeking help. PTSD assessments are needed in order to identify PTSD in a timely way and to provide treatment. In two pilot studies, PTSD assessment and treatment were investigated.

Methods: In the first study a trauma interview (DITS-ID) was adapted for adults with severe to moderate intellectual and developmental disabilities based on clinical experiences and literature. To determine its content and convergent validity, the KJTS3-6 (PTSD screen) and ABC (challenging behaviour screen) were administered. Content validity was also investigated by comparing proxy scores of individuals with and without a PTSD classification. In the second study, the effectiveness of EMDR on PTSD symptoms (DITS-ID) and challenging behaviour (BPI) was investigated in a multiple baseline design study.

Results: Results will be presented at the conference.

Conclusions: The two pilot studies are part of a project aiming to improve recognition and treatment of PTSD in people with severe to moderate intellectual and developmental disabilities. After the pilot studies, the findings will be investigated more comprehensively in larger groups.

Setting up a new team of support staff for people with mild intellectual disabilities and severe challenging behaviour

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Background: So far, studies about teams of staff supporting people with intellectual disabilities have focused on team performance of existing teams. This study aims to gain insight into the factors that are most important in the *process* of setting up a *new* team of support staff working with service users with mild intellectual disabilities or borderline intellectual functioning and severe challenging behaviour.

Method: Three participant groups (i.e., service users, direct support staff, and people providing organizational support) participated in a concept mapping procedure. First, statements about what is particularly important when setting up a new team of support staff for people with mild intellectual disabilities or borderline intellectual functioning and severe challenging behaviour were collected by individual interviews (service users) and focus groups (direct support staff and those providing organizational support). Next, participants were invited to cluster and prioritize the statements. Based on these data, concept maps were computed and interpreted by an expert group.

Results: Results will be available and shared during the IASSIDD conference.

Conclusions: With this study, we intend to identify essential factors when setting up a new team of support staff for people with mild intellectual disabilities or borderline intellectual functioning and severe challenging behaviour that may help disability service organizations provide an environment matching service users' needs.

Opinions of people with intellectual disabilities on measuring challenging behaviour/psychotropic drug effects: Delphi study

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Background: Focus groups of clients and parents investigated domains of quality of life and functioning concerning targets for treatment of challenging behaviour (CB), the role of psychotropic drugs (PD) and the best way to measure the treatment effects on the selected issues.

Method: Focus groups discussed domains of well-being and the role/effects of PD-use in management of CB. Focus groups assessed existing outcome measures, to determine how best to measure the severity of CB and effects of PD in treatment of CB. The Delphi-method was used, in which, through several survey and feedback rounds, consensus was achieved among focus group members. The Appropriateness Method by the RAND Corporation/University of California at Los Angeles is used to analyze data.

Results: Selected subjects were: CB, (side) effects of PD, quality of life, daily functioning and caregiver burden. So far, selected outcome measures were: two behavior scales, two side effects scales and three health-related quality of life scales. Final set of instruments will be presented.

Conclusions: Clients and parents reached consensus on subjects, domains and a set of outcome measures for treatment targets of CB. We will make recommendations towards the field of intellectual disability on preferred outcome measures. Final conclusions will be presented.

Problem behaviour, psychotropic drug prescription and coercive measures: How do they relate?

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Background: Problem behaviour is frequent in people with intellectual disability. Although often undesirable, psychotropic drug (PD) prescriptions and coercive measures were used as an intervention in managing problem behaviour. We aimed to study the relationship between symptoms of problem behaviour, PD prescription and coercive measures in people with intellectual disabilities.

Method: In this cross-sectional study, data of 40 residential facilities of six organizations providing care for people with intellectual disabilities in the Netherlands were used. Data on PD prescriptions and standardized questionnaires were used to assess problem behaviour and to record the use of coercive measures. The relationship between problem behaviour, PD prescriptions and the use of coercive measures has been assessed by means of multi-level analysis.

Results: In this study, 251 patients were included. Together they used 416 PDs. Behavioural outcomes and coercive measures were scored for 213 patients. On unilevel analysis, more severe problem behaviour was associated with a higher total use of PDs, the presence of poly-psychopharmacology, the use of antipsychotics, antidepressants, anxiolytics/hypnotics and antiepileptics. Results of the multi-level analysis will be presented.

Conclusions: Preliminary results show that the use of more and different PDs is associated with more severe problem behaviour.

Pilot results of a group music intervention for people with an intellectual disability

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Background: This is a pilot study of a randomized controlled trial to study the effect of a group music intervention on executive functioning (EF), challenging behaviour (CB), wellbeing, social acceptance and self-confidence in adults with mild to moderate intellectual disability or borderline intelligence.

Method: There were 29 participants, who were randomized into a music intervention or a general activities group (i.e., an active control group). Sixteen intervention sessions of one hour were performed within twenty weeks. EF was measured by three different tests (Sun-Moon Test, Dots Test and Circlespan), CB was measured by the Adult Behaviour Check List, wellbeing by the Basic Psychological Need Satisfaction and Frustration Scale – Intellectual Disability, social acceptance by the Social Acceptance scale and self-confidence by the Global Self-Esteem scale of the Self-Perception Profile for Adolescents. Measurements were at baseline, post- intervention and at 11 weeks follow- up.

Results: Pilot results will be presented.

Conclusions: To our knowledge, this is the first study that randomized people with intellectual disabilities into a music group intervention and an active control group. By ensuring that all participants received the same amount of attention, the extra effect of making music could be studied. Implications for future research will be addressed.

EMDR in people with intellectual disabilities, difficulties and adaptations: A systematic review

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Background: This systematic review focuses on Eye Movement Desensitization and Reprocessing (EMDR). This is a therapy for psychological trauma, increasingly applied in treatment of people with intellectual disabilities. The first research aim is to identify the difficulties in applying EMDR for people with intellectual disability and the adaptations that are made in the clinical field to overcome these challenges. The second aim is to substantiate whether therapy outcome in EMDR can be improved by incorporating an attachment-based approach, such as Gentle Teaching.

Method: Systematic searches were conducted in three different bibliographic databases. Two reviewers independently screened all potentially relevant titles, abstracts and if necessary, the full text for eligibility. The full texts of the selected articles (10) were further reviewed.

Results: Difficulties and adaptions were identified in three areas: cognitive, physical and social-emotional.

Conclusions: Analyses of the adaptations in the social-emotional area indicate that incorporation of an attachment-based approach, such as Gentle Teaching, could help to overcome difficulties and therefore improve EMDR therapy outcome for people with intellectual disabilities. These findings will be the base for further research in the form of case series in order to enhance effective clinical treatment options.

Challenging behaviour: The inside view of adults with intellectual disabilities living in Swiss residential settings

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Background: In Switzerland, ʻChallenging Behaviour of Adults with ID in Residential Settings' is the title of a national study, funded by the Swiss National Science Foundation. It aims at generating a sound empirical database on the prevalence of challenging behaviour, the existing forms, the management and the consequences they entail. A sub-study focuses on the inside view of adults with intellectual disabilities and challenging behaviour.

Method: The qualitative sub-study reflects the views of 17 adults with intellectual disabilities who live in Swiss residential settings and show challenging behaviour. To collect the data, methods such as interviews, video and participating observations were used in order to reveal their views. The collected data was analysed using Qualitative Content Analysis.

Results: Adults with intellectual disabilities and challenging behaviour highlight—among other things—several measures that help them to avoid or reduce challenging behaviour. Three main preventive measures were focusing a) the establishment of a professional relationship with care staff, b) the interaction and communication between them and their primary carers, and c) general preventive measures on different levels.

Conclusions: The elaborated preventive measures were integrated into a good practice model showing obstructive as well as beneficial aspects, thus helping staff to manage challenging behaviour in residential settings.

Post-traumatic stress in adults with intellectual disabilities: Study on the efficacy of trauma-focused CBY and EMDR therapy

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Background: Adults with mild intellectual disabilities or borderline intellectual functioning (IQ 50-85 and adaptive functioning deficits in conceptual and practical domains) are at greater risk than the general population of exposure to potentially traumatic events and the development of Post-Traumatic Stress Disorder (PTSD) (Karatzias et al., 2019; Mevissen et al., 2020; Santoro, Shear & Haber, 2018). However, in this population trauma and stressor related disorders such as PTSD are frequently underdiagnosed and undertreated. Despite the availability of multiple types of trauma-specific treatments for the general population, there is a gap in understanding these collective interventions in persons with intellectual and developmental disabilities literature (Keesler, 2020).

Method: For this study data of 100 adults with mild or borderline intellectual disabilities (IQ 35-85) were included. All of them suffered from post-traumatic stress symptoms and were offered Trauma-Focused Cognitive Behavioural Therapy (TF-CBT)or Eye Movement Desensitisation and Reprocessing Therapy (EMDR).

Results/Conclusions: At the start of therapy and at the end of therapy they filled in a short questionnaire, the KKL (Korte Klachten Lijst/ Short Complaints List). An effect size on the results of the KKL, and compared with the effect sizes described in randomized controlled trials, will be presented.

Reducing aggressive behavior in people with intellectual disability with dietary supplements

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Background: To test if multivitamin, mineral and n-3 fatty acids (FA) supplementation reduces the frequency of aggressive incidents among people with intellectual disability.

Methods: We conducted a randomized, double-blind, placebo-controlled, intervention trial of 16 weeks. Upon completion, participants could enter a crossover phase while maintaining the blind. People with intellectual disabilities aged between 12 and 40 years, living at a care or treatment facility or receiving day care, and showing aggressive behavior at least once a week were included. The main outcome was the number of aggressive incidents during the trial period, as measured daily using the Modified Overt Aggression Scale (MOAS).

Results: In total 114 participants (35.1% ♀), with mean age of 23.0 years ($SD = 7.4$) were randomized, of whom 24 continued with the cross-over trial. The level of intellectual disabilities varied from profound and severe intellectual disabilities ($n = 40$), moderate intellectual disabilities ($n = 18$), mild intellectual disabilities ($n = 29$) and borderline intellectual functioning ($n=27$).

Conclusions: We will finish the trial phase and thereafter analyses the data. Finding will be presented at the congress.

The impact of COVID-19 on the mental health and wellbeing of adults with an intellectual disability

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Background: To identify, evaluate, and summarise the findings of all relevant studies relating to the impact of COVID-19 on the mental health and wellbeing of adults with an intellectual disability.

Methods: Electronic databases searched: CINAHL, PyscINFO, EMBASE, Web of Science and Medline. A number of grey literature databases were also searched and the reference list of included studies manually searched. Screening was carried out independently by two reviewers.

Results: A limited number of studies are available relating to the topic. A meta-analysis was performed where studies were homogenous in nature. A narrative synthesis was used to summarise the study article data and relevant information. Thematic analysis of the semantic and

latent topics of the articles guided the derivation of a framework for the analysis of the outcome data. Statistical comparisons of article data were completed on a case-by-case basis. The review supported mental health and wellbeing consequences.

Conclusions: Studies among the general population report the negative impact that COVID-19 and associated restrictions have on mental health and wellbeing. There is an increased need for research into this impact for individuals with intellectual disability in order to inform planning and policy for further waves and their aftermath, and for future pandemics.

COVID-19 lockdown's impact on life satisfaction: comparison between autistic and non-autistic adults

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Background: Public health measures taken to limit the spread of COVID-19 led to changes in all individuals' lifestyle (e.g., personal and professional roles and routines, ways to carry out activities). Additionally, fears about the virus, unpredictable events, and confusion around public health measures may have fuelled an anxiety-provoking climate and altered the quality of life for many people. This research aimed to assess the quality of life of autistic and non-autistic individuals before and during the COVID-19 lockdown.

Method: A survey was launched among Quebec (Canada) adults during the summer of 2020. Data analysis relies on descriptive and non-parametric statistical tests.

Results: Slightly over 400 adults responded to the survey, one-quarter of whom were autistic. Autistic participants self-reported a lower quality of life compared to non-autistic adults. While both groups reported a decreased quality of life during the COVID-19 lockdown, the discrepancy (before – during the lockdown) was lower in autistic adults.

Conclusions: Results highlight the influence of environmental and occupational contexts on quality of life in autistic and non-autistic adults, thereby reinforcing a socio-environmental understanding of autism. Other quantitative and qualitative analyzes will be carried out to understand the impacts of the pandemic on quality of life.

Wave: The value and irritability of an outsider's perspective

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Background: Since spring 2019, 14 people without healthcare experience – but with relevant knowledge and experience – have conducted participant observations as outsider-researchers in six intellectual disability service organisations.

Method: Each of them focuses on one case regarding one protagonist with challenging behaviour, half a day for two years. When opportunities arise, they offer ideas and opinions. We want to discuss the rationale, process and preliminary findings, before facilitating a dialogue on this unique way of conducting collaborative, care ethics research.

Results: We will reflect on some of the experiences of two outsider-researchers, by using verbal and audio-visual means. We will engage the audience in some of the tensions, struggles and gains that come along with navigating the outsider-insider complexities of WAVE. Two preliminary findings we would like to focus on: 1) experimenting is rarely allowed when it is deemed too strange (i.e., when it doesn't resemble or align with dominant practices, routines and logic), and 2) how outsider-researchers try to navigate this resistance towards their otherness, and the consequences thereof.

Conclusions: We would like to reflect on pitfalls and gains of radical alternative ways of conducting collaborative research within highly institutionalized contexts such as care for people with severe intellectual disabilities and challenging behaviour.

Learning from COVID-19: Barriers and facilitators to coping with routine disruption in autism

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Background: To capture the factors that acted as barriers or facilitators to coping with the first COVID-19 UK lockdown from the perspective of parents of autistic children with complex support needs.

Method: Nine parents were interviewed about their child's experience of the first month of lockdown. The International Classification of Functioning, Disability and Health (Bölte et al., 2014) was used as a framework to identify personal and environmental factors that were either helpful or detrimental to adapting to the lockdown. A thematic analysis was conducted to identify overarching themes.

Results: Findings indicated that children coped well with short-term changes but struggled with long-term disruptions. In addition, more verbally able children showed greater tolerance in the short term, but disproportionate preoccupation with COVID-19 in the longer term. Parents generally opted for limiting potential distress by facilitating a child-led daily schedule. Children tended to stay within a self-defined "safe space," and substituted former activities (e.g., school, friends/relatives) with others (TV, parent). Availability of resources, particularly support networks and space, positively contributed to the child's (and parent's) ability to cope.

Conclusions: This study provides valuable insights to support autistic children with complex needs as we continue to experience disruption from the COVID-19 pandemic.

The SOOTHE eQuilt of mental health and wellbeing

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Background: The unfettered voice of people with intellectual disabilities is often absent in research into issues that are of importance to them. Voice is particularly important in consideration of mental health and wellbeing. Facilitation of same underpinned the EIT-Health funded SOOTHE study. The eQuilt sought to provide a means for supporting voice whilst also normalising discussion of mental health.

Method: Self-consenting adults with intellectual disability across Ireland, Spain and Netherlands were invited to create and anonymously submit electronic images of mental health and wellbeing, with support where necessary. Many were accompanied by textual explanations. Images were thematically grouped, and electronic quilt/collages prepared.

Results: Six thematic areas were identified: Covid-19 and wellness; enjoyable activities; nature; people, relationships and love; home and safety; colours and patterns. Working on these images facilitated discussions about mental health and wellbeing which participants found useful, especially as they took place during Covid-19 related restrictions.

Conclusions: The SOOTHE eQuilt provides insights into people with intellectual disabilities' understandings of mental health and wellbeing. The process also provides a platform for supporting mental health discussion between people with intellectual disabilities and their formal/informal carers.

Using advanced AI technology to automatically analyze the emotional expression of people with intellectual disabilities

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Background: People with intellectual disabilities are still underrepresented. Theoretically, it can be assumed that the expression of emotions of people with intellectual disabilities partly deviates from that of the general population. This raises the question of whether an AI-based facial expression recognition software (Affectiva) can reliably analyze the emotional expression of people with intellectual disabilities.

Method: The study aims to investigate the expression of emotions of people with intellectual disabilities ($N = 30$) elicited by images of the IAPS related to basic emotions (fear, happiness, sadness, anger, and disgust) and neutral content. Each session lasts 15-25 minutes, will be videotaped, and analyzed using Affectiva (Affdex SDK). Additionally, 10% of the recordings will be coded manually.

Results: Based on previous studies, we will investigate whether the participants show similar reactions to the presented pictures as people without disabilities. To verify the results, automated and manually coded facial expressions will be compared.

Conclusions: This study will improve the understanding of the emotional expression of people with intellectual disabilities and investigate whether an automatic approach is feasible.

Physiological stress as early-warning signal and the synchronization between client and caregiver

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Background: Clients with severe to profound intellectual disabilities and challenging behavior and their professional caregivers are vulnerable to experience high levels of stress. Stress is believed to impact the occurrence and maintenance of challenging behavior. We will present patterns of physiological stress preceding incidents of challenging behavior in a person with severe to profound intellectual disabilities. Additionally, the interplay between the stress levels of the person and a professional caregiver is presented.

Method: Physiological stress is measured with the Empatica E4 in a person with severe to profound intellectual disabilities and challenging behavior and a professional caregiver. From the perspective of complex-systems theory, we test whether early-warning signals of clients' physiological stress predict transitions in the behavior of the person. In addition, cross-Recurrence Quantification Analysis is performed.

Results: Results show whether early-warning signals in physiological measures can be used to predict transitions in behavior. Recurrence plots show the (de)synchronization between physiological stress levels of the client and the caregiver, as well as who is leading in the pattern of physiological stress prior to an incident of challenging behaviour.

Conclusions: Insights into the physiological stress levels of a client and caregiver may contribute to a reduction of challenging behavior and an improvement of the client's and caregiver's well-being in clinical practice.

