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ABSTRACTS

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TRACK 7: HEALTH & BEHAVIOURAL ISSUES SYMPOSIA

1. Health 1

5513 | Poor oral health in adults with intellectual disabilities and its determinants

D. Kinnear; J. Morrison; L. Allan; A. Henderson;
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Background: Adults with intellectual disabilities experience extensive health inequalities; some evidence suggests they also have greater dental treatment needs. We investigated prevalence and determinants of poor oral health in adults with intellectual disabilities.
Method: The adult population (16 years+) of people with intellectual disabilities living within one geographical area, were recruited. Each participant underwent a dental examination. We compared this with dental data on the Scottish general population (Scottish Health Survey). Descriptive statistics on prevalence and determinants of poor oral health were generated.
Results: 560 adults with intellectual disabilities participated; 298 males (53.2 %) and 262 (46.8%) females, aged 46 years (16–79). 178 (31.8%) were edentulous (complete absence of teeth) compared to 384 (15.1%) of the general population; this inequality was evident from early adulthood, and widened with progressive age groups. Edentate adults had more severe intellectual disabilities, took antipsychotic medication, and lived in both the least and most deprived areas. Type of accommodation, autism, and problem behaviours did not predict being edentate.
Conclusion: Adults with intellectual disabilities need proactive supportive oral care to avoid their ability to eat and quality of life deteriorating from this largely avoidable condition, regardless of where and with whom they live.

6023 | What type of toothbrushes are used by adults with ID to clean their teeth? Results from Wave 3 of IDS TILDA

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Background: This study aims to report the frequency of tooth-cleaning techniques used by people with intellectual disabilities (ID) to maintain their oral health. A better understanding of the nature of oral-care by adults with ID would allow for accurate interventions to improve oral-care.
Method: Adopting a cross-sectional survey design, participants with ID aged 50 years and older in Wave 3 IDS-TILDA were asked if they had support brushing their teeth and what oral hygiene aides they used.
Results: 245 (40.2%) people with ID reported that they clean their teeth without assistance; 133 (21.8%) clean teeth with assistance; 127 (20.9%) were totally dependent on another person to clean teeth and 15.6% (n = 95) had no teeth to clean. Only 2.3% (n = 14) used floss or interdental cleaners; 388 (63.7%) reported using standard toothbrushes; 4.9% used modified toothbrushes (n = 30); 8.0% used electric toothbrushes and 4.5% used other techniques.
Conclusion: Despite some evidence that modified and electric toothbrushes are associated with better oral health for people with ID, there does not seem to be widespread adoption of these aides. Oral-hygiene interventions should aim to introduce these aides, while accommodating the widespread use of conventional brushes. Interdental cleaning is concerningly low.

6003 | Contextual and conceptual conditions and potentials of professional nursing care in special schools

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Background: The present qualitative study focuses on the disciplines of education and nursing-care from a holistic and system-constructivist approach. Based on exploratory research, it examines the current structural and conceptual conditions as well as the development potentials of nursing-care structures at special schools with particular regard to their relationship to pedagogical processes.
Method: A research strategy was specifically developed for the current study to optimally use the triangulation of research methods and perspectives. The conditions of care-structures at special schools were observed and analyzed on the basis of 60 care situations; a special emphasis was put on the evaluation of 40 guided multi-perspective interviews with nurses, school directors, and teachers.
Results: Based on interviews in 30 special schools, the present evaluation of the data proves the great significance of caring for the students at special schools and reveals differentiated intersubjective results which contribute to new perceptions of the understanding of "educational nursing-care".

Conclusion: As a final consequence, comprehensive recommendations could be made for the development of a future concept of educational nursing-care.

5964 | Laxatives use and constipation among intellectually disabled older people, prevalence, pattern and association: a cross-sectional observational study

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Background: Chronic constipation is a prevalent issue in older people with intellectual disabilities (ID). Laxative use has not been adequately studied in these individuals. The aim was to examine the prevalence, pattern and dosage of laxatives among a representative sample of older adults with ID.
Method: Data was extracted from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA), wave two (2012–2013). Descriptive statistics, bivariate analyses and logistic regression were carried out.
Results: Among overall cohort $n = 677$, chronic constipation is 38.5% ($n = 257$). 281 participants (41.5%) received 431 laxatives (mean 1.53 ± 0.736), among them 74.3% ($n = 209$) reported chronic constipation. There were 40% ($n = 113$) of the users on 2+ laxatives, within which, 59% ($n = 67$) were using combination from same laxative class. Laxative users were significantly different in most demographic and clinical characteristics compared to non- users. Chronic constipation, living in residential care, exposure to anticholinergics and following soft liquidized food were significant correlates with laxative use.
Conclusion: Chronic constipation and the use of laxatives were highly prevalent. Use of more than one agent from the same pharmacological class was surprisingly frequent. There is an urgent need for evident- based treatment guidelines specialized for people with ID to provide effective quality of care.