A call to focus on mental stress in individuals with intellectual and developmental disorders and mental or behavioural disorders

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Background: Mental stress can be a trigger for or a component of mental and behavioural disorders. Diagnosing mental and behavioural disorders in individuals with intellectual and developmental disabilities is challenging and fosters diagnostic dynamics. This study aims to uncover these dynamics by presenting selected consequences for indicated treatment and intends to identify first approaches to prevention.

Method: A review of published articles in Academic Search Complete, PsycINFO, PSYNDEX, SpringerLink and Web of Sciences is used to investigate the consideration of mental stress in the diagnostic assessment and treatment of the individuals concerned. A selection of 47 articles is analysed thematically.

Results: Thematic analyses show that the diagnostic dynamics lead to mental stress either not being explicitly named or recognised as a factor of the (psychiatric) diagnosis in the diagnostic assessment, or not being explicitly named or considered in the indicated treatments. Furthermore, the diagnosis is an interdisciplinary call to action to address mental stress appropriately.

Conclusions: The results indicate that mental stress has to be consciously named and conceptually established in approaches to assessment and treatment to ensure that the resulting needs are specifically addressed in treatment. As a contribution to mental health, initial interdisciplinary approaches are presented and discussed.

Polypharmacy and psychotropic polypharmacy in adults with intellectual disability

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Background: Adults with intellectual disability are prescribed high levels of medication, with polypharmacy and psychotropic polypharmacy common. The objective of this study was to determine the prevalence of medication use and factors associated with polypharmacy and psychotropic polypharmacy in a population-level sample of adults with intellectual disabilities.

Methods: An administrative total-population sample of adults (≥18 years) (n=217) defined as having an intellectual disability in Jersey participated (sampling frame n=285). We examined associations of polypharmacy and psychotropic polypharmacy with socioeconomic status, health and demographic variables using univariate and multivariate analysis.

Results: 83.4% of participants were prescribed medication (Mean=4.58 SD=4.42) with high doses common. 38.2% of participants were exposed to polypharmacy while 23% of participants exposed to psychotropic polypharmacy. In adjusted comparisons polypharmacy was significantly associated with older age, increased severity of intellectual disability, living in a residential setting and having increased co-morbidities. Psychotropic polypharmacy was associated with being male, being aged 50+ years and having had a psychiatric diagnosis over the life course.

Conclusions: Our results indicate that medication use, in high doses, alongside polypharmacy and psychotropic polypharmacy is highly prevalent in adults with intellectual disability. This increases the risk of developing adverse drug events, drug-drug interactions and medication-related problems.

Therapists' experiences using videoconferencing during the COVID-19 pandemic

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Background: Due to the restrictive COVID-19 measures, therapists in the care and support of people with intellectual disabilities were, from one moment to the next, forced to work remotely. This study explored the experiences of therapists who provided therapy to people with mild intellectual disabilities. This qualitative pilot study is a first step to describe the therapists' perspective on using video conferencing.

Method: To determine relevant themes, a thematic analysis with an inductive method was deployed on self-recorded audio/email messages of seven therapists.

Results: Four main themes about the experiences of therapists could be distinguished: 1) Confronted with a new reality, 2) Missing appropriate equipment, 3) Dealing with the needs of people with mild intellectual disabilities, and 4) Unexpected opportunities.

Conclusions: Preliminary findings - Video conferencing might be a promising alternative for providing therapies for people with mild intellectual disabilities, but is not a “one size fits all”-solution. The perspectives of people with mild intellectual disabilities need further exploration.

Neurocognitive assessment in adults with Down Syndrome and other intellectual disabilities

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Background: This study investigates the measures used to detect cognitive changes in adults with Down Syndrome and other intellectual disabilities.

Methods: We conducted a systematic review focused on neurocognitive disorders assessment tools adopted in Down Syndrome and other intellectual disabilities samples. The searches were carried out in the databases Web of Science, PubMed and PsycINFO in October 2020, including papers published in English, Spanish and German. The inclusion criteria were: 1) studies focused on screening age-related cognitive changes in people with DS and OID, 2) samples composed of adults or older adults, 3) scales and batteries applied for cognitive assessment.

Results: The findings were organised by diagnosis including 4,650 people with Down Syndrome and 1,801 with other intellectual

disabilities. Concerning the study design, there were 48 cross-sectional and 27 follow-up studies. We identified proxy and self-report measures (39 scales, questionnaires and inventories, and 13 batteries) for assessing cognitive and behavioural changes in adults in Down Syndrome and other intellectual disabilities.

Conclusions: This review highlights the need for unified and standardised measures that allow the synthesis of research results and greater consistency of diagnosis in clinical practice. We recommend the use of specifically designed instruments to assess cognitive functioning and behaviour changes in people with Down Syndrome and other intellectual disabilities.

CBT for men with intellectual and developmental disabilities and harmful sexual behaviour: Outcomes for men with autism vs. men with intellectual disabilities

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Background: Men with intellectual and developmental disabilities sometimes engage in harmful sexual behaviour (HSB). They are not always prosecuted and are not often offered treatment. Nevertheless, it is important not to simply risk manage such behaviour, and the SOTSEC-ID model of group cognitive behavioural treatment has shown promise in previous studies.

Method: 15 sites ran 26 CBT treatment groups, using the SOTSEC-ID model, for 98 men. The SOTSEC-ID model is group CBT especially adapted for men with intellectual and developmental disabilities and HSB. Measures of harmful sexual behaviour, sexual knowledge, victim empathy and cognitive distortions were taken before and after the one-year long treatment groups, and were repeated at six month follow-up.

Results: There were low levels of further HSB, and significant improvements in sexual knowledge, victim empathy and cognitive distortions after treatment, maintained at follow-up. However, the men with autism did consistently worse than the men with intellectual disabilities only.

Conclusions: Men with intellectual and developmental disabilities showed improvements after group CBT for harmful sexual behaviour. However, men with autism spectrum disorders did consistently less well than the men with intellectual disabilities only. An RCT is now beginning to test whether CBT using SOTSEC-ID is better than no treatment for men with intellectual and developmental disabilities.

Insomnia in people with intellectual disabilities: A treatment protocol

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Background: People with an intellectual disability are prone to sleep problems inherent to their compromised brain function. In addition, daily caregivers determine a great deal of the daily routines which may lead to conditions for a(n) (un)healthy sleep. We studied the effect of a modified insomnia protocol in intellectual disability patients.

Methods: A cohort of 92 patients with intellectual disabilities referred to our tertiary sleep wake centre underwent a workup consisting of questionnaires, clinical interviews, actigraphy and polysomnography. We developed a treatment protocol for insomnia treatment, based on the CBT-i protocol of the European Guidelines for Insomnia, tailored to specific care needed by individual patients with intellectual disabilities.

Results: Insomnia was diagnosed in 60 patients. 26 patients completed the protocol, 18 patients were treated successfully. Fit for age time in bed, more (physical) activities, enhanced light/dark regime and carefully designed bed ritual were the most successful interventions.

Conclusions: Causes of sleep problems in people with intellectual disabilities are comprised of an intertwining of intrapersonal and environmental conditions. Inadequate time in bed and lack of (physical) activities are most common, and in the majority of cases treatable, reasons for insomnia.

Responding to mental health concerns in older adults with intellectual disability (SOOTHE)

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Background: Older people with intellectual disability experience poorer mental health than those in the mainstream population. A recovery framework underpinned the SOOTHE study. The overall aim of the study was to address mental health and well-being among older people with an intellectual disability and develop user-derived solutions to maximise their mental health and well-being.

Method: This ethically approved, EIT-Health funded, practice innovation study comprised two work packages, each with three sequential focus groups. Participants were older adults ($n=7$) with a moderate intellectual disability. Due to COVID-19 restrictions virtual focus group interviews were utilised.

Results: Participants articulated their understanding of mental health and well-being and focused on how COVID-19 was impacting upon their mental health. This resulted in increased negative emotional responses especially around how restricted movements affected socialisation. Engaging in structured activities were important to their mental health and well-being. Three digital user-derived solutions were developed in response to their identified psychosocial needs focusing on socialisation, music and independence.

Conclusions: Participants articulated what mental health and well-being meant to them, and how the restrictions of COVID-19 were

impacting upon their mental health. Three digital user-derived bespoke prototypes were developed to address psychosocial issues and concerns identified by the participants.

Supporting couples when one partner has a diagnosis of dementia

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Background: We are seeking insight into day-to-day experiences of couples with intellectual disability. A key aim is to identify factors that support sustainability in relationships when one partner has a dementia diagnosis.

Method: This qualitative study involves focused conversations with ten couples with intellectual disability, and semi-structured interviews with practitioners, parents or siblings who provide support for one or both partners (n=30). Focused conversations are a structured process with less emphasis on direct questioning, enabling participants to identify what may help in the future. Data will be thematically analysed.

Results: The study is ongoing. We will present scoping review findings demonstrating rationale for the study. This highlights lack of previous research with couples affected by dementia when both partners have an intellectual disability. Methods of data collection and methodological approach will be shared, including how people with intellectual disability have been involved in the inception, planning and development of the study.

Conclusions: Relationships and marriages of people with intellectual disability are to be celebrated. Simultaneously, we know of the increased risk of dementia in people with intellectual disability, particularly Down syndrome. Study findings will have implications for integrated support across families, health, allied health, and social care sectors.

The use of smart wearables for early notification of stress in people with intellectual disabilities

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Background: Challenging behavior and related stress in people with intellectual disabilities is a persistent problem. It has negative consequences on the quality of life, and it increases drop-out of care professionals. Early notification of stress via smart wearables enables caregivers to better respond to client needs, thereby reducing the number of incidents against significant cost savings.

Method: We present the results of a validation study in which artificial intelligence models were used for stress detection. 50 intramural clients with an intellectual disability were included in the study. During events of challenging behavior, the physiological responses (such as skin conductance and heart rate) were measured with wearables and video recordings for behavior analysis were taken for validation.

Results: The study showed that the trained model was well capable of notifying stress in people with an intellectual disability. Escalations were clearly reflected in physiology and well recognized by the model. In addition, the study demonstrated its potential for effect studies on interventions.

Conclusions: The study showed the great potential of sensor-based stress detection in the daily support of people with challenging behavior. Stress detection has value in both the early notification and avoidance of escalations and to measure the effect of interventions.

Blended music intervention for people with an intellectual disability and challenging behaviour

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Background: This study of a blended music intervention has two primary aims: 1) to evaluate its feasibility for people with a mild or moderate intellectual disability and challenging behaviour, and 2) to study its effect on wellbeing and challenging behaviour.

Method: Ten participants received sixteen individual music sessions of one hour over a period of eight weeks. The music sessions were carried out by trained music professionals in accordance with a manual and could be carried out digital or face-to-face. Data was measured at baseline and post-intervention. Wellbeing was measured with the Personal Wellbeing Index-ID, and challenging behaviour was measured with the Aberrant Behaviour Checklist. Feasibility measures focused on acceptability and practicality.

Results: Pilot results will be presented.

Conclusions: To our knowledge, this study is the first investigation of a blended music intervention for people with mild to moderate intellectual disability and challenging behaviour. Implications for future research will be addressed.

POSTER PRESENTATIONS

A scoping review of the trauma literature for adults with an intellectual disability

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Background: To identify the current status of the existing research literature on the broader context of trauma that is specific to adults with an intellectual disability.

Method: A scoping review was conducted using the Arksey and O'Malley (2005) framework and the PRISMA-ScR. Forty international papers were reviewed spanning 2000–2020, and the quality assessed using the Mixed Methods Appraisal Tool.

Results: The results are as follows: 1) aggressive behaviours can be symptoms of trauma, 2) there are appropriate assessment tools for assessing the impact of trauma, 3) evidence-based interventions for trauma in the general population may be effective, and 4) that factors associated with disability can be traumatic for people with an intellectual disability.

Conclusions: There is a growing body of literature highlighting assessment needs and potential interventions for people with an intellectual disability who have experienced psychological trauma. Further research needs to be conducted to develop and assess interventions and move towards trauma informed pathways of care.

Psychotropic drugs intake in older people with intellectual disability

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Background: Older people with intellectual disability have a poorer health status than their peers without intellectual disability, and the prevalence of mental health conditions and challenging behaviors in this group is significantly higher. Psychotropic medication is commonly used to manage these conditions, although its adverse effects can affect people's health, especially that of the most fragile ones. The aim of this study is to analyze what factors predict the intake of psychotropic drugs in older people with intellectual disability in Spain.

Method: A questionnaire was elaborated to collect data regarding psychotropic medication in older people with intellectual disability. The sample includes 991 people over 44 years with intellectual disability. Data were obtained from professionals and relatives who knew the person well. Binary logistic regression was performed to identify factors associated with psychotropic drugs intake.

Results: Older people, with severe/profound intellectual disability, suffering from a mental health condition, presenting challenging behaviors or living in residential settings, were more likely to take two or more psychotropic drugs.

Conclusions: Aging people with intellectual disability are more sensitive to medication adverse effects. It is important to consider other non-pharmacological therapies to manage challenging behavior and ensure an adequate health status.

Longitudinal study on adaptive behavior of children with moderate or severe intellectual disability

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Background: This longitudinal study investigated the developmental characteristics of adaptive behavior in children with moderate or severe intellectual disabilities through six school years in special needs school.

Method: A survey was conducted with 32 moderate or severe intellectually disabled children enrolled in a special support elementary school in Tokyo. The breakdown was 16 children with Down syndrome and 16 children with autism spectrum disorders. Their average IQ was 35.4 (Down syndrome; 40.5, autism spectrum disorders; 31.2) in the first grade of special needs school. The new version of the S-M social life ability test was used in the survey.

Results: Results suggested that the social life index of children with intellectual disabilities at admission did not change substantially until graduation. The development of each area differed as the school year increased, such that Self-Help, Locomotion, Occupation, and Self-Direction developed adequately, whereas Communication and Socialization developed relatively moderately. Also, developmental differences between these areas widened as the school year increased.

Conclusions: The acquisition of "Self-Help," "Locomotion," "Occupation," "Communication" and "Self-Direction" for children with moderate or severe intellectual disabilities was mostly dependent on the child's mental age (intellectual developmental stage) and did not differ by the type and characteristics of disability.

Mental ill-health in mothers of people with intellectual disabilities: A meta-analysis

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Background: Mothers of people with intellectual disabilities may be more prone to experiencing mental ill-health compared to mothers of typically developing people, which may differ at different stages of the caregiving trajectory. We aimed to systematically review evidence in this area.

Method: Prospero registration: CRD42018088197. Medline, Embase, CINAHL and PsycINFO databases were searched. No time limits were applied. Studies were limited to English language. Only studies which had a comparison group of mothers of typically developing/ed children were included. Where possible, meta-analyses were performed.

Results: 32/3,089 retrieved articles were included, of which 10 reported on anxiety, 21 on depression and 23 on other indicators of mental ill-health. Mothers of individuals with intellectual disabilities experienced poorer mental health. Meta-analyses revealed significant findings for anxiety, depression, parenting stress, emotional burden, common mental disorders, but not for somatic symptoms. Research on mental ill-health of mothers of adults with intellectual disabilities at different stages of the caregiving trajectory was lacking.

Conclusions: There is evidence of poorer mental ill-health in mothers of people with intellectual disabilities compared to mothers of typically developing people, but lack of focus on different stages of the caregiving trajectory, methodological inconsistencies between studies, and lack of robust studies pose limitations.

Mental health needs of people with intellectual and developmental disabilities and their caregivers: Approaches for intervention

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Background: People with intellectual and developmental disorders are at a higher risk mental health problems than their peers without intellectual and developmental disorders. Mental health needs are one of the major reasons for caregiver's stress, stigma, extended hospitalization and institutional care. Unmet mental health needs can impact the quality of life of both individuals with intellectual and developmental disorders and their caregivers. But, the mental health needs are not adequately met for various reasons that are related to the condition, caregivers' attitude, professionals' knowledge and attitude, and systemic gaps in service delivery. Cognitive and communication deficits, psychosocial masking, baseline exaggeration and diagnostic overshadowing can contribute to underreporting of mental health problems among individuals with intellectual and developmental disorders. Even if the mental health needs are identified, the persons with intellectual and developmental disorders may not be owned by mainstream mental health systems nor the non-medical settings which take care of the education and vocational services are well equipped to address these issues. As a result of these issues, individuals with intellectual and developmental disorders will slip through the gaps in services delivery.

Method/Results/Conclusions: In this context, the aims and objectives of the discussion are as following: Understand the nature and intensity of mental health needs in people with intellectual and developmental disorders. Reviewing the challenges related to identification and intervention of mental health needs in intellectual and developmental disorders. Identifying and narrowing the gaps in mental health service delivery for people with intellectual and developmental disorders and their caregivers. Supporting the caregivers, families and communities in accessing and delivering mental health services for people with IDD.

Delusions in people with intellectual disabilities and schizophrenia

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Background: Delusions are commonly understood as fixed beliefs which are impervious to conflicting evidence. Although they can occur in different psychiatric and neuropathological conditions, they are a key diagnostic criterion of schizophrenia. The content of delusions can include different delusional themes which are linked to the patient's life and sociocultural embedding. People with intellectual disabilities have a higher risk of comorbid psychotic disorders such as schizophrenia. At the same time, diagnosing schizophrenia in people with intellectual disabilities can be challenging. Despite the importance ascribed to delusions in diagnosing schizophrenia, only little is known about the presentation of delusions in patients with intellectual disabilities.

Method: Therefore, medical records of 929 delusional patients hospitalized for schizophrenia were analysed. 4% of this sample had an additional diagnosis of intellectual disability.