2. HEALTH II

5514 | Multi-morbidity in a cohort of adults with intellectual disabilities, with and without Down syndrome

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Background: Most physical ill-health and multi-morbidity studies in people with intellectual disabilities are small scale or methodologically limited. We investigated prevalence of multi-morbidity in adults with intellectual disabilities with and without Down syndrome.
Method: The adult population (16 years+) with intellectual disabilities living within one geographical area were recruited. Participants underwent a comprehensive health assessment. Descriptive statistics were generated.
Results: 1,023 people with intellectual disabilities participated; 562 (54.9%) males and 461 (45.1%) females aged 43.9 years (16–83). 186 (18.2%) had Down Syndrome. Mean number of physical health conditions/participant was 11.04; the five most prevalent were visual impairment, obesity, epilepsy, constipation and ataxic/gait disorders. 98.7% had multi-morbidity; the pattern of multimorbidity differed to that in the general population, and was across the entire adult life course. The extent of multi-morbidity was similar in the adults with and without Down syndrome but disease clusters differed.
Conclusion: Using a robust study design, we report high prevalence of health conditions and multi-morbidities. Multi-morbidity increases complexity of medical management that secondary health care services and medical education are not yet geared towards, being focused on single conditions. As multi-morbidity patterns differ from the older general population, attention is needed to develop suitable care pathways/guidelines.

6044 | Addressing diversity and complexity in developing guidelines for the health care of people with intellectual and developmental disabilities

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Background: Diversity and complexity in the health care of PWIDD require types of reasoning and judgments that often draw on broader sources of knowledge than those typically considered for evidence-based medicine (EBM). These include abductive and means-ends reasoning and knowledge of the diverse perspectives and contexts of PWIDD. Systems thinking explains why, in addition to typical EBM-type knowledge, healthcare professionals need to consider expert knowledge, knowledge of the perspectives of PWIDD and their caregivers, and knowledge of local health and support systems to make sound medical and ethical judgments. These sources of knowledge can account for variability, uncertainty, ambiguity and emergence of new factors in health care of PWIDD who are a heterogeneous and diverse group of patients and often have unique and complex health needs.
Conclusion: Expanding the sources of knowledge considered in developing guidelines for the health care of PWIDD improves their capacity to help clinicians address diverse and complex health needs of PIWDD. We give an example of this, in developing the 2018 Canadian consensus guidelines for primary care of PWIDD.

5507 | Survival rates and hospitalization rates of people with down syndrome born in Scotland 1990–2015: a population based cohort study

L. Hughes-McCormack; R. McGowan; J. Pell; D. Mackay;
A. Henderson; L. O'Leary

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Background: To describe survival rates and hospitalisation patterns for children and young people with Down syndrome in Scotland over a 25 year period.

Method: All live-births of individuals with Down syndrome, 1990–2015, identified via Scottish regional cytogenetic laboratories, each age-gender-neighbourhood deprivation matched with 5 non-Down syndrome controls, using Scotland's unique NHS identifiers (CHI). Record-linkage to routinely collected hospital statistics data (Scottish Morbidity Records 01), and National Records of Scotland death data.

Results: 1,458 people with Down syndrome, 689 females (47.3%) and 769 males (52.7%). In total, 96 (6.6%) people with Down syndrome had died compared to 23 (0.4%) without Down syndrome. 1,162 (78.5%) with Down syndrome had been admitted to hospital at least once, compared to 3,362 (52.1%) controls. Average hospital stay was 3.5 days for people with Down syndrome and 1.6 days for controls. Further analyses are in progress.

Conclusion: Children and young people with Down syndrome have high admission rates, highlighting need for family support. Survival of people with Down syndrome is improving: information on survival trends is important for families, and for service planners.

5506 | Prevalence and general health status of people with intellectual disabilities in Scotland: a total population study

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C. MacIntyre; J. Rintoul; S.-A. Cooper

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Background: To investigate in a whole country population (1) prevalence of intellectual disabilities, and age of identification, (2) general health status compared with the general population.

Method: Data was from Scotland's Census, 2011. We calculated the prevalence of intellectual disabilities by age; reported general health status; and the extent of health-related limitations to daily activities. We conducted logistic regressions to determine the odds ratios of intellectual disabilities predicting poor general health, and the associations with age and gender.

Results: 26,349/5,295,403 (0.5%) had intellectual disabilities; 15,149 (57.5%) males and 11,200 (42.5%) females; 5,234 (0.6%) children (0–15), and 21,115 (0.5%) adults (16–75 +). Identification of intellectual disabilities rises until age 5 years, with a further small rise by age 9. Children and adults with intellectual disabilities reported poorer general health (47.9% and 40.3%), than the general population (2.1% and 13.8%), and were more limited in activities by their health. Intellectual disabilities had an odds ratio of 9.2 (95% CI: 8.9–9.4) in predicting poor general health.

Conclusion: People with intellectual disabilities have poorer general health than other people, especially children and young people. Accurate information on population prevalence and health status is essential to plan appropriate resources.

3. HEALTH III

5562 | Do congenital heart defects contribute to the reduced life expectancy of females with Down syndrome?

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Background: There is a highly significant excess of male births in Down syndrome. Yet males with Down syndrome outlive females. To investigate whether congenital comorbidities contribute to these findings, comprehensive demographic and health data have been collated on all Down syndrome births in Western Australia (WA) from 1980 and 2009.