Results: In this subsample, 27% experienced polythematic delusions. On average, a patient had 1.3 delusional themes. 65% had delusions of persecution and 41% delusions of reference, followed by delusions of poisoning (8%) and religious delusions (8%). Less often, patients showed hypochondriacal delusions (5%), nihilistic delusions (3%) and delusional infestation (3%).

Conclusions: In addition, the subsample with intellectual disabilities is compared with the sample without intellectual disabilities and implications for research and practice are discussed.

Perceptions of communication and interaction in teletherapy and traditional face-to-face therapy

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Background: The aim of the project was to compare the perceptions of students with neurodevelopmental disorders, and Speech and Language Therapists, of communication and interaction in teletherapy and face-to-face therapy. Communication and interaction with our clients is thought to be important in our therapy since this could facilitate therapeutic alliances (Lawton et al, 2018). There is already some research to support delivery mode specific differences (O'Malley et al., 1996).

Method: This was a preliminary project using both quantitative and qualitative methods. Using questionnaires, three SaLTs and six FE college students were asked to evaluate their communication and interaction with their partners in face-to-face and teletherapy.

Results: In line with research findings, all SaLTs and some students perceived mode specific differences in communication and interaction. SaLTs found the differences rather hard, but our students gave more positive impressions of Teletherapy than SaLTs, probably reflecting their interests in technologies. Their perceived differences between the two modes were much smaller than the SaLTs, possibly due to their limited awareness of norms for communication.

Conclusions: As a result of the project, training needs for both SaLTs and students on video conferencing platforms and online communication skills were identified.

People with an unknown cause of intellectual disability use more psychotropic drugs

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Background: To investigate the differences in psychotropic drug use between people with intellectual disability with a known genetic cause compared to people with intellectual disability due to non-genetic or unknown causes.

Method: Adults with intellectual disability ($n = 812$), living in Dutch residential care settings, were included in this cross-sectional, multicentre study. Data was collected between 2016 and 2019 and retrieved from pharmaceutical and medical records.

Results: Almost half of the study population used psychotropic drugs (49.4%). Of the people with a genetic cause of intellectual disability ($n = 180$), 34.4% used psychotropic drugs. Of the people with a non-genetic cause of intellectual disability ($n = 197$), 40.6% used psychotropic drugs, as did 59.5% of the people with an unknown cause of intellectual disability ($n = 435$). Females used psychotropic drugs significantly less often than males (OR=0.681; p=0.021). Additionally, people with an unknown cause of intellectual disability used a significant higher number of different psychotropic medications (1.17; SD 0.93) than those with a genetic (0.57; SD 1.17) or non-genetic cause (0.77; SD 1.29). Between the two groups with a known cause of intellectual disability, there was no significant difference in the number of psychotropic drugs used.

Conclusions: Fewer psychotropic drugs are used in people with a known cause of intellectual disability.

A study of sexual victimization among people with developmental disabilities

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Background: The aim of this study is to clarify the situation and the cause of sexual victimization among people with disabilities, in order to enable us to support to them.

Method: The study was conducted for the service users of the café for the people who have, or who are suspected of having a developmental disability. In this cross-sectional study, 32 of them answered the questionnaire survey, 13 of them were interviewed in a focused group and three of them were interviewed individually.

Results: Based on the results of the questionnaire survey, 71.9% of people with developmental disability experienced sexual victimization. The result suggests that people with developmental disability are at greater risk of sexual victimization, compared to those without a disability. The interview study showed that risk of sexual violence was attributable to characteristics shared by people with developmental disability, such as low self-esteem and social isolation.

Conclusions: The analysis identified a number of ways to offer support for victims of sexual victimization among people with developmental disability, including the need for sexual education and human rights education for these people, as well as the need to develop support systems for the victims and place legal restrictions on perpetrators.

Hair glucocorticoids in adults with intellectual disabilities and depressive symptoms

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Background: The aim of this study was to explore long-term biological stress levels in adults with intellectual disabilities and depressive symptoms by measurement of hair glucocorticoids (cortisol and cortisone), and to investigate the effect of bright light therapy (BLT) on these hair glucocorticoid levels.

Methods: Scalp hair samples were used to retrospectively examine hair glucocorticoids levels by liquid chromatography-tandem mass spectrometry (LC-MS/MS) on baseline and post-BLT (with 10.000 lux) and dim light (300 lux). Anxiety and depressive symptoms were measured with the Dutch version of the Anxiety, Depression and Mood Scale (ADAMS) and the Signalizing Depression List for people with Intellectual Disabilities (SDL-ID). Participant's life events were counted with the Checklist Life Events (CLE).

Results: Hair samples of 14 participants were included, and we found a significant correlation between baseline hair cortisol and baseline scores of depression. Only hair cortisone was significantly increased after a light intervention in our total sample, particularly after dim light.

Conclusions: The use of hair glucocorticoids to retrospectively examining biological stress levels in adults with intellectual disability may be a promising objective method to gain more insight in the level of stress they have experienced.

Rather this way! From controlling “behavioural problems” towards catalysing “quality of life”

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Background: “Rather this way” is a new approach we developed in De Lovie vzw (Belgium) to support people with intellectual disabilities and challenging behaviour. This approach aims at moving towards more support instead of control and coercion.

Method: Theory on Triple C, New Authority, Self Determination and theory of Social-Emotional Development formed the fundament of the project “Rather this way.” We organised focus groups and formulated questions and dilemmas for clients and their families, for colleagues and other stakeholders. Thus, literature research and focus groups formed the basis for developing the new approach in November 2019. From there, we started up the bottom-up improvement processes on micro and meso level.

Results: This new approach helps us to focus on needs, instead of control. A lot of frustrating rules were being questioned. Another way of being clear and providing guidance was found. We saw a decrease of problem behaviour, but even more important an increase of quality of life.

Conclusions: “Rather this way”—our newly developed approach—helps us to tackle “behavioural problems,” helps us to focus on quality of life and to find new ways to support our clients.

Development of a clinical screening instrument for depression symptoms in children with autism

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Background: Depression is common in children and young people with autism spectrum disorder, and current screening measures have been developed for, and validated with, typically developing people.

Method: We developed a brief screening tool to enable clinicians from diverse professional backgrounds to identify depression symptoms more accurately in children and young people with autism spectrum disorder. Items from 11 existing depression measures were extracted into a database. An expert panel utilised clinical and research knowledge relating to depression and autism to identify a pool of 25 individual items for further consultation with autism professionals, children and young people with autism spectrum disorder and their parents. Interviews were conducted with young people with autism spectrum disorder (aged 9-18 years) without co-occurring intellectual disability and their parents (N=16 dyads), and autism spectrum disorder practitioners (N=18) to ascertain the content validity, necessary adaptations, acceptability and readability of the items using a co-production model.

Results: Those items deemed to have greatest face validity, acceptability and readability following triangulation of findings from interviews with the three informant groups comprise the final item scale. To ensure multi-informant integration, child and parent report versions of the depression screener were developed.

Conclusions: This Neurodevelopmental Depression Inventory is a novel depression symptom screening tool for use in routine clinical services and to advance research.

Evaluation of an mindfulness-based intervention for people with mild intellectual disability: A multiple single-case study

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Background: Stress is a common problem for individuals with mild intellectual disability, and can lead to behavioural and psychological problems. This study examined the effects of an individual mindfulness-based cognitive training (MBCT) program adjusted for individuals with mild intellectual disability. The intervention aimed to reduce stress and improve coping with stress.

Method: Within a multiple-baseline repeated single-case study with an AB1B2-design seven participants daily reported stress levels and weekly reported personal stress symptoms and coping style by using visual analog scales during a baseline period of 3-6 weeks, followed by a 10-week training and six-week follow-up. In addition, the adjusted Perceived Stress Scale (PSS-10) and the Coping Inventory for Stressful Situations (CISS-21) were administered four times, at baseline, pre- and post- intervention and at follow-up.

Results: Data are currently collected. Data of the first three to four participants will be presented.

Conclusions: This study aims to contribute to the evidence- base of the individual mindfulness-based cognitive intervention for individuals with mild intellectual disability who experience stress. Daily and weekly collected data in this multiple single-case study adds value to clinical practice.

Track 3c: Profound and Multiple Intellectual Disabilities (PMID)

PRESENTATIONS IN A SYMPOSIUM

Challenges for persons with profound and multiple disabilities

Exploring vulnerabilities in the pandemic: Ethical concerns and methodological consequences

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Background: Persons with profound intellectual and multiple disabilities are commonly considered particularly vulnerable. While health problems and lack of opportunities to participate have been a reality for them long before the outbreak of the global pandemic, the current crisis most likely leads to a deterioration of their situation. However, the pandemic is also said to have the potential to make their needs and demands more visible. In this presentation, we want to reconsider this assumption and thus aim at exploring their complex vulnerabilities in this special situation.

Methods: While participatory research approaches would be in order to investigate vulnerabilities, they do not come into question – ironically, because close contact between researchers and study participants enhances the same vulnerabilities this study wants to explore. The presentation reflects this paradox and in addition, it provides first insights from a systematic literature review on this phenomenon.

Results: Research with (and for) persons with profound intellectual and multiple disabilities has always had to carefully consider their vulnerabilities. The major particularity in the current situation is that their vulnerabilities are now medically underpinned.

Conclusions: In situations such as the current global pandemic new methodological approaches are needed in order to involve the perspective of persons with profound intellectual and multiple disabilities.

Communicating (in) the crisis: Outline of a research project

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Background: This presentation gives an overview of the research project “Communicating (in) the Crisis” (ComCri) which investigates the situation of persons with profound intellectual and multiple disabilities in the context of the COVID-19 pandemic. It aims at exploring the complex vulnerabilities and communicational needs of persons with profound intellectual and multiple disabilities, and at investigating health literacy among persons with profound intellectual and multiple disabilities and their caregivers.

Methods: ComCri pursues a triangular approach: A literature review and a Delphi study serve as a starting point to map the research field. These findings are incorporated in a questionnaire that is sent out to care practitioners and supporters. A short ethnographic field phase complements the empirical data.

Results: The presentation outlines the methodological approach and provides insight into the current state of research. Here, the focus is placed on conceptual considerations on the interrelation between health literacy, communication capacities and vulnerabilities of persons with profound intellectual and multiple disabilities.

Conclusions: Although there is an increased public awareness of the situation of vulnerable persons during the pandemic, persons with profound intellectual and multiple disabilities still occupy a marginal position in public discourse. By providing research-based knowledge to service providers as well as advocacy organisations and policymakers ComCri contributes to raise the public awareness of the specific needs and demands of these persons.

Involving people with profound intellectual and multiple disabilities in service design

Caren Keeley[1]
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Background: In order to plan care services for persons with profound intellectual and multiple disabilities and to broaden the variety and quantity of these services, it seems imperative to take into account the perspective of those affected and to ask them about their opinions, needs and requirements. Challenges arise mainly from limited verbal language and barriers to understanding processes. The presentation provides a theoretical review of methodological and pedagogical concepts and methods which focus on the subjective perspectives of persons with profound intellectual and multiple disabilities. It aims at showing possible approaches to involve persons with profound intellectual and multiple disabilities into user surveys.

Method: Existing approaches (e.g. diagnostic procedures, pedagogical concepts, research methodological approaches) will be analysed and transferred to the needs of people with profound intellectual and multiple disabilities by a theoretical review.

Results: Specific methods are needed to involve people with profound intellectual and multiple disabilities in the design of services. These can only be developed in an interdisciplinary way. The present considerations show possible developments.

Conclusions: “Nothing about us without us”: this also applies to people with profound intellectual and multiple disabilities in all areas of life, which is why it is imperative to include them in the development of person-centred services. The results of this discussion will be fundamental with regards to the research design of the presented project.

Barrier-free communication in the COVID-19 pandemic? Health literacy among persons with profound intellectual and multiple disabilities

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Background: Communication processes are of central importance for prevention, health promotion and the favourable course of a disease. Concepts of individual and organisational health literacy include these processes but do hardly acknowledge communicative diversity and exclude persons with profound intellectual and multiple disabilities, who mostly communicate nonverbally. This study aims to explore health literacy among individuals with profound intellectual and multiple disabilities under a critical perspective of barrier-free communication during the COVID-19 pandemic and beyond.

Method: A literature review will outline interdisciplinary perspectives on health literacy and the extent to which persons with diverse communication access and needs are included. Additionally, qualitative interviews with experts in barrier-free communication are presented to explore possibilities to engage persons with profound intellectual and multiple disabilities in health-related issues.

Results: Barrier-free communication on health-related topics is not sufficiently available for persons with profound intellectual and multiple disabilities, as evidenced by a lack of 1) inclusion of communicative diversity in health literacy-concepts, and 2) multimodal communication offerings on health topics during the current pandemic.

Conclusions: This research contributes to expanding health literacy concepts to an inclusive concept, valuing communicative diversity and respecting the rights to education, communication and health. Professional and nonprofessional supporters are identified as important persons to consider in research and practice within health literacy among persons with profound intellectual and multiple disabilities.

Pain in people with severe or profound intellectual and multiple disability (S/PMID)

Pain assessment in adults with profound intellectual and multiple disabilities

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Background: It remains unknown if POSAID, a recently developed pain observation scale for adults with profound intellectual and multiple disabilities, is sensitive enough to properly assess differences in pain severity in people with profound intellectual and multiple disabilities. The objective of this study was to determine the psychometric properties of the POSAID scale using a polytomous scoring method based on the intensity of pain.

Method: The POSAID item pool, consisting of 15 items, was used to determine which of those items form a strong scale that satisfies the assumptions of the Mokken scale model using a polytomous scoring method. Internal consistency was measured with Rho. Interrater and intrarater reliability were analysed and compared with the POSAID scale with a seven-item scale using a dichotomous scoring method. In total, 85 adults with profound intellectual and multiple disabilities participated.

Results: Preliminary results are promising when it comes to forming a strong scale to assess pain based on the intensity of pain. Interrater and intrarater reliability seem to be sufficient. Further details about the psychometric properties of the POSAID will be presented at the congress.

Conclusions: The POSAID seems to have sufficient psychometric properties in assessing pain. Further research is necessary to determine to which extent the POSAID can differentiate between different pain situations.

A mobile application to signal pain: Adults with severe or profound intellectual disabilities

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Background: Recognizing pain in adults with severe or profound intellectual and multiple disabilities is difficult and exacerbated by their inability to clearly express pain or communicate about it to their caregivers. The research presented focuses on an alternative way to measure acute pain, by physiological measurement and a mobile application.

Method: The visual for the mobile application of pain was developed during a co-productive process including parents, caregivers, researchers and designers. The possibility to measure physiological pain responses was tested on 30 healthy adults without intellectual disabilities during relaxation, pain caused by submerging a hand in cold water and no pain, while participants self-reported their pain level on a seven-point scale.

Results: The visual for application of practice is developed and evaluated by caregivers. Next, preliminary results indicate a sufficient possibility that the physiological response to acute pain can be measured in adults without severe or profound intellectual and developmental disabilities.

Conclusion: This study is a first assessment for a caregiving aid for measuring acute pain. The next step in the development of the application is to examine the reliability of the pain measuring system in adults with severe or profound intellectual and developmental disabilities.

Attachment, social relationships and pain in children or adults with intellectual disability

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Background: The presence of an attachment figure, like a parent, when a child or person with severe or profound intellectual disability has pain is thought to be beneficial and necessary, but the research on the relation between the experience of pain and attachment or social relationships has not yet been reviewed.

Method: A systematic literature search was conducted through several international databases (e.g., Worldcat, Wiley Online Library, Springerlink, ScienceDirect) with search terms child+, adolescent, intellectual disability, combined with pain and social relationships or attachment, for peer-reviewed articles and reviews published from 2005-2020 in English, German or Dutch. References were searched for additional articles.

Results: The primary search resulted in 306 hits, for which 17 articles met inclusion criteria. From the reference search 15 articles met inclusion criteria, resulting in a total of 32 articles for review. Themes were:

secure and insecure relationships with parents; relationships with peers, chronic pain and pain tolerance.

Conclusions: The results indicate that there is a clear relationship between secure attachment, warm caring relationships and coping with pain. Next to general medical care, more attention should be given to the importance and presence of caring parents and caregivers during pain and in coping with pain.

WORKSHOPS

Introduction to using the Visual Assessment Scale CVI-PIMD, an assessment of visual functioning

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Description: The workshop will consist of a video presentation and include interaction with participants. The VAS CVI-PIMD is available online, and this workshop will encourage participants to use it in practice, in addition to the manual. The VAS CVI-PIMD is the only instrument to assess visual functioning of persons with profound intellectual and multiple disabilities in a uniform manner. It is based on scientific research.

Contribution: After the workshop, participants will be able to use the VAS CVI-PIMD in daily practice. The VAS CVI-PIMD is an assessment instrument that combines the results of the observations on visual functioning by a multidisciplinary team, after the ophthalmological examination and the formal assessment of visual functions. Using their own observations, all aspects of visual functioning and characteristics of CVI are compiled in the VAS. Based on these results, mild or severe CVI can be detected. The many items recorded in the VAS also give a solid base for treatment. The VAS can be used again after a period of time, to show changes. The VAS CVI-PIMD is an instrument that records the diversity in visual functioning, valuing each aspect of it within daily life.

ORAL PRESENTATIONS

Communication intervention for people with profound intellectual and multiple disabilities: Implications from a systematic review

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Background: Communication is a human right. Children and adults with profound intellectual and multiple disabilities experience profound developmental delay, and communication, mobility and sensory difficulties, restricting their access to this basic right. A range of communication interventions is available to increase interaction and participation, but there is limited high-quality supporting evidence. The aim of this paper is, through a systematic review, to identify evidence-based communication interventions for practitioners and to inform the design of future research.