Method: Data on 1,045 Down syndrome cases were identified from the WA State Disability Services files, and co-analysed with information from three complementary State health sources containing codes for Down syndrome: Hospitalisations, Death Records, and Birth Defects.

Results: At birth the male/female sex ratio was 1.22. Across the study group at least one birth defect was diagnosed in 852 (81.6%) of Down syndrome cases, with a sex ratio of 1.24. Congenital heart defects (CHD) accounted for 34.8% of all birth defects, and among the 379 individuals with at least one CHD the sex ratio was 0.94.

Conclusion: No convincing explanation has been advanced for the greater longevity of males with Down syndrome, which is contrary to the pattern observed in the general population. The present data suggest that, at least in a proportion of cases, the reduced life expectancy of Down syndrome females may be associated with CHD.

5517 | Prevalence and types of unexplained symptoms in adults with intellectual disabilities

D. Kinnear; M. Osugo; J. Morrison; L. Allan; S.-A. Cooper

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Background: Medically unexplained symptoms and signs are common in the general population, and respond to appropriate managements, but is less investigated in adults with intellectual disabilities. We investigated types and prevalence of unexplained symptoms and signs in adults with intellectual disabilities, and associated factors.

Method: In a population-based study, adults (16 years+) with intellectual disabilities living within one geographical area were recruited. Detailed health assessments systematically considered symptoms and signs. Descriptive analyses generated types and prevalence of unexplained symptoms and signs; regressions determined associated factors.
Results: 1,023 people with intellectual disabilities participated. Medically unexplained symptoms and signs were present in 664 (64.9%), 3.8 times higher than the general population. 470 (45.9%) had multiple unexplained symptoms or signs. Some were similar to reports in the general population (e.g. dyspnoea, dyspepsia, headache, nausea, dizziness), whereas others were not (e.g. dysphagia, ataxia, polyuria, oedema, skin rash). Unexplained symptoms and signs were independently associated with older age, female gender, not having Down syndrome, extent of intellectual disabilities, and more GP visits, but not with living in deprived areas, type of living/support arrangements, number of hospital visits, smoking, autism, problem behaviours, or mental disorders.
Conclusion: People with intellectual disabilities have substantial additional unexplained painful/disabling symptoms and signs.

5465 | Pilot feasibility study of the Walking Away from Diabetes program for adults with ID in two further education colleges

A. Maine; M. Brown; A. Dickson; M. Truesdale

Background: People with ID remain at high risk of developing type 2 diabetes (T2D) due to lifestyle associated risk factors, such as diets high in saturated fats and low physical activity levels. Structured educational interventions have been adapted to the needs of people with ID which target ongoing T2D self-management. However, there are no adapted programs which aim to prevent T2D through reducing risk factors. The present study initiates the addressing of this gap.
Method: Two further education colleges in Scotland were recruited to take part in a feasibility study using the Walking Away from Diabetes program for people with ID. A process evaluation was conducted which assessed recruitment, retention, acceptability and accessibility, using the discussions from four focus groups of students and teaching staff. Baseline ambulatory activity and physical activity knowledge was recorded as secondary measures.
Results: Results of the demographic data and analysis of focus groups will be presented, highlighting the student and teaching staff experiences of participating in the program.
Conclusion: Findings will be discussed alongside mainstream studies and adapted self-management programs. Implications for further research, policy and practice will be raised.

5375 | Making reasonable adjustments to osteoporosis assessment and screening for people with intellectual disabilities

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Background: People with intellectual disabilities (IDs) are a high risk population for developing osteoporosis, due to factors which are Specific to this population (Down's syndrome, antiepileptic medication and immobility). They experience barriers to accessing osteoporosis assessment and screening (gold standard DXA scans). The aim was to identify and implement reasonable adjustments with a convenience sample of adults with IDs and their supportive carers, to enable DXA bone scans.
Method: 30 adults with IDs (mean age 44 years) completed DXA bone scans once reasonable adjustments (e.g. use of a hoist or more time during appointment) had been identified and implemented. Post-scan, participants, their supportive carers, and the osteoporosis health professionals provided feedback.
Results: 29 adults with IDs completed a hip and spine DXA scan, and 1 participant completed a wrist and forearm DXA (as a reasonable adjustment), but their individual bone scan result was unclear. Of the 29, osteopenia/osteoporosis was detected in 23 (79%). The vast majority of participants were very/happy with their reasonable adjustments, and all (n = 8) osteoporosis health professionals found them to be very/important and very/easy to implement.
Conclusion: People across all levels of IDs can complete DXA scans once reasonable adjustments have been identified and implemented.

4. HEALTH IV

5932 | The role of the community intellectual disability nurse in supporting access to acute healthcare: an exploration

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Background: To explore how Community Intellectual Disability Nurses (CIDNs) support adults with Intellectual Disabilities (ID) in Wales to access acute healthcare.
Method: Two stage mixed method study. Stage one comprised qualitative interviews with CIDNs (n = 14) using Critical Incident Technique (Flanagan, 1954). These were thematically analysed. Stage two employed quantitative questionnaires completed by CIDNs (n = 102). Data was entered into SPSS and analysed using descriptive statistics.
Results: 4 key themes were identified: Proactive/Preparatory work; Therapeutic Relationships; Coordination and Influencing healthcare outcomes. Analysis of questionnaires highlighted the differences in

the role of the CIDN in terms of grading and if there was an ID acute liaison nurse employed within the health board.

Conclusion: CIDNs have an important role to play in supporting people with ID to access acute healthcare although their role varies where ID acute liaison nurses are employed. Countries where there are no specialist ID nurses may wish to consider how the liaison role can be promoted within their healthcare system to improve access to acute care for people with ID.

5930 | Developing machine learning models to predict poor bone health among people with intellectual disabilities

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Background: To develop a machine learning model that identifies the presence of poor bone health in adults with ID.

Method: Using data collected as part of the Intellectual Disability Supplement to the Irish Longitudinal Study on Aging consisting of objective measurements and interview responses pertaining to health and wellbeing, we constructed machine learning models for use in predicting the presence of poor bone health based on generic features and risk factors that had previously been identified. We compared various common modeling strategies such as Random Forest and Gradient Boosted Machines (GBM) using an 80:20 (training: test) split and k-fold cross-validation for training with k = 5. The resulting models' predictions on the test set allowed the most effective model to be selected.

Results: GBM trained on an upsampled training set outperformed the other candidate models, achieving an accuracy of 0.74, a sensitivity of 0.82 and a specificity of 0.50. By comparison, the best performing random forest model achieved an accuracy of 0.72, sensitivity of 0.82 and specificity of 0.46.

Conclusion: The final model that has been selected will feed into further work to develop a proof of concept for a clinical tool in predicting poor bone health based on generic input features.

5691 | Is the MOBID-2 Pain Scale usable for adult people with intellectual disabilities

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Background: To assess pain in adult people with intellectual disabilities (ID) is challenging due to the reduced capacity to self-report. The Mobilization-Observation-Behaviour-Intensity-Dementia (MOBID-2) pain scale is a validated tool used to assess pain among people in the general population with severe dementia. The form is based on touching and observation. We wanted to investigate if the pain scale is usable for people with ID.

Method: The pilot study was performed in two residentials (shared accommodation). Sixteen caregivers received training and follow-up on how to use MOBID-2. After three weeks, they received a Questback via email with seven questions. The response rate was 81%.

Results: 84.6% of the respondents evaluated the MOBID-2 form to be intuitive and easy to use. 61.5% found it difficult to assess intensity of the pain and fill in the form. 61.5 % uncovered pain using the MOBID-2. However, 41.7% found it difficult to use the pain scale on residents who became anxious and were sceptical about new routines.

Conclusion: Based on the positive preliminary results from this pilot study, we need to investigate MOBID-2 in a larger project to evaluate the reliability and validity of this pain-scale assessment tool for people with ID.

5. HEALTH V

5825 | Many unplanned healthcare visits among older people with Down syndrome despite medical guidelines being in place for 20 years

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Background: Down syndrome is a well-researched syndrome with unspecific-age medical guidelines published since more than 20 years back on common comorbidities. The aim was to survey patterns of unplanned visits to in- and outpatient specialist healthcare among older people with Down syndrome.

Method: Individuals with Down syndrome with service and support according the LSS-law, alive and at least 55 years old in the end of 2012 (*n* = 472) were included. Data on healthcare utilization were collected from the national patient register (NPR) for the time 2002 – 2012, recorded according ICD10 chapters. Data was collected on outpatient and inpatient specialist healthcare; planned or unplanned and recorded diagnosis, primary and secondary.

Results: A total of 3841 registrations were identified during the 11 years, 55% (2101) were planned visits, 44% (1684) unplanned and 1.4% (56) un-known. Unplanned visits were mostly internal medicine and 60% of these were inpatient healthcare (*n* = 259). Only 45% had a planned visit to an eye clinic during this 11 year period. Fewer individuals than expected had several earlier reported common comorbidities. The two most common primary diagnoses were pneumonia and epilepsy. Pain and fractures were also present frequently.

Conclusion: Raised awareness about the medical guidelines is needed.

5621 | Experiences of healthcare professionals involved in out-of-hours care for people with intellectual disabilities

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Background: People with intellectual disabilities (ID) have a higher risk of demanding out-of-hours general practitioner (GP) care, and have different needs in this setting, intended for urgent requests when compared to the general population. There is abundant evidence on barriers to safe and assessable healthcare for people with ID. It is however unknown how healthcare professionals experience the out-of-hours service use of people with ID, and how they see ways forward.

Method: GPs, triage nurses, and daily care professionals were interviewed using a structured interview guide on their experiences with people with ID requesting out-of-hours care based around two GP services in The Netherlands. The interview guide included questions on an case from recent experience, the most commonly presented health problems, effects on everyday practice, and suggestions for improvement of care.

Results: Themes common to GPs, triage nurses, and daily care professionals were structured in a framework. Themes distending from their everyday experiences in out-of-hours care for people with ID include partnership, workload, and reasonable adjustments.

Conclusion: Shared experiences will be useful to scrutinize support and care practices to the specific needs of people with ID. Suggestions for improvement will guide further research on reasonable adjustments to out-of-hours GP services.