Methods: A systematic review was undertaken, conforming to PROSPERO guidelines. Quality appraisal was conducted using Crowe's Critical Appraisal Tool (CCAT). Findings are reported according to PRISMA.

Results: Few good-quality evaluations of communication intervention were found; however, some cautious recommendations can be made for teaching and therapy. Challenges to research rigour include the diversity of children and adults with profound intellectual and multiple disabilities, small sample sizes and difficult decisions regarding who should intervene, assessment consistency, acceptable intervention intensity and the management of fidelity.

Conclusions: Whilst further high-quality research is needed, some interventions with either cognitive or interactive bases can be cautiously recommended. Researchers could consider greater use of single case experimental designs and the involvement of parents, teachers and therapists in delivering interventions.

Teacher-student relationship in process of educating people with profound intellectual disability

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Background: The relationship existing between a teacher working with a student who has profound intellectual and multiple disabilities is a sine qua non condition for the education process. It sets the framework for their meetings and affects the quality of education. It is the teacher who is always responsible for the quality of the relationship and its course.

Method: The theory of attachment (Ainsworth, Bowlby) and the theory of intersubjectivity (Threvarten) set the theoretical framework for the issues raised in the speech which will present the results of the research project adopting the interpretive paradigm with the use of qualitative interviews with the teachers of PIMD students.

Results: The project aimed at presenting the nature of relationships during the education process from the teacher's perspective. The speech will focus on the difficulties arising in the course of relationships, which result from the specific functioning of teachers and people with PIMD, and the ways of dealing with them (including: "student as a screen" or “imputing an identity").

Conclusions: The summary will discuss conditions related to the mentalizing process (Fonagy), the fulfillment of which is important for the quality of a teacher-student with profound intellectual and multiple disabilities relationship.

Selection of the best screening tools for use with the Nigerian adolescent population: Focus group

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Background: The aim was to examine the validity and cultural appropriateness of measures for screening for autism spectrum disorder and intellectual disability in Nigerian adolescents, and to make recommendations for measures to be included within a future validation study.

Method: Findings of a recently completed systematic review were used to select four screening tools (two for each of autism spectrum disorder and intellectual disabilities), which were presented to a focus group conducted following the guidelines for use of the nominal group technique. The group was comprised of a parent and professionals.

Results: Autism spectrum disorder: The group reviewed the Social Communication Questionnaire (SCQ) and the Autism Spectrum Quotient (AQ-10), and the SCQ was agreed as the most appropriate for use. Intellectual disability: The Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q) and the Screener for Intelligence and Learning Disabilities (SCIL) were reviewed, and the SCIL was agreed as the most appropriate. Minor adjustments were made for cultural appropriateness.

Conclusions: The SCQ was preferred as it has two versions; lifetime and current, which will enable information gathering for adolescents who had never been screened. The SCIL was validated for use with a broad age range. Inclusion of the DSM-5 items, and the wide age range made it a preferred option.

Odor detection in children with profound intellectual and multiple disabilities

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Background: Olfactory perception is a "basal" sensory modality. The olfactory functioning of people with profound intellectual and multiple disabilities is poorly known, even if it is highly stimulated in educational tasks. This study aims to identify the signs and manifestations of olfactory reception (i.e., odor detection) in children with profound intellectual and multiple disabilities.

Method: Twenty-two children with profound intellectual and multiple disabilities (7–18 years old; $M=13.09$; $SD=3.3$) were exposed to Sniffin' Sticks with 18 odors versus a neutral condition (empty stick) in a within-groups design. The set of stimuli has been chosen with the research partners. Both the order and the side of stimuli presentation have been counterbalanced. Participants' behaviours were filmed in odor versus neutral conditions. Participants' odor detection responses were inferred from behavioural data such as head alignment on the stick, smiles, vocalizations, mouth movements, grimaces, global motor movements, etc. Data have been coded using EUDICO Linguistic Annotaor (ELAN, v. 5.9) in terms of occurrences or duration. Inter-observer reliability, calculated on 20% of the data, was found to be fair.

Results: Analyses are currently in progress. *Conclusions*: The results are expected to enable a better understanding of children's odor treatment skills.

Following children with severe disabilities and their parents through a communication intervention

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Background: We aimed to 1) identify change in parent-child communication following the parents' participation in a communication course and 2) to explore how parents' experiences of the intervention related to observed, communicative behaviours in parent and child.

Method: Participants were two children with severe to profound intellectual and multiple disabilities and their mothers. Data consisted of filmed parent-child play with repeated measures before, during and after the communication course and longitudinal parent interview data. Filmed data were coded for parents' communication style and use of alternative and augmentative communication (AAC) and children's interactive engagement and were statistically analyzed. Parent interviews were analyzed thematically.

Results: The statistical analysis revealed no patterns of change. The parents experienced that the intervention was a process that affected their knowledge and thinking about communicating with their children. Both parents also exemplified changed, communicative behaviours on their part.

Conclusions: The failure to observe any actual change in communicative behaviours raises questions about the relationship between parental knowledge, skills and implementation as well as the mechanisms of change in communication development for children with profound intellectual and multiple disabilities. A number of methodological issues, including choice of outcome measures, are considered, but so is the nature of parental communicative training and change.

Co-production of a multisensory music drama intervention for a student with profound intellectual and multiple disabilities

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Background: The knowledge regarding educational support for children with profound intellectual and multiple disabilities needs to be developed. Research has stressed that social interaction, including music therapy, may contribute to enhanced alertness and engagement in people with profound intellectual and multiple disabilities. Multisensory music drama (MSMD) is a partly new pedagogical approach combining interactive music with props-supported story presentation. The aim of this study is to describe the co-production process between a teacher of a student with profound intellectual and multiple disabilities and a researcher while developing MSMD sessions. Research questions focus on the teacher's perspectives of the feasibility of MSMD in the school context and with a student with profound intellectual and multiple disabilities.

Method: A qualitative approach with stimulated recall interviews were used to investigate the applicability of MSMD in the pedagogic context as well as to form and iteratively improve MSMD in design-based cycles.

Results: Preliminary findings will be presented, which may reveal implications for research and practice concerning feasibility of the MSMD intervention and research designs of co-production between stakeholders to students with profound intellectual and multiple disabilities and researchers.

Conclusions: It will potentially contribute to the evidence-based knowledge of how to support development and educational approaches for the target group.

Caring for unfamiliar persons with profound intellectual and multiple disabilities

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Background: Persons with profound intellectual and multiple disabilities are highly dependent on others to get their needs fulfilled (Granlund, Wilder, & Almqvist, 2015). Therefore, high-quality care is crucial. One important element of care is the relationship between direct support persons (DSPs) and the person with profound intellectual and multiple disabilities (Nieuwenhuijse et al., 2020). This study addresses the experiences DSPs have made in caring for unfamiliar persons with PIMD. Implications are derived on how high-quality care can be assured in such care scenarios.

Method: A multi-perspective approach revealed the experiences of twelve participants (seven professional DSPs, three relatives, two persons without experience with people with profound intellectual and multiple disabilities) within a group discussion and three problem-centered interviews. Data collection and analysis were oriented towards Grounded Theory Methodology (Strauss, 1998; Strauss & Corbin, 1996).

Results: Caring for people with profound intellectual and multiple disabilities goes along with different forms and degrees of insecurity in DSPs. Handling these insecurities covers various strategies: unassisted acting, cooperation and adhering to common (institutional) regulations.

Conclusions: The study revealed the complexity of having to deal with insecurities in care situations including unfamiliar persons with profound intellectual and multiple disabilities. Actions to support DSPs in such scenarios need to be undertaken. A follow-up study focuses on the role assistive technology could play to do so.

Odor detection in children and teens with profound intellectual and multiple disabilities

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Background: People with profound intellectual and multiple disabilities are polymedicated. Some drugs have side effects on odor and/or taste through neurological mechanisms. This study aims to study the influence of medication on the olfactory detection responses in children and teens with profound intellectual and multiple disabilities.

Method: Twenty-two children and teens with profound intellectual and multiple disabilities (7-18 years old; M=13.09; SD=3.3) took part in this between-groups study design. The participants' psychopharmacological profile was determined after analysis of their drug consumption. Sub-groups were formed based on known effects of drugs on olfaction and/or taste according to PubMed, Swissmedicinfo and Micromedex. Participants were exposed to two Sniffin' Sticks with alimentary standardized odors (orange, garlic). Both the order and the side of stimuli presentation were counterbalanced. Participants' behaviours were filmed in odor versus neutral condition. The response variable is head alignment on the stick. Data have been coded using EUDICO Linguistic Annotaor (ELAN, v. 5.9) in terms of occurrences or duration. Inter-observer reliability, calculated on 20% of the data, was found to be fair.

Results: Analyses are currently in progress.

Conclusions: The results are expected to enable a better understanding of children's odor treatment condition.

Research agenda for profound intellectual and multiple disabilities from professionals' perspective

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Background: Persons with profound intellectual and multiple disabilities may benefit from research that is specifically targeted at them and their support. This study aims to identify research priorities from professionals' perspective, as input for further research.

Method: A broad range of Dutch professionals in the support of persons with profound intellectual and multiple disabilities participated in this study. The research agenda was composed based on three phases. The first phase consisted of an online inventory of themes or questions professionals deemed important for future research. Professionals were asked to mention up to five questions that persons with profound intellectual and multiple disabilities might benefit from if studied. In the second phase, professionals could choose their priorities from main themes and sub-themes that were based on analyses of the first phase. The third phase consists of a focus group with professionals, in which the preliminary research agenda can be discussed.
Results: This study is currently being conducted. We aim to present a final research agenda regarding profound intellectual and multiple disabilities from Dutch professionals' perspective.
Conclusions: The research agenda for profound intellectual and multiple disabilities from professionals' perspectives can be used as practice-based input for further research. Additionally, answers available from research that are supposed to be of benefit can be shared with or implemented in practice.

Emotions in daily life of people with profound intellectual and multiple disabilities: Analysing the influence of physiological changes

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Background: Due to the highly individual behaviour signals of people with profound intellectual and multiple disabilities, achieving a deeper insight into their emotional expression is difficult. Our research aims to discern the potential relationship between physiological changes and inner states to reduce their dependence on others, improve their communication and address their needs.
Method: Within a single case research approach, baseline phases and daily activities of two persons with profound intellectual and multiple disabilities were recorded with additional measurement of heart rate (variability) for more than seven months. Afterwards, the recordings were annotated using an emotional valence scale. These annotations of inner states serve as the basis for statistical analysis regarding physiological differences between the different activities and for training of machine-learning models.
Results: Regarding the correlation between heart rate (variability) and inner states, an evaluation is conducted to analyse the assumption of their meaningful relationship followed by testing if the features of different inner states are statistically different. To predict the potential inner state, machine-learning models are created and evaluated using established machine-learning metrics. The results will be presented.
Conclusions: The results will broaden the understanding of emotional expression of people with profound intellectual and multiple disabilities, and provide implications for their daily life embedded in a quality of life concept.

Assessing cognition of persons with PIMD with the Tactile Working Memory Scale

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Background: The aim of this study was to develop and adapt methods of assessing cognition, especially the working memory, in individuals with profound intellectual and multiple disabilities, and therefore often considered as difficult to be assessed by standardized psychological assessment instruments.
Method: Three young person with severe or profound intellectual and multiple (including sensory) disabilities participated this qualitative research. They were assessed with individually modified Bayley Scales III. The assessments were video recorded and further analyzed by using the Tactile Working Memory Scale (TWMS), a method for observational assessment of persons with congenital deafblindness.
Results: Preliminary results about the usability of the TWMS to assess persons with profound intellectual and multiple disabilities, and the inter-rater reliability of observations through TWMS, will be presented. These preliminary results suggest that the TWMS is an applicable method for analyzing tactile working memory in videoed assessments, with some limitations regarding the environmental and interactional arrangements of the situations.
Conclusions: Based on the preliminary results, there are applicable methods and practices to assess cognition of persons with profound intellectual and multiple disabilities, but the elements of interaction, environmental elements and the assessor and observer effects must be regarded carefully.

Ecological self-awareness (ESA) development in children with PIMD: a longitudinal study

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Background: The aim of the study is to observe the evolution of ESA expressions 5 years after a first measurement.
Method: ESA is a primary and pre-reflexive form of self-awareness, developed through the interaction of the infant with its body and physical environment. The Self-Awareness Observation List for children with profound intellectual and multiple disabilities (SAOL-PIMD) (Dind, 2020) was developed in order to observe expressions of ESA in this target-group. In 2015, the SAOL-PIMD was administered to 18 children with profound intellectual and multiple disabilities (aged 7-12 years). Results allowed to distinguish three profiles of ESA expressions, contrasted by the quantity, diversity and complexity of behaviors expressed. Five years later, the SAOL-PIMD has been administered again to five participants, following the same procedure.
Results: Analysis are currently in progress.

Conclusions: This longitudinal study is the first to observe the development of ESA in children with PIMD. It will allow to verify if ESA develops naturally in children with PIMD over the years as in typical children. Next step will be to implement an intervention program aiming to teach ESA related skills.

Track 3d: Diverse Conditions

PRESENTATIONS IN A SYMPOSIUM

The body in diagnostics and interventions

The body experience questionnaire for adults with mild intellectual disability or borderline intellectual functioning: Development and initial evaluation

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Background: Body experience is an important facet of psychosocial functioning that affects one's (mental)health and behaviour. To date, no questionnaire exists to measure body experience in adults with mild intellectual disability or borderline intellectual functioning. Therefore, the aims of this study were to develop a Body Experience Questionnaire (BEQ) tailored specifically to this group, and to evaluate its applicability, comprehensibility and reliability.

Method: The BEQ-mb was developed in five stages: concept development, focus group with six psychomotor therapists, cognitive interviews with five-, and pilot testing with 85 adults with mild intellectual disability or borderline intellectual functioning, and evaluation of the results of the pilot test.

Results: Some of the BEQ-mb items were evaluated as too abstract and therefore revised or removed. The internal consistency is good for the total scale ($\alpha = 0.84$) and the subscales body awareness ($\alpha = 0.84$) and body satisfaction ($\alpha = 0.80$), but low for the subscale body attitude ($\alpha = 0.48$). The test-retest reliability is excellent for the total scale and the subscales (ICC = 0.76 - 0.85).

Conclusions: With the development of the BEQ-mb, new opportunities for clinical examination and research on body experience are unlocked. Future research is needed to investigate its structural and convergent validity.

Interoceptive awareness and coping skills in relation to aggressive behaviour in people with mild intellectual disability or borderline intellectual functioning

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Background: Psychomotor therapy (PMT) is often used in Dutch care facilities to reduce aggressive behaviour in people with mild intellectual disability or borderline intellectual functioning. The aim of the present study is to evaluate the impact of interoceptive awareness (IA) and adequate coping skills (CS) on aggressive behaviour, and the correlation between these two mechanisms.

Method: Participants with mild intellectual disability or borderline intellectual functioning (n = 218) completed the Anger Bodily Sensations Interview - intellectual disabilities (ABSI-id) and the Coping Inventory for Stressful Situations (CISS-21). Their caregivers completed the Social Dysfunction and Aggression Scale (SDAS-9). IA and CS in the aggressive group (n = 111) and the non-aggressive group (n = 54) were compared. The correlation between IA and CS, and the difference in correlations between the aggressive and non-aggressive groups were also evaluated.

Results: The aggressive group scored significantly higher on IA than the non-aggressive group, while the non-aggressive group scored significantly better on task-oriented CS. Correlations between IA and CS were moderate.

Conclusions: Future research is needed to further clarify the impact of IA and CS on aggressive behaviour.

Clients' experiences of psychomotor therapy for anger regulation problems and aggressive behaviour

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Background: Psychomotor therapy (PMT), an experiential treatment with body experience and movement as cornerstones of its approach, is often applied in Dutch clinical practise to address aggressive behaviour in people with mild intellectual disabilities or borderline intellectual functioning. The aim of this study is to explore clients' experiences of PMT.

Method: Seven clients were interviewed about the perceived outcomes and the helpful aspects of PMT. All clients completed their treatment a month prior to the interview. An Integrative Phenomenological Analysis was used to analyse the data.

Results: According to the clients, becoming aware of increasing tension and/or learning to down regulate the tension were targeted at in therapy. They emphasised both the possibility to learn by doing as well as the therapeutic alliance as essential to create a save though motivating context where clients can experiment with alternative behaviour. As a result, the clients perceived fewer aggressive outbursts and an increased self-esteem.

Conclusions: People with mild intellectual disabilities or borderline intellectual functioning experience PMT as a helpful intervention to learn to deal with anger and aggression. By taking the body as a starting point in PMT, opportunities are created to explore as well as to experiment with emotion recognition and (new) behaviour.

Evaluation of a psychomotor intervention for people with mild intellectual disabilities or borderline intellectual functioning who have experienced sexual abuse

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Background: People with mild intellectual disability or borderline intellectual functioning who have experienced sexual abuse, experience a broad range of behavioural, psychological and body-related problems. The aim of the present study is to evaluate a recently developed psychomotor intervention, based on theory and practice-based consensus. This intervention aims to regain a feeling of safety by recovering contact with and control over the body and by enhancing contact with other people. Improving body experience, regulating arousal and emotions and obtaining adaptive coping skills are important themes.

Method: Within a (non-concurrent) multiple baseline across subjects design, ten participants weekly report on designated outcomes using a personalised questionnaire. In addition, the short version of the Brief Symptom Inventory (BSI-18), the Diagnostic Interview of Trauma and Stressors for people with MID (DITS-MID), the Coping Inventory for Stressful Situations (CISS-21) and the Body Experience Questionnaire for MID-BIF (BEQ-mb) were administered at baseline, pre- and post- intervention and at follow-up.