5564 | Breast Screening, mental capacity and women with intellectual disabilities

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Background: Participation in breast screening is considerably lower for women with intellectual disabilities (ID) compared to the general population. Barriers to screening include poor mobility and behavioural difficulties. The aim of the study was to fill in the research gap exploring the relationship between mental capacity and breast screening for women with ID.

Method: The current study was a cross sectional survey. Eight different support providing charities within England and Wales were included. In total, data from 131 women with ID were collected. Participants, or their staff if they lacked capacity, completed an online or paper survey.

Results: The findings indicated that women who lacked capacity were less likely to engage in breast screening. It also demonstrated that the processes outlined in the Mental Capacity Act (2005) were not always followed, women were not routinely being assessed if there was doubt regarding their decision-making ability and best interest, meetings were not always held if the person lacked capacity regarding breast screening.

Conclusion: Further research is needed to give a broader understanding of how professionals make decisions surrounding breast screening for women with ID if they are unable to decide this independently.

5754 | Health and lifestyle within Nepal and its relationship to intellectual disabilities

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Background: In Nepal, the estimates of the prevalence of disabilities vary, and there is sparse information especially about people with intellectual disabilities. Existing data suggest higher rates of prevalence of ID in the more remote northern area due to use of non-iodized salt, lack of health facilities and extreme poverty. Still Nepal has a superstitious belief about the causes of ID and are widespread that prevent people from accessing physical and mental health. When pregnant women in remote areas and low income groups are deprived of nutritious foods and proper health services, the children are at higher risk to be born with sensory, physical, and intellectual disabilities due to mutations and also lack of health promoting behaviors. Additionally, those with intellectual-disabilities are not able to lead a dignified life as they are mocked and isolated by their family and society. The health disparity in terms of determinants of health (genetic-social-circumstances-individual-behaviors-environmental, and health-care access) has a higher prevalence of-adverse conditions; inadequate-attention, focus on health-promotion and access to quality-health care services.

Conclusion: Healthier lifestyles, better nutrition, medical advances, involving-supporters, health care access and greater surveillance of health-risks, health-promotion and monitoring can bring an outcome of improved health, being empowered, and enhanced-quality of life and reduce health-disparities.

6. HEALTH VI

5768 | A trans-national study of obesity and underweight in European children and adults with intellectual disabilities

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Background: Increased levels of obesity have been reported for people with intellectual disabilities, but existing information is largely drawn from selected, mostly high-income countries. Likewise, a few studies internationally have focused on underweight among these children and adults.

Method: Data on obesity and underweight were analysed from over 20,000 children and adults with intellectual disabilities, living in 61 countries throughout Europe and Eurasia, who attended Special Olympics, Healthy Athletes events in the past 10 years.

Results: Higher rates of obesity were found among athletes compared to the general population in nearly all countries. Binary logistic regressions identified higher levels of obesity for adult athletes living in high income countries compared to middle income countries (27.0% vs. 6.7%) whereas rates of underweight were higher for both youth (15%) and adults (10%) in middle income countries where the incidence of poverty was higher compared to high income countries (4.5% youth and 3.7% adults).

Conclusion: Contrasting intervention strategies tailored to national circumstances are needed to address these dual challenges across Europe and Eurasia in order to help people with intellectual disabilities achieve healthy weight.

5745 | Effects of lifestyle change interventions for people with intellectual disabilities: systematic review and meta-analysis of randomized controlled trials

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Background: Promotion of a healthy lifestyle of people with intellectual disabilities (ID) is important, however the effectiveness of lifestyle change interventions is unclear. This research examined the effectiveness of lifestyle change interventions for people with intellectual disabilities.

Method: Randomized controlled trials (RCT) of lifestyle change interventions of people with ID were included in a systematic review and meta-analysis. Data on study and intervention characteristics were extracted, as well as data on the outcome measures and results. Internal validity of the selected papers was assessed using the Cochrane Collaboration's risk of bias tool.

Results: Eight RCT's were included. Multiple outcome measures were used, whereby outcome measures targeting environmental factors and participation were lacking and personal outcome measures were mostly used by a single study. Risks of bias were found for studies. Meta-analyses showed some effectiveness for lifestyle change interventions and a statistically significant decrease was found for waist circumference.

Conclusion: Some effectiveness was found for lifestyle change interventions for people with ID. However, the results were only statistically significant for waist circumference, so current lifestyle interventions may not be optimally tailored to meet the needs of people with ID.

5824 | Lifestyle approaches for people with intellectual disabilities: a systematic multiple case analysis

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Background: It is unknown to what extent crucial factors for successful implementation of a healthy lifestyle (physical activity and nutrition) are taken into consideration by health care organizations supporting persons with intellectual disability (ID). Therefore, the aim of the study was to analyse intervention components, levels of influence, explicit use of theory, and conditions, for sustainability of currently used lifestyle interventions within lifestyle approaches of health care organizations.

Method: In this descriptive multiple case study of nine health care organizations, qualitative data of the lifestyle approaches with accompanying interventions and their components were compiled with a newly developed online inventory form.

Results: Included were 59 interventions, of which 31% aimed to improve physical activity, 10% nutrition, and 59% a combination of both. Most interventions aimed at the educational component, and less at evaluation, daily, and generic activities. Most interventions targeted people with ID and professionals; social levels were underrepresented. Although 52% of the interventions were structurally embedded, only 17% were theory-driven.

Conclusion: Implementation of a healthy lifestyle within health care organizations supporting people with ID could be improved by using comprehensive, sustainable, theory-driven approaches aiming at multiple levels.

5668 | Pilot feasibility study of the walking away from diabetes program for adults with ID in two further education colleges

A. Maine; M.J. Brown; A. Dickson; M. Truesdale

Queen's University Belfast, Glasgow Caledonian University, Edinburgh Napier University, UK

Background: People with ID remain at high risk of developing type 2 diabetes (T2D) due to lifestyle associated risk factors, such as diets high in saturated fats and low physical activity levels. Structured educational interventions have been adapted to the needs of people with ID which target ongoing T2D self-management. However, there are no adapted programs which aim to prevent T2D through reducing risk factors. The present study initiates the addressing of this gap.
Methods: Two further education colleges in Scotland were recruited to take part in a feasibility study using the Walking Away from Diabetes program for people with ID. A process evaluation was conducted which assessed recruitment, retention, acceptability and accessibility, using the discussions from four focus groups of students and teaching staff. Baseline ambulatory activity and physical activity knowledge was recorded as secondary measures.
Results: Results of the demographic data and analysis of focus groups will be presented, highlighting the student and teaching staff experiences of participating in the program.
Conclusions: Findings will be discussed alongside mainstream studies and adapted self-management programs. Implications for further research, policy and practice will be raised.

7. HEALTH VII

5980 | Using quality improvement to ensure best practice use of medication for challenging behaviour

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Background: To use a systematic quality improvement methodology to ensure that medication is only used for people with intellectual disability who have challenging behaviour in accordance with the NICE (UK National Institute for Health and Care Excellence) best practice guidance on Challenging Behaviour.
Method: We used a systematic approach designed by the Institute of Healthcare Improvement. We audited our compliance with the NICE guidance, and where gaps were identified we made use of change ideas developed with staff working directly with people with intellectual disabilities. We used Plan Do Study Act (PDSA) cycles to achieve rapid and reliable improvements, explicitly testing ideas and measuring change on a week-to-week basis.
Results: The series of PDSA cycles enabled us to improve the recording of the indication for medication and its review to ensure that any medication was a necessary part of a holistic intervention package that included psychosocial interventions, to ensure that healthcare needs were met, including medication monitoring, and to improve the implementation of Positive Behavioural Support.
Conclusion: Using Quality Improvement methods enabled us to significantly reduce the risk of inappropriate medication use for Challenging Behaviour.

5833 | Classification of intellectual disability according to domains of adaptive functioning and between-domains discrepancy in adults with epilepsy

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Background: In the DSM-5, the diagnostic criteria of intellectual disability (ID) include three domains of adaptive deficits: the conceptual, social, and practical domain. We explored the associations between epilepsy characteristics and both ID domains and domain discrepancies (i.e., substantial intra-individual differences between domains).
Method: Among 189 adults with epilepsy and ID, each domain of adaptive deficits was assessed separately, using subscales of the Vineland-II for the social and practical domains, and cognitive instruments for the conceptual domain. A set of standardized criteria is proposed to identify an ID domain discrepancy.
Results: An ID domain discrepancy seemed present in 33% of subjects, particularly in those with moderate ID (53%). The discrepancy was most often at the expense of the social domain, and was significantly related to a focal (localized) epilepsy type and a mixed seizure type. Epilepsy characteristics that are indicative of more severe epilepsy were significantly related to more severe impairments in conceptual, social and practical adaptive behaviour.
Conclusion: With a substantial proportion of the subjects suffering from both ID and epilepsy with an ID discrepancy, professionals should be aware of this concept and take all domains of ID into account when studying or working with this vulnerable population.

5826 | What about psychogenic non-epileptic seizures in adults with intellectual disability and epilepsy? A matched case-control study

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Background: To describe the characteristics of psychogenic non-epileptic seizures (PNES) in adults with epilepsy and intellectual disability (ID), and to analyse differences regarding psychosocial functioning and epilepsy severity between individuals with and without PNES.

Method: Medical records of 240 individuals with ID living at an epilepsy care facility were screened for PNES and evaluated by a neurologist. A control group consisting of subjects with epilepsy and ID, without PNES, were matched according to age, sex and level of ID. The subject's nursing staff provided characteristics of PNES, epilepsy and psychosocial functioning, retrieved from patient charts or collected by standardized questionnaires.

Results: The point prevalence of PNES was 7.1%. The subjects with PNES were most often female, had a mild or moderate level of ID, showed higher levels of depressive symptoms, experienced more negative life events and had more often an ID discrepancy as compared to controls. Stress-related triggers were recognized in a large majority.

Conclusion: PNES appears to be a relatively rare diagnostic entity among inpatients with both epilepsy and ID. It may be under diagnosed, however, given the complexity to diagnose PNES in this population. Diagnostic challenges of PNES and a reinforced behavioural pattern as (sub) category are discussed.