Results: Data are currently being collected. The intervention and preliminary results will be presented.

Conclusions: This study contributes to the development of an evidence-based psychomotor intervention, focused on regaining a feeling of safety and diminishing the negative impact of sexual trauma for people with mild intellectual disabilities or borderline intellectual functioning.

ORAL PRESENTATIONS

Epilepsy and nonepileptic myoclonus in adults with Angelman syndrome

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Background: Epilepsy occurs frequently in individuals with Angelman syndrome. In a Dutch study on Angelman syndrome in adulthood, epilepsy appeared to change into adulthood. Some adults developed prolonged episodes of rhythmic shaking while awake, known as nonepileptic myoclonus (NEM). The aim of this study was to provide insight into the characteristics of epilepsy and nonepileptic myoclonus in Angelman syndrome in adulthood.

Methods: A descriptive, cross-sectional study was conducted among adults with Angelman syndrome. Information was obtained by questionnaires, (telephone) interviews and study of medical records and video fragments.

Results: 67 adults with Angelman syndrome (aged 18-82 years), of whom 84% had epilepsy, were included in the study. Active seizures were present in 41% of the adults. Tonic-clonic seizures and absences were most common. Anti-epileptic drug (AED) withdrawal failed in 86%. NEM occurred in 25 adults, and started first in puberty. Duration of the episodes varied from seconds to hours. Triggers for NEM were identified in 88% of adults. Most frequent triggers were fast or unexpected movements, tiredness, menstruation and illness.

Conclusions: A significant number of the adults with Angelman syndrome still experience seizures, and AED withdrawal failed in the majority. Nonepileptic myoclonus is common in adults, and often triggers can be identified.

Identifying barriers to quality of life in charge syndrome: A systematic review and meta-analysis

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Background: CHARGE syndrome (OMIM #608892) is a rare multisystem neurogenetic condition associated with variants in the CHD7 gene. The aim of the study was to systematically review the prevalence of behavioural and comorbid psychological, cognitive and physiological characteristics reported in the CHARGE syndrome literature.

Method: In accordance with PRISMA guidelines, the databases Ovid MEDLINE, Ovid PsycINFO, Ovid Embase, and PubMed were searched from database inception to May 2019 using OMIM terms for CHARGE syndrome. Pooled prevalence estimates were calculated using reliable, prespecified quality weighting criteria. The sensitivity of the results was analysed and meta-regression was conducted to identify the influence of co-occurring characteristics as a potential source of heterogeneity.

Results: Of the 46 eligible studies, data could be extracted for 1,860 participants. Among these, prevalence estimates were highest for developmental delay (79%), intellectual disability (63%), aggression (51%), self-injurious behaviour (47%) and sleep difficulties (46%). Meta-regression indicated statistical associations between self-injury and aggression, Autism and gross motor difficulties, sleep difficulties and heart defects and sleep difficulties and growth deficiency.

Conclusions: The review is the first to provide quality weighted pooled prevalence estimates for diagnostic signs, behavioural, psychological, cognitive and physiological characteristics, and comorbidities associated with a diagnosis of CHARGE syndrome.

Pediatrician's perspectives of the Autism Spectrum Disorder (ASD) Diagnostic Hub model

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Background: In response to a provincial need to increase access to timely assessment of autism spectrum disorder (ASD), a community-based capacity building model, the Diagnostic Hub, was developed in Ottawa, Canada. This model was designed by a specialized children's treatment centre, wich provided specialized support to community pediatricians to assess clients under the age of four with a suspected diagnosis of ASD. The present study is a program evaluation of this quality improvement initiative.

Method: Six participating pediatricians ($n=6$) agreed to participate in the semi-structured interviews consisting of 18 questions, which lasted between 20–30 minutes. The interviews were intended to gather perspectives of the pediatricians regarding the Diagnostic Hub model. The pre-structured case summary approach was used to analyze the data.

Results: Four primary themes emerged: the training offered, the multidisciplinary approach, the network of support, and the communication with the lead organization. Model strengths included the specialized training and access to resources and ASD specialists, while improvements could be made to reduce the post-assessment workload.

Conclusions: Preliminary evidence suggests that participation in the Diagnostic Hub may increase access to resources and support which in turn, may increase ASD assessment and diagnostic capacity among community-based pediatricians.

Intellectual disability and behavioural problems in Smith-Magenis syndrome

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Background: Smith-Magenis syndrome (SMS) is a genetic neurodevelopmental disorder characterized by intellectual disability and major sleep and behavioural disturbances. SMS is caused by a 17p11.2 deletion or mutation of the *RAI1* gene. This retrospective study explored intellectual disability severity and behavioural problems in these groups.

Method: We reviewed medical records from 84 individuals (aged 0-45 years), ascertained through a Dutch SMS specialty clinic.

Results: We included a total of 66 individuals with data on intellectual disability ($n=53$) and behavioural problems obtained with the Child Behaviour Checklist ($n=39$). Forty-seven individuals (71%) had a 17p11.2 deletion and 19 (29%) a *RAI1* mutation. The proportion of moderate/severe intellectual disability was higher ($p=0.01$) and median full scale IQ scores were lower (56.0 vs. 73.5, $p=0.001$) in the 17p11.2 deletion group. Median CBCL 6-18 scores were higher in the RAI1 group for: total (73.5 *vs* 66.0, $p=0.02$), somatic complaints (68.0 *vs*. 57.0, $p=0.000$), withdrawal/depression (69.5 *vs*. 55.0, $p=0.02$), and internalizing behaviour (66.0 *vs*. 55.0, $p=0.002$).

Conclusions: The results suggest that intellectual functioning is higher and behavioural problems are more severe in individuals with a *RAI1* mutation compared to those with a 17p11.2 deletion. This supports that genotype must be taken into account in research and clinical practice.

Engaging people with Down syndrome in a virtual drawing task: An experimental study

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Background: Down syndrome is a cause of intellectual disability which can greatly undermine an individual's success in learning environments. Participation in new and enjoyable activities, such as virtual reality (VR), may improve in-class behaviour and engagement. The primary aim of this study was to assess whether a VR leisure experience would improve classroom behaviour in young adults with Down syndrome.

Method: Seventeen young adults with Down syndrome were recruited from an organisation in South Australia. All participants completed two interventions in a within-subjects design: drawing in VR (Tilt Brush, developed by Google) and conventional drawing (paper and pencils). Participants returned to usual classroom activities after each intervention, on two separate days. On a seven-point scale, two educators observed changes in behaviour from better (+3) to worse (−3). Specifically, educator's assessed changes in mood, attention, activity, impulses, anxiety and withdrawal.

Results: Classroom behaviour significantly improved after VR drawing and conventional drawing, respectively. Irrespective of the intervention, participant's mood, attention and overall behaviour significantly improved. No significant differences were found between VR drawing and conventional drawing interventions.

Conclusions: This study adds to a sparse literature, demonstrating the benefits of a VR exposure to improve learning experiences for young adults with Down syndrome.

Arterial stiffness, physical activity and sedentary levels in adults with and without Down syndrome

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Background: To describe and compare physical activity levels (PAL), sedentary behaviours (SB) and arterial stiffness (AS) in adults with and without Down syndrome.

Method: Sixteen adults with Down syndrome (27±5yrs) and 16 adults without Down syndrome (27±5yrs) participated in this study. Informed consent was signed by each participant and legal guardians. Brachial and central systolic and diastolic blood pressure (BSP; BDP; CSP; CDP), central augmented pressure (AP), augmentation index (AIx), AIx normalized at 75 beats/min (AIx@75) and AS (carotid-femoral pulse wave velocity [cfPWV]) were measured by using the SphygmoCor-Xcel device. PAL and SB were assessed with GT3X-Actigraph accelerometers.

Results: Non-significant differences were found for SB (Down Syndrome = 458.48±108.78 vs. non-Down syndrome = 515.35 ±71.78 min/day), BSP/BDP (DS=116.31±10.9/68.4±9.3 vs. Non-Down syndrome=123.43±8.8/71.6±6.6 mmHg); CSP/CDP (DS=103.6±8.5/61.1±9.3 vs Non-DS=107.0±7.6/71.6±6.6 mmHg) and cfPWV (Down syndrome=5.5±.6 vs. Non-DS=5.8±.7 m/sec). The non-DS-group engaged in more moderate to vigorous PA than the Down syndrome group (66.71±22.10 vs. 31.76±17.37 min/day). The AP (Down syndrome=6.4±2.7 vs. non-Down syndrome=1.8 ±3.2 mmHg); AIx (DS=18.1±6.3 vs Non-Down Syndrome=4.9±10.3) and the AIx@75 (DS=12.3±8.8 vs non-Down syndrome=-1.6±11.7) were significantly higher in the Down syndrome group.

Conclusions: In the present study, both groups had similar values of central and peripheral blood pressure. Nevertheless, the Down syndrome group showed higher AP, AIx and AIx@75 values, which may be due to a higher aortic wave reflection.

Evaluating social cognition outcome measures in youth with Down syndrome

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Background: A 2015 NIH working group on Down syndrome identified the need for evidence-based outcome measures, and currently no measure of social cognition has been validated in youth with Down syndrome.

Method: Seventy-four youth ages six to 19 years old with Down syndrome were assessed on social cognition subtests of the NEPSY-II [Theory of Mind (ToM) and Affect Recognition] at two time points. Caregivers also completed the Social Responsiveness Scale, 2nd edition (SRS-2). Measures were evaluated for feasibility, test-retest reliability, practice effects, and convergent validity.

Results: Regarding feasibility, 87% completed the ToM, 71% completed Affect Recognition, and 77% of parents completed the SRS-2. Test-retest reliability ranged from poor to excellent (ICC = .40-.92), practice effects were not found, and convergent validity was poor to adequate.

Conclusions: All social cognition measures met criteria for a portion of the psychometric indices evaluated and would be appropriate for use in clinical trials with youth with Down syndrome. Results suggest the ToM subtest was the strongest measure, with high feasibility, adequate test-retest, no practice effects and adequate validity.

Knowledge gaps in Tuberous Sclerosis Complex (TSC)-Associated Neuropsychiatric Disorders (TAND) research: A scoping review

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Background: Tuberous Sclerosis Complex (TSC)-Associated Neuropsychiatric Disorders (TAND) encapsulates the non-physical characteristics associated with Tuberous Sclerosis Complex. Across the TAND levels of behavioural, psychiatric, intellectual, academic, neuropsychological and psychosocial difficulties, seven "natural clusters" have been identified. However, a comprehensive review of the TAND research literature across levels, methodologies and clusters has not been performed to date.

Method: Using a scoping review methodology, a systematic search of 12 electronic databases was conducted in February and March 2020. In accordance with PRISMA guidelines, inter-rater reliability was established by two reviewers at each stage of abstract screening, full text review and data extraction. Quality appraisal ratings were also assigned to determine the overall quality of published TAND studies.

Results: 2,841 results were returned, with 231 studies included in the final analysis after sequential elimination (67% cohort studies, 20% case studies, 13% animal studies). Few studies explored TAND manifestations in older adults (<1%), with an overall paucity of interventional TAND research and studies specifically relating to scholastic and psychosocial quality of life clusters.

Conclusions: This scoping review contextualises the existing TAND research landscape. It is evident that several TAND clusters are under-researched. Greater emphasis also needs to be given to remote methodologies and behavioural interventions in future TAND research.

Clinical variability in individuals with ATR-X syndrome in the Netherlands

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Background: The Alpha Thalassemia mental Retardation syndrome, X-linked (ATR-X syndrome) is a rare genetic disorder characterized by alpha thalassemia, intellectual disability, facial characteristics and genital abnormalities. Detailed descriptions of the clinical phenotype are rare. The aim of this study was to describe the clinical phenotype of ATR-X syndrome.
Methods: Data was collected through questionnaires, interviews, physical examination and the study of medical records.
Results: Twenty-two individuals, aged 2-68 years old, were included. Three individuals were deceased at the time of the study. All individuals had a variable degree of intellectual disability. Alpha thalassemia was found in 30% and genital abnormalities in 70% of the individuals. First health problems, most frequently feeding problems, started in the neonatal period in the majority. Other main reported health problems were reflux (59%), constipation (72%), periods of not eating or drinking (45%), heart defects (28%), epilepsy (33%), scoliosis/kyphosis (48%), visual impairment (61%) and hearing loss (38%). Behavioral problems (90%) and sleeping problems (64%) also occurred frequently.
Conclusions: We report on the largest cohort of clinically studied individuals, including the oldest individuals, reported to date. Clinical knowledge is essential to improve care for the individuals with ATR-X and to evaluate future therapies for this group.

The power of 1: N-of-1 studies in rare genetic neurodevelopmental disorders

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Background: Millions of people worldwide are affected by one of the nearly 6000 rare genetic disorders, often associated with intellectual disability. Interventional research is challenging due to vulnerable, small and heterogeneous patient populations. To improve the use of N-of-1 studies, randomized, controlled, multiple crossover trials within single patients, in rare genetic neurodevelopmental disorders, we systematically reviewed the literature and formulated recommendations for future studies.
Method: EMBASE and MEDLINE were searched for N-of-1 studies in rare genetic neurodevelopmental disorders. Information was recorded on types of interventions, outcome measures, validity, strengths and limitations. Qualitative and descriptive analyses were performed.
Results: Twelve studies met inclusion criteria, including both single trials and series. Main strengths were the use of personalized and clinically relevant outcomes. Limitations included lack of power analyses and the use of ancillary statistical analyses. Generalizability was compromised due to limited use of validated and generalizable outcome measures.
Conclusions: Properly executed N-of-1 studies may provide a powerful alternative to larger randomized controlled trials in rare disorders. We provide recommendations for future N-of-1 studies with a focus on patients with ID, ultimately optimizing evidence-based and personalized care.

Methylphenidate for ADHD in Smith-Magenis syndrome: A protocol of an N-of-1 series

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Background: Smith-Magenis syndrome (SMS) is a rare genetic neurodevelopmental disorder characterized by intellectual disability (ID) and severe behavioural and sleep disturbances. Many patients with SMS are diagnosed with attention-deficit/hyperactivity disorder (ADHD), a condition often treated with methylphenidate (MPH), although efficacy may differ with regards to aetiology and comorbidity. The primary aim is to examine the effectiveness of MPH in individuals with SMS and ADHD.
Method: We will apply an N-of-1 series of double-blind randomized and placebo-controlled multiple crossover trials in six participants. Each N-of-1 trial will consist of a baseline period, a dose titration phase, three cycles of alternating intervention periods each followed by a 7-day washout period, and a follow-up measurement. The primary outcome measure is the Strengths and Difficulties Questionnaire. Secondary outcome measures include the Emotion Dysregulation Inventory and Goal Attainment Scaling.
Results: Participants will receive personalized evidence of the effectiveness. Data will be aggregated to investigate the effectiveness of MPH for ADHD in the whole SMS population.
Conclusions: The protocol presents the first properly powered N-of-1 study in a genetic syndrome incorporating personalized outcome measures. It provides a much-needed bridge between practice and science, ultimately optimizing evidence-based and personalized care.

Initial diagnosis of autism spectrum disorder in adults in the Geneva area: Clinical, personal and procedural aspects

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Background: Our outpatient clinic, affiliated to the Geneva University Hospitals (Switzerland), is dedicated to mental health of adults with intellectual and developmental disabilities and/or autism spectrum disorders. We assessed the new demands for care in 2018, and especially for diagnostic evaluation of autism spectrum disorders.
Methods: Retrospectively, clinical and demographic data were analyzed. Our diagnostic assessment of autism spectrum disorders is

based on a psychiatric interview by experienced clinicians (psychologist, psychiatrist), screening instruments (Empathy Quotient, Autism Spectrum Quotient) structured assessments (Autism Diagnostic Observation Schedule, Autism Diagnostic Interview-Revised) and the medical history of the developmental period. This is completed by the assessment of frequent comorbidities such as mood and anxiety disorders, attention deficit disorder, intellectual and developmental disorders, and others.

Results: 86 adults initiated clinical visits in 2018. 43 diagnostic first lifetime ASD assessments were conducted. For 29 patients, a diagnosis of autism spectrum disorders was established (13 females, 42%; 16 males).

Conclusions: The high number of first lifetime diagnosis of autism spectrum disorders in adults is intriguing, and especially the important part of newly diagnosed female patients. Several explications are discussed, among them: the increasing awareness in patients and clinicians, the adequacy of the diagnostic criteria of autism spectrum disorders for female patients, the importance of immigration.

Exploring sensory profiles in children with neurodevelopmental conditions

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Background: The release of the *DSM-5* brought changes to the classification of autism spectrum disorders. These include highlighting hyper- and hyporeactivity related to sensory stimuli, as well as emphasizing sensory interests as diagnostic criteria. Although sensory features are neither pathognomonic nor exclusive for autism spectrum disorders, they appear to be significantly more common in people with autism spectrum disorders than in people with other neurodevelopmental disorders.

Method: A thorough understanding of children's sensory specialties is important because they can lead to behavioral and performance problems and can interfere with a child's integration into a community. An understanding of the specific patterns of sensory specialties can help develop explanatory models for the formation and maintenance of sensory specialties and it provides the basis for more effective prevention and treatment strategies. The aim of the project is to compare sensory characteristics of children with ASD with a group of children with intellectual disabilities as well as with a control group of typically developing children ($N = 30$ per group). Sensory specificities are assessed by the Sensory Profile 2, a short form parent questionnaire for children.

Results/Conclusions: Similarities and differences of the groups are discussed and implications for research and practice are elaborated.

Ocular findings in 142 individuals with 22q11.2 deletion syndrome

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Background: 22q11.2 deletion syndrome (22q11.2DS) is a multisystem disorder caused by heterozygous microdeletions on chromosome 22q11.2, with an incidence of 1:3000 live births. Characteristics include congenital birth defects, intellectual disability and neuropsychiatric disorders. Previous studies on ocular findings in children, reported an increased prevalence of refractive errors and strabismus.

Method: A retrospective chart review of individuals with 22q11.2DS who underwent ophthalmic examination in one of three Dutch hospitals. Visual acuity, refraction, orthoptic, fundoscopy and slit lamp results were extracted.

Results: One hundred and forty-two individuals (44% male, median age 8.5 [0.0-56.8] years) were included. Retinal tortuosity was reported in 32%, posterior embryotoxon in 21%, strabismus in 13%, optic disk abnormalities in 15% and amblyopia in 11%. Three percent had low vision (≥0.5 logMAR). The majority of individuals had mild (33%), moderate (24%) or severe (18%) farsightedness. Nearsightedness was seen in 13%. High astigmatism was seen in 27% of individuals. Weak positive correlations were found between age and astigmatism ($p<0.05$, R 0.2-0.3) and a shift from farsightedness towards nearsightedness with age ($p<0.05$, R0.24-0.26).

Conclusions: Clinicians should be aware of strabismus and amblyopia in 22q11.2DS at young age and refractive errors at all ages.

Age-related high-frequency hearing loss in adults with microdeletion 22q11.2

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Background: 22q11.2 deletion syndrome (22q11.2DS) is a multisystem disorder caused by heterozygous microdeletions on chromosome 22q11.2, with an incidence of 1:3000 live births. Characteristics include birth defects, intellectual disability and neuropsychiatric disorders. We studied hearing loss in adults with 22q11.2DS, an understudied topic in this genetic condition.

Method: A retrospective chart review including adults who visited an otolaryngologist at the 22q11.2 expert center of MUMC+ for routine health check including audiologic testing. Hearing loss was defined as >20 decibel at the range of 250-8000Hz.

Results: Thirty-two adults (47% male, mean age 26.3±10.7 years) with a molecularly confirmed 22q11.2 deletion were included. Hearing loss was found in 81% (95% CI: 67-96%), of whom 39% had a documented history of hearing loss. Forty-one percent of ears showed high-frequency hearing loss; most commonly sensorineural (45%), followed by conductive (19%), and mixed (5%). Moderate to weak positive correlations were found between age and hearing loss averaged over 0,5-1-2 kHz (r=0.45 p=0.000) and at 8000Hz (r=0.35, p=0.004).

Conclusions: High-frequency hearing loss appears to be common at a relatively young age, and increasing with age, in adults with 22q11.2DS. Our findings may have implications for future revisions of the practical guidelines for managing adults with 22q11.2DS.

The fear of being laughed at in neurodevelopmental disorders

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Background: This study is about gelotophobia, i.e. the fear of being laughed at, in individuals with different developmental disorders. Individuals with high-functioning autism spectrum disorder have been shown to have higher levels of gelotophobia than typically developing individuals. In this study, we first investigate whether this fear is syndrome-specific for autism spectrum disorder or whether individuals with other developmental disorders, specifically Williams syndrome and Down syndrome, also experience this. Second, we explore which traits could explain high levels of gelotophobia.

Methods: Parents of individuals with autism spectrum disorder (N=31), Williams syndrome (N=37) and Down syndrome (N=60) answered a series of questionnaires about gelotophobia, social impairments and personality traits.

Results: Results confirmed that individuals with autism spectrum disorder have significantly higher gelotophobia scores than the other groups (*p*'s < .001). They also reported comparatively more pronounced social impairments and a higher level of seriousness and bad mood, as well as a lower level of cheerfulness. A regression analysis showed that among all these factors, bad mood and seriousness were the most important predictors of gelotophobia.

Conclusions: The experience of gelotophobia seems to be a specificity of autism spectrum disorder, which appears to be related to their *negativity bias*, rather than to social cognitive impairments.

The process and logistics of testing motor competencies in children with autism spectrum disorder in the Czech context

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Background: Motor competencies and their early diagnosis play the key role in the development of children with autism spectrum disorder. The starting point is the use of diagnostic instruments which can be managed by these children. For the Czech environment, it is necessary to adjust the management and logistics of the standard TGMD-3 and MABC-2 instruments from the original environment. Such adjustments are the aim of the study.

Method: Investigations of motor competencies using TGMD-3 and MABC-2 were conducted in 37 participants with autism spectrum disorder aged 7-10 years. The reactions were recorded: understanding, implementation, timing.

Results: Children cope with the testing with respect to the following criteria: before starting the testing, a visualized course is presented. The last station is a reward. Stations are arranged in a semicircle, progress arrows visibly marked beginning and end. Subtests are visually highlighted. Each participant has an assistant, who motivates to complete, but does not intervene. Sufficient time is allowed for probands.

Conclusions: Children with autism spectrum disorder aged 7-10 years can handle the standardized TGMD-3 and MABC-2 motor tests, with some adjustments to the communication and motivation channels, as well as management and logistics of the investigation process. Further work is being done to specify the manual, including the role of the assistant.

POSTER PRESENTATIONS

Puberty induction in boys with CHARGE syndrome and hypogonadism: Experiences of patients and parents

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Background: CHARGE syndrome is a rare and complex disorder with an incidence of 1:15000 to 1:17000 live births and is associated with a wide range of issues, including, but not limited to, coloboma, congenital heart disease, atresia of the choanae, retardation of growth and development, hypogonadotropic hypogonadism, ear abnormalities and hearing loss. Due to hypogonadotropic hypogonadism, 60-88% of children with CHARGE syndrome have no spontaneous pubertal development and need hormone replacement therapy. There is a lot of uncertainty about the optimal treatment, including concerns regarding possible side effects like an increase of behavioural problems. In boys, decision-making is even more challenging because of the availability of two different treatment options: human chorionic gonadotropin (HCG) and testosterone supplementation. We want to learn more about the effects of the different treatment modalities and the experiences of boys and men with CHARGE syndrome and their parents, in order to make a tool to guide the decision-making process.

Method: We aim to achieve this by a mixed-methods approach which includes in-depth interviews, questionnaires and medical chart review.

Results/Conclusions: Here, we will present the results of the in-depth interviews.

Comparison of intelligence tests in children with autism and impaired adaptive functioning

Chantanee Mungkhetklang[1]
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Background: To examine the difference between the Stanford Binet Intelligence Scale-Fifth Edition (SB5) and the Wechsler Nonverbal Scale of Ability (WNV) in children with low functioning autism.

Method: Thirty-seven children with autism aged 3-15 years (Mean= 6.45, *SD* = 3.49), who have Adaptive Behavior Composite scores from Vineland Adaptive Behavior Scales below than 30, were assigned. The participants were asked to do the WNV and nonverbal domain in the SB5. The IQ scores from both tests non-normally distributed were analyzed using the Wilcoxon signed-rank test.

Results: The results revealed that the IQ scores from the SB5 (Mean = 51.05, *SD* = 12.07) were significantly higher ($Z = -2.483$, $p= 0.013$) than the WNV (Mean =47.16, *SD* = 12.23). Furthermore, the subtest materials in the SB5 are more convincing for low functioning autism, as it mostly asks participants to use hands to do trial and error tasks rather than mostly pointing for the WNV.

Conclusions: The SB5 may be a better choice for pulling out the potential of the children with low functioning autism, which is usually underestimated due to their limited language skills. Our results are expected to raise awareness and enlighten practitioners about the differences in various cognitive tests, which would help to enhance the effectiveness of intelligence assessment of these individuals.

Scoping review of strategies for parent management of elopement behaviour among children with autism spectrum disorder

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Background: Participation in community recreation and leisure for children living with autism spectrum disorder contributes to health and quality of life. Child elopement is one barrier that can impede participation. Through this scoping review, we aim to assess the literature on strategies to support parents and caregivers with managing elopement behaviour.

Method: We are conducting a scoping review, guided by the Arksey and O'Malley framework and PRISMA-ScR checklist. The aim is to review literature regarding strategies to support parent and caregivers with managing children elopement behaviour in home and community environments. Search procedures were developed in consultation with a university librarian and included five electronic library databases. Two reviewers assessed abstracts and full text articles and a third reviewer provided arbitrations.

Results: A summary of the search results and key findings will be presented. Findings will include information on the types of studies, characteristics of the interventions or strategies, and related parent/caregiver attitudinal or behavioural outcomes.

Conclusions: This review will contribute to understanding about how parents and caregivers of children with autism spectrum disorder can be supported in home and community environments through addressing child elopement behaviour, an issue that may often prevent family participation in community recreation and leisure activities.

Track 4: Ethics, Politics and Diversity

PRESENTATIONS IN A SYMPOSIUM

Self-advocacy for policy priorities

Health and social policy priorities of adults with intellectual disability in South Africa

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Background: The aim of this study is to explore the health and social policy priorities identified by people with intellectual disability in South Africa.

Method: A scoping review from 1994-2020 on policy priorities for people with intellectual disability will be conducted. Semi-structured interviews will document the views of South African adults with intellectual disability on their policy priorities, a sample of approximately 10 participants with intellectual disability, aged 18 years and above.

Results: This presentation will report on the findings of the scoping review and preliminary findings on the policy related concerns of South African participants with intellectual disability.

Conclusions: The implications of participants priority health and social policy concerns will be considered in relation to current public health and social policies which impact on the lives of people with intellectual disability in South Africa.

Developing a conceptual framework for policy self-advocacy by adults with intellectual disability

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Background: This study aims to inform the development of a conceptual framework for self-advocacy by persons with intellectual disability in the South African context.

Method: Empowerment theory, and the social and the human rights models will be used as theoretical frameworks for this study. Participants will be purposefully sampled. Data will be collected through a scoping literature review, semi-structured interviews and focus groups with policy makers and implementers, carers and persons with intellectual disability, with interviews analysed thematically using Atlas-ti.

Results: This presentation will report on preliminary findings to inform a contextually appropriate conceptual framework for policy related self-advocacy by adults with intellectual disability in South Africa.

Conclusions: The implications of the suggested components of a self-advocacy framework to support policy input by adults with intellectual disability will be considered in terms of what may best accommodate the active participation of adults with intellectual disability in influencing public health and social policy decisions which impact on their lives

Strategies to promote self-advocacy for people with intellectual disability in South Africa

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Background: This study investigates what strategies are best suited to develop the capacity of people with intellectual disability to self-advocate for inclusion of their priorities in social and health related policy and service development processes in South Africa.

Method: Triangulation of data from a scoping literature review, document analysis and semi structured interviews with people with intellectual disability and other staff working at non-governmental and disabled people's organisations will inform the development of a local self-advocacy toolkit.

Results: This presentation will report on preliminary findings to inform tangible strategies to improve the self-advocacy skills of people with intellectual disability in a South African context.

Conclusions: The implications of identified strategies for skills training to enhance policy participation will be considered in terms of what may best accommodate adults with intellectual disability's active participation in influencing public health and social policy decisions which impact on their lives.

ORAL PRESENTATIONS

Detection of abuse of adults with intellectual and developmental disabilities in services

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Background: The review aimed to address the following research questions: "How is abuse detected within services for adults with intellectual and developmental disabilities?" and "How can we improve such detection?"

Method: The global literature in PsychINFO, PsychARTICLES, Medline, CINAHL Plus with Full Text, Criminal Justice Abstracts, SCOPUS and PubMed were searched. Ancestry searches were conducted. Studies referring to children or adolescents, older adults, and adults without intellectual or other developmental disabilities were excluded, as were non-empirical items (i.e., books, letters, reviews), those not written in English, and those where the topic of the article did not relate to abuse perpetrated by professionals or staff, or quality of care within services. The methodological quality of studies was assessed using the Mixed Methods Appraisal Tool.

Results: Searches resulted in 48 articles being identified. Several risk factors and protective factors related to victim characteristics, perpetrator characteristics and organisational factors were summarised. Strategies for detecting abuse within services include overt or covert surveillance and measures of service culture and atmosphere. However, methodological constraints limit the reliability and validity of findings.

Conclusions: Evidence suggests the abuse of adults with intellectual and developmental disabilities in services is common, but may be predictable and preventable.

Distory: Intergenerational learning about the history of intellectual disability in Canada

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Background: The *DiStory* project supports intergenerational sharing of knowledge about the history of institutionalization of people with intellectual disabilities and its harmful legacy. The purpose is to guide development of curriculum materials for postsecondary social service students. Here we focus on an ethical tension arising in this knowledge sharing.

Method: The inclusive project team includes co-researchers with intellectual disabilities (survivors of institutions and younger individuals growing up in community) and academic and community-based co-researchers. Arts-based workshops and small group and one-on-one discussions are used to share knowledge and design curriculum materials reflecting co-researchers' ideas about what students need to know.

Results: Through sharing difficult experiences, survivors and younger co-researchers gained knowledge and different perspectives about institutionalization and ongoing impacts of institutionalized care. Despite preparation and provision of ongoing support to both co-researcher groups, some younger co-researchers felt silenced, understanding their negative experiences as "not as bad" as those of survivors. Survivors empathized, yet some still struggled to make space for younger co-researchers' stories.

Conclusions: Intergenerational transmission of experience was identified as important for social change by co-researchers with intellectual disabilities. Unanticipated ethical tensions necessitated vigilance, immediate attention, thoughtful and collaborative responses to promote safe and caring experiences with intergenerational learning.

Personalism and new eugenics movement

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Background: The aim of the paper focuses on research by Reinders et al. (2021) on the new eugenics movement. They claim that euthanasia and physician assisted suicide for poor Quality of Life reasons may be the emergence of a new eugenics movement. This paper argues a corollary follows from the nexus between the "internal" and "external" practices of different views of intellectual and development disabilities.

Method: The methodology is through philosophical lens of Personalism. The paper explains Personalism and uses Reinders et al.'s research to explore their claim. The methodology is interpreted to develop a personalist corollary.

Results: The research finds the claim has validity.

Conclusions: The paper's corollary notes that albeit international conventions, unless persons living with the experience of an intellectual disability and/or developmental disability lives are valued and considered as important to society, such persons are at risk having disposable lives.

CEOs' strategies to stimulate the sharing and application of knowledge in intellectual disability care organizations

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Background: To improve and innovate the quality of care of people with intellectual disabilities, healthcare organizations are challenged to optimize the sharing and application of knowledge. Although CEOs play a key role in these processes, it is still unclear how they fulfil this role. Therefore, we explored their strategies to stimulate professionals to share and apply knowledge in their daily work, as well as the contextual factors influencing these strategies.

Methods: Data were collected through individual semi-structured interviews with eleven CEOs of care organisations for people with ID in the Netherlands. The interview guide was based on our systematic review (Kersten et al., 2018) and on theoretical insights. Data were analysed using an inductive, thematic approach.

Results: We have discerned four strategies applied by CEOs. According to the CEOs, the execution of these strategies was influenced by factors related to the internal and external context. In the internal context persons and the organizational context are en/disabling. The external context involved the socio-political environment and collaborative partnerships ID care organisations are involved in.

Conclusions: While aiming to optimize knowledge processes in their organisations, CEOs appear to be actively involved in both the design and the execution of strategies.

Bridging the know-do gap: Contextual factors stimulating new professionals to apply knowledge

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Background: While aiming to improve and innovate the quality of care and quality of life of people with intellectual disabilities, healthcare organizations deploy strategies to stimulate the sharing and application of knowledge of (new) professionals. However, the use of (new) knowledge in daily practices, in other words: bridging the know-do gap, remains challenging to healthcare organizations. Therefore its worthwhile to explore what new professionals themselves consider to be the most essential contextual factors to improve the application of knowledge.

Methods: A concept mapping study in which groups of new professionals participate is conducted. In order to collect statements on ways in which their organizations can stimulate the application of knowledge focus groups were organized with influx of direct care staff, intellectual disability physicians and psychologists and new direct care staff from outside the care sector. Afterwards, participants individually prioritized and clustered these statements, resulting in concept maps. An expert group has interpreted the concept maps.

Results: During the presentation we will provide an overview of the contextual factors which according to new professionals stimulate their application of knowledge.

Conclusions: The results of this study are a starting point to further explore how care organizations effectively can bridge the know-do gap.

How news portrayals about prenatal diagnosis affect stigma toward mothers and people with trisomy 21

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Background: News portrayals of affected individuals (i.e., exemplars) are frequently used by journalists to illustrate or personalize abstract or complex issues, and to evoke emotions (Zillmann, 2006). Little is known about how rather subtle changes in exemplar depictions may increase or reduce the stigmatization of social groups like persons with trisomy 21. This study aims to examine possible unintended stigmatizing exemplar effects, such as increased negative emotional reactions and social distance towards mothers and people with trisomy 21, resulting from reading news portrayals about prenatal diagnosis.

Method: In a $2 \times 2 \times 3$ between-subjects online experiment $N = 958$, respondents read stimulus articles featuring an exemplar of a pregnant woman that was manipulated regarding *age* (27 years vs. 41 years), *relationship status* (romantic relationship vs. single), and *prior knowledge* about trisomy 21 (positive vs. negative vs. none).

Results: Depictions of older and single mothers in a supposedly disadvantageous situation evoked negative emotions. Social distance was directly affected by depicted age and indirectly affected by the combined exemplar characteristics via anger as mediator.

Conclusions: Overall, our findings highlight the manifold effects of news articles about prenatal diagnosis. Moral, journalistic, and practical implications for strategic anti-stigma communication will be discussed.

UN CRPD: Does it need to be that hard?

Cath Basterfield[1]
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Background: The United Nations Convention on the Rights of Persons with Disabilities 2006, Article 21 says in part "…access to information ….provid(es) information intended for the general public to persons with disabilities in accessible formats." This paper will ask how does the UN CRPD document address Article 21?