8. HEALTH VIII

5946 | Engaging with 'Easy Read' health literature: an exploration of the profiles of literacy skills demonstrated by adults with intellectual disabilities (I/DDs) and the strategies they utilized for understanding written information about healthy eating

S. Buell

University of East Anglia, UK

Background: This was an observational exploratory study that aimed to establish qualitative variations in patterns of reading skills and strategies utilized by participants when they engaged with 'Easy Read' material about healthy eating.

Method: Sixty adults with IDs undertook a developmental reading assessment that measured reading accuracy, speed and comprehension. Scores were calculated and descriptively analysed. All participants were then given an 'Easy Read' document and answered eight questions about the information it contained. Strategies utilized by participants were observed and noted, for example, whether they choose to read aloud or silently, whether responses included pointing to specific pictures or words and how often and how successfully participants scanned the text or referred back to it for answers to questions.

Results: A varied range of reading profiles was revealed and clear patterns of participant engagement with the adapted texts were evident. Two thirds of participants demonstrated a preference for reading aloud and a similar proportion visually scanned the text for answers.

Conclusion: The diversity of reading skills and the patterns of learned reading behaviour revealed a range of individual abilities that might combine and compensate to uniquely support personal construction of meaningful information from adapted 'Easy Read' texts.

5873 | Physical-activity support for people with intellectual disabilities: a cross-sectional study examining the direct support professionals' perspective

L. Bossink; A. van der Putten; C. Vlaskamp

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Background: There is growing recognition that interventions aiming at promoting physical-activity participation for people with intellectual disabilities should also target their physical and social environment. A large and essential part of this physical and social environment can be attributed to the support provided by direct support professionals. This study investigated the degree and type of behavioural determinants for direct support professionals in regard to their support of physical activity and its relationship to personal and contextual factors.

Method: A total of 247 direct support professionals participated in the study. Data concerning the behavioural determinants were collected by means of a theoretically based questionnaire. Relationships to personal and contextual factors were analysed using item response theory analyses.

Results: Results are not yet available.

Conclusion: It is anticipated that the findings provide important targets for a comprehensive approach to changing direct support professional behaviour and thus promoting the support of physical activity in people with intellectual disabilities. Implications will be discussed.

5868 | Facilitating motor activation in people with intellectual and multiple disabilities

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Background: People with intellectual disabilities (ID) are at risk to be physically inactive. Especially when the level of ID increases and also motor disabilities are prevalent, support lacks structural implementation of movement-oriented activities. Therefore, these people can hardly benefit from the positive effects physical activity can generate. The aim of this presentation is to give an overview and introduction of knowledge and projects that contribute to movement oriented support in people with ID and with special attention to people with profound intellectual and multiple disabilities.

Method: Knowledge and projects will be categorized into the different domains of the socio- ecological framework of Sallis et al., (2006): characteristics of the targeting individuals, social environments, organizational, physical environments and policies.

Results: Three projects will be introduced: 1. Evaluation of the implementation of a movement intervention. 2. Analysis of life style approaches implemented in health care organizations. 3. The role of direct support professionals.

Conclusion: This presentation provides a framework that overviews current knowledge available to increase physical activity levels in people with ID, which can be the basis of discussion and further developing of interventions. This knowledge can be implemented into the support of people with ID.

5842 | Evaluation of implementation of a motor activation program for people with profound intellectual and multiple disabilities

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Background: The support of people with profound intellectual and multiple disabilities (PIMD) rarely focused on motor activation, which negatively influences the functioning of people with PIMD. The authors developed and implemented a 12-week needs-led motor activation program for people with PIMD. The aim was to evaluate the implementation of this program.

Method: The motor activation program consisted of four elements with individual motor profiles resulted in everyday motor activation and 3–5 goal oriented motor activities per week evaluated on an individual level. The implementation process and the programs of nine participants with PIMD within a 24-hour residential facility in The Netherlands were analysed.

Results: The motor activation program was implemented and performed for an average of 8.6 weeks (min = 8.0, max = 10.0) for five participants. Only 1–3 elements of the program were implemented for four participants in a 12-week period. During the congress we will discuss the different approaches of support professionals in the implementation process, the type of motor activation performed and the gains in goal attainment.

Conclusion: This study will increase the knowledge about factors that facilitate or hamper the implementation and performance of a motor activation program in the support of people with PIMD.

9. HEALTH IX

5710 | Adults with learning disabilities in the “Mental Health and Learning Disability Inpatient Bed Census”, Scotland, 2014 and 2016

K. Dunn; A. Henderson; S.-A. Cooper

University of Glasgow, UK

Background: The aim was investigate psychiatric hospital admissions for adults with intellectual disabilities compared with other adults, in 2014 and 2016.

Method: The data source was Scotland’s “mental health and learning disability bed census”, conducted on 29.10.14 and 31.3.16. Descriptive statistics were generated, comparing adult in-patients with and without intellectual disabilities.