Method: A number of versions of the UNCRPD were reviewed, including: 2007 Easy Read (English), 2020 Easy English, publicly accessible Plain Language and original legalese.

Results: These were analysed on a like for like basis using the Flesch-Kincaid Reading Scale. There was no significant difference in the equivalent reading level of the plain language and Easy Read, being 8.3 and 8.2. The legalese was significantly higher, at an equivalent of 18.4 grade reading level. The Easy English was significantly lower at an equivalent grade 3.3 reading level. Language analysis, including sentence length, vocabulary choices and type of sentence structure were completed. Formatting and image selection were also considered.

Conclusions: There is now an Easy English version of the UN CRPD available to the public at a reading level considerate to people who have low literacy. There remains significant work to be done to ensure Article 21 of the UNCRPD is addressed.

Attitudes towards people with intellectual disability associated with integrated sport participation

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Background: The current study had two aims: 1) to compare implicit and explicit attitudes between adults who participated in integrated sport events and a comparison group who did not, and 2) to examine the association between degree of involvement in integrated sport and attitudes about intellectual disability.

Method: 745 adults without intellectual disability completed an online survey measuring implicit and explicit attitudes: 295 who were involved in integrated sport activities with Special Olympics athletes, and a matched-comparison group of 450 adults who were not.

Results: Individuals who participated in integrated sport reported less negative behavioural and affective attitudes relative to the comparison group, with mixed results when examining cognitive attitudes. Groups did not differ on implicit attitudes. Greater involvement in integrated sport was related to some, but not all, aspects of explicit attitudes.

Conclusions: Involvement in integrated sport may be linked to how participants view intellectual disability, which has important implications for both enhancing social inclusion and for informing positive attitudes.

Revelland: A creative accessibility network to make performances both immersive and accessible

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Background: Revelland is a collaborative network (represented in Ireland, the United Kingdom, Belgium, the Netherlands, Bulgaria and Greece) that is passionate about finding ways to make live music performances both more accessible to a broader audience and more immersive.

Method: We aim to transform live music performances into multisensory events. By adding scent, taste, sight and touch, musicians take their audience on a journey of the senses. A journey through the emotions present within the music. An immersive experience that offers the audience a deeper understanding of the music. Making the live performances also accessible to people for whom hearing sound is not possible, attracting a broader audience.

Results: People with hearing impairments are often socially excluded from music performances; by adding sensory effects to live music performances, they will become more immersive and more accessible. This way we will work both on making music more accessible as well as on improving the experience of live music.

Conclusions: Musicians are being trained by international leading sense experts and monitored by an Inclusion Board that manifests the principle "Nothing about us without us." The musicians will get a deep insight in immersion, accessibility and sensory effects, and they will use these insights to transform their performances into multisensory events.

Restrictive measures in Swedish services for people with intellectual disability: What measures are used and why?

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Background: Swedish legislation does not allow the use of restrictive practices in community services for people with intellectual disabilities. The aim of this study was to identify if restrictive measures are used, and the reasons staff give for their use.

Method: A survey was developed, containing four Likert style questions and one free text question. The questions addressed the types of and reasons for restrictive measures, their intrusiveness for service users and the value to staff of their replacement. Respondents were asked what strategies are required to reduce restrictive practices. 250 surveys were completed by staff in group homes and daily activities services in one large Swedish municipality.

Results: Organisational factors outside of the control of staff contributed to the use of restrictive practices, such as the lack of proper staffing, the physical design of services, and available training or supervision. The main reason given for using restrictive measures was to protect and support the well-being of service users. A third of staff reported daily or weekly use of some restrictive measures.

Conclusions: Reducing the use of restrictive measures cannot be the sole responsibility of staff. It requires structural changes with engagement from senior management.

The conflation of theory and metatheory in critical ableism and Disability Studies research

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Background: As a part of my PhD research on the cultural representation of autism, my theoretical sub-aim was to align a consistent understanding of the social model of disability with my Cultural Studies project on the role of knowledge and nuance on autism in contemporary visual culture.

Method: My methodology followed Humanities-based inductive analysis of three case studies of 21st-century visual culture, with the help of existing critical disability theory, predominantly Fiona Kumari Campbell's notion of ableism. My thesis contains a critical review of established "declarations of criticality" in British academia.

Results: The field of Disability Studies revolves around research on the social model of disability, but this conception of disability on its own is meta-theoretical and meta-epistemological, which means that it is largely knowledge about knowledge. The adoption of meta-theory as a theoretical framework could inadvertently cause more difficulty to perform thorough study of diversity and representation because of a greater risk of logical inductive fallacies.

Conclusions: For Humanities research and teaching, I recommend a clearer distinction between theory and meta-theory in order to prevent unnecessary project obscurity in Disability Studies practices. It is important to be vigilant regarding one's motivation and intentions behind one's self-presentation as critical.

Quality of care as act of balancing

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Background: Building good relationships with care receivers is challenging because each of them is different. Person Centred Care requires the ability to individualize and therefore an inner flexibility to deal with judgements, emotions and caring behaviour. The caregiver needs 'inner space' (Carlo Leget).

Method: Based on a scoping review we developed a care model for balancing with regard to caregivers' psychosocial skills. We used the Aristotelian concept of looking for 'the middle' between two extreme opposites.

Results: We found 12 factors involved in inner balancing. Balancing takes place in three domains: the cognitive, the emotional/affective and the motivational/operational domain. They are connected with the capacities of judgment, empathy and creativity. More awareness of this inner dynamics makes it possible for caregivers to become more flexible in caring and working together in a team.

Conclusions: Reflection and self management of psychosocial skills that caregivers use, are needed to enhance the quality of life of care receivers. In order to individualize the caring practice caregivers have to become aware of their inner acts of balancing and how to create more inner flexibility.

Including the voices of people with intellectual disabilities in health research

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Background: People with intellectual disabilities experience health inequalities and face barriers to engagement in research that seeks to understand and address their health needs. The Scottish Learning Disabilities Observatory developed the Research Voices project, the first ever Citizens' Jury of people with intellectual disabilities focused on health research.

Method: A Citizens' Jury is a model of deliberative democracy that meaningfully involves members of the public in decisions that affect their communities. Citizens' Juries are demographically representative, and the process encourages critical engagement with evidence and rigorous deliberation. Over five days, the Jury heard from expert witnesses in policy, practice and lived experience and made 10 recommendations for research.

Results: A demographically representative Citizens' Jury was recruited (12 jurors recruited 16 - 66 years old). Participants deliberated on complex issues in health research including consent, ethical approval and inclusive research. Results include improvements in self-reported confidence and knowledge and demonstrated the importance of skilled facilitation for this group. An in-depth evaluation has identified the barriers and facilitators to engagement in this method.

Conclusions: An adapted Citizens' Jury supported by skilled facilitation can effectively support people with intellectual disabilities to engage with complex information and make informed recommendations on research.

Reclaiming vulnerability for a disability bioethics

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Background: Bioethical questions on disability matters are omnipresent. Disability studies and activism, and bioethics, however, have a conflicted history. Consequently, a thorough framework is lacking to analyse the ethics of clinical and public health interventions for disabled people, incorporating key ideas of disability studies.

In this conceptual study, we explore potential cross-pollination between these two fields, thereby contributing to a nascent *disability bioethics*.

Method: First, we review critiques of ableist biases in bioethics, highlight lacking ethical underpinnings in most claims made in disability studies and problematise the moral ideal of independency in some disability activism. Next, we analyse recent developments in both fields offering the potential for interdisciplinary overlap, such as feminist and queer bioethics, crip theory and the disability justice framework.

Second, we put forward the concept of vulnerability.

Results: Departing from traditional understandings of vulnerability as weakness or lack of autonomy, we build on recent feminist re-interpretations of this concept as a universal condition and a situational, political one at the same time.

Conclusions: Arguably, reclaiming vulnerability for disability purposes may offer the necessary analytical tools to dismiss mainstream bioethics' patronising approach to disability, while providing moral grounds for disability claims to solidarity and empowerment in clinical and public health contexts.

Parents' perceptions of internet opportunities and risks for their adolescents - A comparative study

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Background: To investigate the opportunities and risks of internet use as perceived by parents of adolescents with intellectual disabilities compared with parents of adolescents without intellectual disabilities.

Method: A national survey on Internet use from the Swedish Media Council was used. It was sent to a sample of parents of adolescents with intellectual disabilities, 13–20 years old, in special schools in four municipalities in Sweden ($n = 318$). Data of a reference group of parents with adolescents without intellectual disabilities was obtained from the Media Council. Comparative statistical analyzes were performed, and logistic regression to control for confounding factors.

Results: A significantly lower proportion of parents of young people with intellectual disabilities perceive risks and negative consequences with the internet and playing games compared to the reference group. However, a significantly higher proportion of parents of adolescents with intellectual disabilities perceive that their adolescent never uses smartphones and social media compared to the reference group.

Conclusions: The results provide new knowledge about the opportunities and risks of internet as perceived by parents of young people with intellectual disabilities compared with a reference group. Supporting internet use among young people with intellectual disabilities, in collaboration with their parents, could enable their digital skills and digital participation.

Conceptualizing equal dignity related to persons with intellectual disabilities

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Background: Equal dignity is deemed an underlying moral value of humanity. Consequently, it affects the support of people with intellectual disabilities. Contemporary theories, however, insufficiently help to reflect (inter)actions respecting dignity and (inter)actions witnessing indignity. Hence, a new language was sought that better lives up to the praxis of the moral idea of dignity and indignity, and critical reflection on it.

Method: Between 2015 and 2020 a Grounded Theory method was applied to construct a new language on equal dignity. Data collection comprised 43 written reflections and additional conversations by students Social Work, open observations, literature and researchers' own reflection.

Results: A vocabulary has been developed fostering the thoughts and discourses on equal dignity.

Conclusions: Equal dignity constitutes a social continual dynamic. It appears helpful to describe dignity in gerund-participles and in so doing it provides for a language that helps social work practitioners, researchers and educators to reflect on their work and the professional relationship with service users with intellectual disabilities.

Analysis of an abuse scandal

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Background: In May 2019, the British TV programme *Panorama* showed appalling abuse of people with intellectual disabilities and challenging behaviour in a small UK hospital, filmed by an undercover reporter. The Care Quality Commission (the national regulator for care settings) subsequently asked an independent reviewer (GM) to analyse their records, to examine how this abuse was missed.

Method: The CQC allowed access to all its inspection reports, and 17 CQC staff were interviewed, as well as some previous staff at the hospital, the local health commissioner, the local Safeguarding lead, two whistleblowers, and two advocates.

Results: Six inspections had taken place since the hospital was registered in 2015. There had been high rates of staff turnover, frequent use of agency staff, and high rates of restraint recorded at most inspections, but these data were difficult for inspectors to access. Numerous allegations of abuse had been made by service users; many of these allegations were later retracted. Several inspections rated the service as "good." The people interviewed had not considered abuse was occurring, but several felt "uncomfortable" in the service.
Conclusions: Inspections were very process-driven, examining many written records, but interviewing few service users or carers. Recommendations will be discussed.

Registration of mild intellectual disability in primary care, curse or blessing?

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Background: Knowledge about the existence of mild intellectual disability, can help general practitioners (GPs) in communicating with and (thus) providing appropriate care for the patient with mild intellectual disabilities. Dutch GPs register patients' complaints, symptoms and disorders using the ICPC (International Classification of Primary Care) coding system. But is this also the case for mild intellectual disability, which in fact isn't a symptom or disorder, but a characteristic? The aim of this research was to study whether GPs register and classify mild intellectual disability using ICPC coding.
Method: We compared (on individual level) the number of people with confirmed mild ID in a large Dutch database (Central Bureau of Statistics, CBS) with a database of Dutch GP's (Nivel Primary Care Database). This database uses routinely recorded data from GPs in a representative sample of the Dutch population.
Results: Only 14% of the people with confirmed mild intellectual disability is registered by Dutch GPs using ICPC code P85. Furthermore, only 0,33% of all people in the primary care database is registered using ICPC code P85.
Conclusions: Dutch GPs do not register mild intellectual disability consistently, nor uniformly. General guidelines as well as a clear and appropriate ICPC-code for registration of mild ID are currently lacking.

Assisted suicide and intellectual disability: A review of risks and vulnerabilities

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Background: Assisted suicide is a rapidly evolving phenomenon both in terms of new jurisdictions allowing assisted suicide and in expansion of scope in countries which currently have assisted suicide regimes.
Method: A particular concern is the increase in AS for people with cognitive and mental impairments in several low country jurisdictions and currently being debated in Canada.
Results/Conclusions: This paper will briefly review the developments in AS expansion and evaluate the risks and vulnerabilities that assisted suicide presents for people with intellectual and developmental disability.

Safeguarding the voice of people with a disability: Vulnerabilities in a pandemic

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Background: We propose a model of service delivery informed by citizenship that promotes the voice of people with a disability. The aim of this paper is to describe the vulnerabilities exposed by the pandemic, and suggest ways to mitigate against these vulnerabilities.
Method: A single case study will describe a model of service delivery informed by Ruth Lister's citizenship model, and how this model promotes the voice of a person with a disability with a complex presentation. It will also describe the vulnerabilities of this model in the context of a pandemic.
Results: The pandemic has exposed the fragility of human rights for people with a disability. The case study will describe the vulnerabilities and their impact on the person with a disability: impulses of paternalism, the effects of inconsistent consultation, and lack of systematic and sustained government measures in the early stages of the pandemic.
Conclusions: The citizenship model of service delivery continues to support the inclusion and participation of people with a disability. This paper will discuss the importance of sustained consistent consultation with the person with a disability, resisting the impulses of paternalism, and the need to value the health, safety and well-being of people with a disability.

Policy design during COVID-19 In Israel: The case of family centers for children with disabilities

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Background: This study aims to analyze the process of designing a disability policy as bricolage. We demonstrate our contention by describing the interactions among the multiple layers of governance and the macro, meso and micro conditions involved in delivering services through family centers for children with disabilities in Israel during Covid-19.

Method: The qualitative methodology included a content analysis of the Director General's Circulars dealing with the Covid-19 pandemic and a thematic analysis of two focus groups consisting of directors of centers from regional councils and urban municipalities.
Results: Although the macro level policy was designed to be equivalent throughout the country, there was variation in the supply of services during the first Covid-19 lockdown. Devolution of power to local governments in times of crisis works only partially.
Conclusions: Therefore, the national government officials must work with local authorities and find solutions for financially unstable municipalities and tools to deal with micro level challenges.

Mothers' perspectives on providing supported decision making to adults with Intellectual disability

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Background: To qualitatively examine the mechanisms, conflicts, and any changes experienced by mothers when assisting their loved one with intellectual disabilities in decision-making since the introduction of the Assisted Decision-Making Act 2015.
Method: Seven mothers with an adult child attending an adult care service for people with intellectual disabilities participated in one-to-one, semi-structured interviews about their experiences of assisted decision-making. Interviews were recorded with consent and transcribed verbatim. Data were analysed using inductive thematic analysis.
Results: Three main themes and 10 subthemes were identified. These were Care (Family, Services, Routine), Decision Making (Importance, Ability, 2015 Act), and Challenges (Conflict, Time, Limitations, Vulnerability). Decision-making was a challenging issue for families of adults with intellectual disabilities. The desire to protect often outstripped participants' acknowledgement of the individual with intellectual disabilities' right to choose. The 2015 Act was agreed with in principle, but caused concern in practice.
Conclusions: Research on assisted decision-making in an Irish context has been limited to date, particularly under the new legislation. This study attempted to provide a nuanced view by asking those directly affected, instead of discussing abstract implications. The findings indicate greater support and training in assisted decision-making is required for people with intellectual disabilities and their family members.

Using routine care data: Opinions and beliefs by people with intellectual or visual disabilities

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Background: In formal care for people with disabilities, data are routinely collected such as on physical, psychological, and practical characteristics, which could be a source of insights for improving care practices. With regard to the governance over care data for research, this study collected the opinions and experiences on this topic from people with intellectual disabilities or visual impairment (low sighted or blind).
Method: 36 adults took part (18-65 years old; M=42.2; SD=14.7; 47% female) of whom 20 with intellectual disability and 16 with visual impairment. 18 of the interviewees were from England, the United Kingdom, and 18 were from the Netherlands. Opinions and beliefs were assessed with a semi-structured interview and data were analysed inductively using the Framework approach (Ritchie & Spencer, 1994).
Results: People from both countries and both disability groups in general believed that using and sharing routinely collected care data, which they considered their own, would be important to improve the care and lives of people with disabilities. They also expressed concerns and worries.
Conclusions: Benefits, risks, and issues of ownership need to be taken into account in research with routinely collected care data. Implications for data governance are discussed.

Big ideas that changed the world of disability: Accessible theory for inclusive researchers

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Background: We aim to 1) explore how researchers with learning/intellectual disabilities can use and apply disability theory in their work, and in understanding their own experiences; 2) show academics that sharing theory with self-advocates is highly effective in changing our approach to research.
Method: We ran a webinar series for self-advocates and inclusive researchers, focusing on thinkers who have influenced the field of disability studies. These included the social model (Mike Oliver), eugenics (Darwin, Galton), power and surveillance (Foucault), suppression (Spivak) and access to knowledge (Freire). Each workshop used the principles of co-production to: present and explain the ideas; develop understanding through engagement in a practical activity; and discuss and relate to lived experience, with particular reference to COVID-19. An observer present at each session evaluated the success of the webinar in relation to the aims.
Results: The results are presented in the form of vignettes of each session.
Conclusions: Our research shows that people with intellectual disabilities are more than capable of understanding, applying and extending

theoretical ideas when these are presented in a meaningful way. Their contribution is essential in challenging exclusion and developing research in this field.

Moral values and the stigmatization of people with intellectual disabilities in personnel decisions

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Background: Based on the theory of intuitive moral judgements (*Moral Foundations Theory*: Haidt & Joseph, 2004), the current research aimed to shed some light on the role that moral values play for personnel decisions related to people with intellectual disabilities as applicants.

Method: A mixed-methods study (embedded parallel design) was conducted to investigate personnel decision-makers' moral values and attitudes towards people with intellectual disabilities. Qualitative and quantitative data of 109 German personnel decision-makers was collected via online surveys. Participants answered open and standardized questions about their values, company values and their attitudes towards the employment of applicants with intellectual and developmental disabilities (i.e., Down syndrome, autism spectrum disorder).

Results: Results indicate that a high emphasis on individual or progressive values (i.e., care, fairness and liberty) is associated with positive attitudes towards people with Down syndrome and autism spectrum disorder, while strong orientations towards loyalty, authority, and purity were linked with more stigmatizing attitudes (i.e., focus on lower efficiency).

Conclusions: The results allow a better understanding how moral values affect the stigmatization of people with intellectual disabilities in personnel decisions. They are also helpful for developing targeted interventions for the destigmatization of this group in employment contexts.

Inclusive translation and dissemination of special olympics health data

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Background: Special Olympics Research and Evaluation (R&E) supports Special Olympics International (SOI)'s health work by monitoring progress and measuring the impact of SOI's strategic plan. This presentation covers a collaboration between SOI and the University of Illinois at Chicago (UIC) to promote inclusive translation and dissemination and increase the accessibility of resources for a variety of audiences.

Method: Not all evaluation findings are accessible to athletes with disabilities, despite their participation in evaluation projects. UIC reviewed research materials, assisted SOI in the creation of an accessible and inclusive dissemination strategy, modified existing and developed new accessible resources, acquired feedback from an advisory group of self-advocates and other stakeholders, and assisted in dissemination. UIC collaborated with an athlete who served as a co-evaluator in this project. The co-evaluator provided feedback on the resources, recruited self-advocates for the advisory groups and co-facilitated these groups.

Results: This presentation will cover the lessons learned in the partnership between SOI and UIC and will provide examples of how the inclusivity and accessibility of resources was improved in the course of the collaboration.

Conclusions: Knowledge translation of research is key to empowering adults with disabilities to become health advocates and to participate in future health interventions.

Effects of labor rights education with video modeling on self-advocacy of students with intellectual disability

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Background: The purpose of this study was to examine the effects of the education on human rights of labor with video modeling on self advocacy of high school students with intellectual disabilities.

Method: An experimental group (15 students) was selected from special education school. This study consisted of 15 sessions, including three different situations depending on the four types of labor rights violations; wage arrears, verbal abuse, assault, sexual harassment, industrial accidents and unfair dismissal. Self-advocacy consisted of problem awareness and communication, and "Self Advocacy Assessment Tools" developed by the researchers.

Results: The results of this study are as follows: 1) It was confirmed that the self-defense post-scoring score was significantly higher than the total score of prior scores (repeated measurement *t* test); 2)Self advocacy according to the four situations of labor rights infringement has all been improved;(3) Both problem awareness and communication have been improved; 4) The self-advocacy total and the components' Cohen's d and Hedge's g showed values greater than .8.

Conclusions: This study is meaningful in that it conducted labor human rights education that comprehensively covered workers' rights and obligations based on the specific situation of the working environment. It is effective as a practical arbitration in that it used student-motivated educational materials.

Excess deaths and the pandemic: The history of the1918 influenza pandemic in one institution

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Background: To consider the patterns of death in 1918-1920 in residents of Leavesden Hospital (LH), an asylum for the "imbecile poor" managed by the Metropolitan Asylums Authority (MAB), in order to explore the effect of the Influenza pandemic of 1918-19 on people with intellectual disabilities.

Method: Detailed examination of death and burial records from LH, including basic demographics, cause of death, month of death, length of stay before death, and place of burial.

Results: Higher death rates were seen in 1918 than in subsequent years in all MAB institutions. 520 died in LH, 30.6% from influenza and 30.1% from tuberculosis. Mean age at death was 44.2 years for men 51.3 years for women. 25–50% of deaths occurred within a year of admission. Newer arrivals were less likely to be buried in the hospital cemetery.

Conclusions: The deaths of people with intellectual disabilities in LH during the 1918 pandemic occurred against a background of very high premature mortality. The impact of war-time on the inhabitants was greater than that of the pandemic. Influenza alone cannot explain the excess deaths, frequent even before the pandemic struck in autumn 1918. Parallels and divergence between the 1918 pandemic and the Covid-19 pandemic will be discussed.

POSTER PRESENTATIONS

Conceptual model of the emergence of the real utility of people with disabilities

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Background: With regard to stigma theory, perspective theory and the concept of information asymmetry, we suggest that one of the major obstacles that people with disabilities face in being socio-economically inserted is information asymmetry on their degree of real usefulness, due to the stigmatization of which they are victims. It creates a gap between their real utility and the utility perceived by applicants for labor power.

Method: The best way to explode the real utility of people with disabilities is to unleash their creativity through entrepreneurship where competition is about the product and not about appearances. Then, communicate widely on the achievements of these initiatives to improve the access of labor force applicants to provide information on the real usefulness of people with disabilities.

Results: This recommendation is also in line with the aspirations of people with disabilities, as demonstrated by the results of empirical studies. In the long term, the effects of this strategy end up having a positive impact on the behavior of applicants for the labor force towards people with disabilities on the salaried labor market.

Conclusions: The whole framework of analysis and intervention that we propose is called the model of the emergence of the real usefulness of people with disabilities.

Development of a critical appraisal tool for intellectual disabilities research

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Background: A critical appraisal tool (CAT-ID) was developed, as no tool in isolation was adequate to critique the different methodologies used in research involving individuals with an intellectual disability.

Method: Since no tool has currently been validated for this population, it was felt pertinent to develop a critical appraisal system. Specific consideration was given to the definition of the sample in line with the World Health Organisation (WHO) definition, public and patient involvement (PPI) in the design of the study, ethical considerations (such as consent, capacity, and coercion) and generalisability to other sub-populations and settings.

Results/Conclusions: The newly developed critical appraisal tool, which was an amalgamation of a variety of critical appraisal tools will be presented. Tools informing the development of the CAT-ID included the Centre for Evidence Based Management (CEBM), the Institute of Health Economics and CASP guidelines for case studies, case series and cohort studies respectively, Downs and Black (1998) checklist, and the CAMELOT tool developed by Munthe-Kaas et al. (2019).

How to develop an online digital tool in Universal Design. The case study of the OLBoT Portal

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Background: An individual with impairment(s) can develop a disability interacting with the environment because of the barriers created by bad designed products and services. Removing those barriers through a quality design can allow an inclusive social spaces development. "Universal design" (UD) "means the design of products, (…) programmes and services (…) usable by all people, to the greatest extent possible" (UN CRPD, Art. 2). [The] "Web removes barriers to communication and interaction that many people face in the physical world" (W3C, 2020). Information and Communication Technologies (ICT) offer incredible opportunities to merge the UN requirements, integrating equity and equality distributing services for all. The OLBoT Portal is developed to verify the hypothesis of an online design for all people, with or without impairment.

Method: Phase 1) Focus Group about Portal's webpages prototypes (6 x Researchers); 2) Web accessibility eTools and Software; 3) Online Survey (ca. 25 Teachers) (quanti-qualitative analyse); 4) eAccessibility and eUsability tests (users with different impairments).

Results/Conclusions: Online artefact for all users; UD knowledge advancement in the Special Educational Needs research about inclusive online social spaces.

Ethical service provision to people with Down syndrome

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Background: Ethics is a wide field comprising many areas of service provision: context, qualifications, quality, etc. According to Downside Up, multiple surveys 41% of Russian families having children with Down syndrome at 0-3 years of age don't get any educational services. Almost 50% of those children who graduate from school (18 years old) don't have any prospective for occupation.

Method: Ethical practices while providing services to people with Down syndrome could be introduced through various instruments: acceptance of basic ethical principles, safeguarding children policies, professional guidelines, protocols describing procedures for specific services to people with Down syndrome and their families. DSU developed and promotes Declaration of Ethical Principles for service provision to people with Down syndrome. DSU has developed and adopted a Safeguarding Children Policy. In order to enhance the quality of medical services in the context of maternity hospitals, DSU developed and promotes in Russia the Protocol for announcing to parents the diagnosis of a child with Down syndrome. DSU pays special attention to the beneficiary-centered approach.

Results/Conclusions: There is no doubt that observation of ethical norms will enhance not only the quality of the services, but also the quality of life of families raising children with Down syndrome.

Art project about ADD/ADHD-I: Want To, Can('t) Do

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Background: As an artist/designer with ADD/ADHD-I, I would like to present a poster presentation about my art academy graduation project that I will be rounding off before July this year.

Method: My project is autoethnographical research, a self-portrait about what I (lovingly) like to call my "divergent brain" and the ways in which I experience and visualize the characteristics of my ADD/ADHD-I. The purpose of this self-portrait is not only to dive inwards and create a cathartic experience that will help me understand myself better, but also to visualize and therefore try my best to present outwards something that might contribute to an important conversation about "diverging brains" and the ways they are often (under)valued in society.

Results: I wish to show the lesser well-known characteristics of my disability and to challenge stereotypical portrayals, and I wish to visualize both my struggles and my positive and even euphoric experiences as a creator with ADD/ADHD-I.

Conclusions: This visual project will be supported by a thesis where I describe myself as a case study and have literary reviews of both academic sources as more subjective experience based sources on ADHD.

Special Olympics Quebec volunteers: Their attitudes toward people with intellectual disability

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Background: The objectives of this study were 1) to document the effects of the involvement of volunteers at the Special Olympics Quebec Summer Games on their attitudes toward people with an intellectual disability and 2) to draw a portrait of the factors that can influence these attitudes.

Method: A repeated measures design with three-week follow-up was used. One hundred and thirty-five volunteers were recruited for this study, and 88 completed the study. The Attitudes toward Intellectual Disability questionnaire (ATTID; Morin et al., 2013) was used.

Results: The results show no significant change in attitudes toward people with intellectual disability among volunteer participants following their involvement in the 2017 Special Olympics Quebec Summer Games.

Conclusions: The lack of significance of the results could be explained by the fact that 65% of the sample reported having frequent or very frequent contact with people with intellectual disability, which suggests that volunteers involved at the Special Olympics Quebec Summer Games would already have positive attitudes toward people with intellectual disability.

Women with intellectual disabilities, care regimes and institutionalised homophobia: A case study from Poland

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Background: The intersection of non-heterosexuality, gender and disability has become a prolific field of research among queer, crip and disability studies scholars, though focusing mainly on Western regions. The research discusses how women narrate their experiences in relation to ableist and heteronormative regimes in the context of Central and Eastern Europe (CEE). The case study of Poland, a country characterized by institutionalization, lack of individualized support for people with intellectual disabilities, and state homophobia contributes to a growing body of research on non-Western sexuality and disability studies.

Methods: Intersectional qualitative research, 11 in-depth interviews with non-heterosexual women with intellectual disabilities, analysed according to the procedures of Grounded Theory.

Results/Conclusions: By tackling care regimes, my analysis explores women's experiences in the context of discursive confusions resulting from being at the intersection of often-contradictory narrations on gender, disability, and sexuality. I identified four intertwined processes to understand how care regimes work in Poland: 1) the separateness between queer and disabled policies and discourses, 2) the co-opting/

obscuring of homosexual relations between women by category of care, 3) familiarisation of care and its consequences for non-heterosexuality, and 4) institutionalised non-responsiveness to the needs of non-heterosexual persons with intellectual disabilities.

Physician assumptions: Prevalence and impact on healthcare of adults with intellectual disability

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Background: This study aimed to identify the assumptions that are considered to be commonly held by physicians and damaging.

Method: Participants will be about 100 Americans with intellectual disability expertise, including family members of children and adults with intellectual disability, health professionals working in the field of intellectual disability (physicians, dentists, nurses, psychologists) and disability professionals (direct support professionals, case managers). A list of initial 100 statements was drafted that related to adaptive behavior, quality of life, and healthcare of adults with intellectual disability. For each draft assumption, participants will be asked the following two questions, to rate on a 5-point rating scale: (1) "How many physicians do you think would agree with this statement?" and (2) "If physicians agreed with this statement, how damaging would it be for the health care of adult patients with intellectual disability?"

Results: The study is in progress and will be concluded in June 2021. The plan is to retain only statements which are deemed commonly held by physicians (average rating of 4-5) and damaging (average rating of 4-5), identified through frequency analysis.

Conclusions: This study will contribute to understand assumptions about intellectual disability, suggesting interventions for medical schools to increase physicians' positive attitude toward adults with intellectual disability.

People with intellectual and developmental disabilities' living conditions: A really ordinary life?

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Background: People with intellectual and developmental disabilities experience specific living conditions. In Switzerland, available national statistical reports offer little or no information about these conditions. Data on the objective living conditions and the subjective perception of people with intellectual and developmental disabilities on these conditions are scarce. This preliminary study aimed to 1) describe people with intellectual and developmental disabilities' living conditions in four areas: living and employment conditions, professional training, social activities and access to information; and to (2) compare these data with those of the Swiss population in general.

Method: An easy-to-read and anonymous survey was developed to assess living conditions and subjective perception of people with intellectual and developmental disabilities in Switzerland. Forty-seven people with intellectual and developmental disabilities completed the survey, either online or on paper. A caregiver was available for participants who experienced comprehension difficulties.

Results: Results highlight major disparities between people with IDD and the general population. The majority of people with intellectual and developmental disabilities live in institutions and work in sheltered workshops, without this necessarily being a choice and without being fully satisfied with it.

Conclusions: This preliminary study expands knowledge on living conditions of people with intellectual and developmental disabilities. How this data can support public health authorities will be discussed.

Inclusive theatre, a matter of language in the research process

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Background: The aim was to contribute to cultural democracy and to strengthen inclusive theatre in which actors with and without disabilities work together.

Method: After a literature search (Nijkamp & Cardol, 2020) researchers with a social or health background and theatre professionals conducted interviews together in couples. We used the method of storytelling within three theatres. Actors with and without disability, professional theatre makers, theatre supporters and directors told us their successes and dilemmas concerning inclusive theatre.

Results: We are at the start of our project and expect to be able to present key-elements of inclusive theatre at the conference. Preliminary results: researchers with a diverse background speak different languages. We had many interesting debates about the concept of inclusion in theatre. Is it possible to keep being inclusive when making a distinction between actors with and without a disability? How does co-creation look like when for instance actors have less verbal possibilities?

Conclusions: Inclusive theatre helps inclusion and especially cultural democracy forward. Lessons from inclusive theatres may also be useful in other practices in which inclusion is strived for.

Raising awareness of the concept of disability in Kinshasa

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Background: The aim was to reduce the stigmatization of the person with intellectual disability; Recognize the rights of people with intellectual disabilities; and integrate the mentally handicapped person with intellectual disability into community life.

Method: Presentation in workshops on mental disability; Broadcasting on television and radio; Sensitization in schools on the inclusion of children with intellectual disabilities.

Results: Change in public behavior towards children with intellectual disabilities; Inclusion of children with intellectual disabilities in schools; Acceptance of the person with an intellectual disability in our communities.

Conclusions: Awareness of intellectual disability begins in school, children transmit positive behavior in our society towards people with intellectual disabilities. Inclusion in our schools is a positive step in eliminating stigma.

What's in a label? Public stigma toward people with intellectual disabilities

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Background: Stigmatisation of people with intellectual disabilities is an underestimated problem that can explain experiences of limited inclusion. We aimed to study the process of intellectual disabilities' stigma within the general public as well as in two targeted groups: mainstream health professionals and care providers in intellectual disability services.

Method: Public stigma (e.g., stereotypes and discrimination) was studied in a survey among a representative sample of the Dutch general public ($n = 892$; response rate 81.6%) using the LISS panel. To explore stigma in the targeted groups, we have conducted two systematic literature reviews.

Results: Public stereotypes of people with intellectual disabilities held a positive and negative valence, for example, “friendly” as well as “in need of help,” and “incompetent.” This ambivalent combination of warmth and incompetence may lead to passive harm. Passive harm was found among mainstream health professionals and care providers, for example, people were being neglected in decisions about their own lives.

Conclusions: The challenge of public stigma toward people with intellectual disabilities seems to lie in its ambivalent nature and discrimination in the form of passive harm (e.g., limited opportunities, neglect). Protest against inequalities and empowering people by self-advocacy groups could be ways to combat this stigma.

Fostering social justice for people with intellectual disabilities through art-based communities

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Background: People with intellectual disabilities experience high rates of social isolation, and encounter social obstacles to freely and autonomously use opportunities to be who they want to be and do what they want to do. Interventions that can increase the quantity and quality of social inclusion are needed. Art-based communities where people come together to paint, draw or sculpt are described as social advocacy activities and seem to offer opportunities, but their theoretical assumptions are not supported by rigorous research. A research project has been designed that explores existing art-based communities and develops knowledge about the design and use of art-based communities to foster social justice for people with intellectual disabilities. In the first study of the project, the focus lies on the question: How can social justice for people with intellectual disabilities be understood and related to art-based communities? Aim: Mapping existing knowledge.

Method: Scoping review. Desk research October 2020 to January 2021. Databases: PsycInfo, Cinahl, Medline, Web of Science, Eric, Google Scholar.

Results/Conclusions: Desk research was not completed on the date of submission. Preliminary results indicate the use of art to support authentic voices to be heard, developing social skills and enabling encounters. New approaches seem to emerge recently.