Results: On the Census dates, 301 (7.6%) patients in 2014, and 266 (7.2%) in 2016 had intellectual disabilities. In 2014, ~14.9/1,000 of all adults with intellectual disabilities were in-patients, compared with ~0.9/1,000 without intellectual disabilities, (~13.2/1,000 compared with ~0.8/1,000 in 2016). More adults with, compared to without, intellectual disabilities were admitted for >5 years (2014: 38.2% versus 11.4%; 2016: 36.7% versus 11.7%), more were subject to delayed discharge (2014: 20.3% versus 6.6%; 2016 22.7% versus 6.3%), and more were detained under the mental health act (2014: 66.9% versus 36.7%; 2016: 75.4% versus 41.4%). Distance from home was similar for patients with and without intellectual disabilities. 2014 and 2016 data were similar.

Conclusion: Population admission prevalence, and higher mental health act detentions suggest the adults with intellectual disabilities were admitted with more severe mental illness. Little progress was made in reducing delayed discharges between 2014 and 2016; policy-driven concerted multi-agency action is needed.

5552 | People with learning Disabilities in Scotland: 2017 Health Needs Assessment update report

M. Truesdale; M. Brown

Edinburgh Napier University, UK

Background: To update the Scottish 2004 Health Needs Assessment report to provide policy makers, service planners, service commissioners and funders and practitioners with a broad overview of the evidence of the health needs of adults with learning disabilities.

Method: Searching research databases, manual hand and library searches and reviewing and scanning references in existing published papers since the publication of the 2004 Health Needs Assessment report undertook the selection of studies and evidence extraction.

Results: The past decade has seen a significant increase in the number of research studies on the wide range of health needs of people with learning disabilities. Researchers have undertaken systematic reviews, syntheses and meta analyses of the research evidence, thereby building up a comprehensive picture and understanding of the true scope and extent of the health inequalities and health needs of people with learning disabilities and the actions necessary to address them.
Conclusion: Priority areas for future research are highlighted for the Scottish Government, Third Sector organizations, Directors of Public Health and Health and Social Care Partnerships for consideration and action to progress work to improve the health of people with a learning disability in ways that are appropriate, meaningful and equitable.

5536 | Health and social profile of people with intellectual disabilities living in non-intellectual disability long term care settings

S. Todd; J. Bernal; R. Worth; J. Shearn

University of South Wales, UK

Background: To describe the population of people with intellectual disabilities (ID) living in non-ID long term care settings.
Method: 70 non-ID care settings in the UK participated in the study, supporting 1838 people. Within this population, 162 people (8.8%) were reported to have ID. Demographic and health data on those people with ID were obtained.
Results: These findings are based only on initial analysis of data. Almost one half of the sample had lived in another care setting prior to their current place of residence. Of those, the majority had moved there from an ID setting. 55% had no recent contact with ID services and this rate was negatively related to length of stay. The average length of stay in their current setting was 5.5 years. Data will be reported on health status and future perceived health status.
Conclusion: (Tentative) there appears to be a drift from ID to non-ID services in later life. The age structure of this latter population of people with ID is considerably older that of those living in ID settings. Given this and the reported health profile of this population, non-ID settings are also significant in the provision of end of life care to this population. These factors highlight the need for more research within this sector of care.

5424 | Health status and use of medical services of people with disabilities – a longitudinal study

M.T. Wicki

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Background: Hardly anything is known about the health status and use of medical services of people with intellectual disabilities (ID) in Switzerland. The aim of the study is a longitudinal assessment of health status and use of medical services of older people with disabilities (age 50–65), living independently or in residential homes.
Method: A representative longitudinal survey (t0, t1) with 500 people with disabilities (defined as persons with disability pensions) in six regions of Switzerland was carried out between July and October 2017 to assess context factors, health status and use of medical services. The second phase will be conducted between July and October 2018.
Results: First results will be available in March 2018.
Conclusion: This study will provide novel insights into health status, development of health status and use of medical services of older people with disabilities in Switzerland. It will be possible to compare this data with the health status and use of medical services of the general population and to identify possible discrimination of people with disabilities.

10. HOSPITALIZATION OF CHILDREN

5983 | Provision of hospital care to children without and with intellectual disabilities in England: Are we delivering an equitable service?

K. Oulton; F. Gibson; L. Carr; A. Hassiotis; C. Jewitt; C. Kenten

Great Ormond Street Hospital NHS Foundation Trust, UK

Background: There has yet to be a comprehensive review of how well the needs of children and young people with intellectual disabilities are met when using hospital services. We describe the organizational context for healthcare delivery to them and their families, in England. We also report staff perceptions of their ability to identify the needs of these families and provide high quality hospital care to meet these needs.
Method: An anonymised online survey (n = 2261) and individual interviews (n = 65) were conducted with staff working with this population in 24 hospitals.
Results: Uncertainty and variation exists within and across hospitals regarding what is currently available and accessed in terms of the organizational policies, systems and practices in place to support this patient group. Staff perceived this population to be included less, valued less, and less safe than those without intellectual disability. Staff also reported having less confidence, capability and capacity to meet the needs of this population compared to those without intellectual disability.
Conclusion: Children and young people with intellectual disabilities may be invisible, unheard and disadvantaged with respect to receiving individualized high-quality hospital care that meets their needs. Understanding the impact this has on them and their families is imperative.

5977 | Staff perceptions of meeting the needs of children and young people with intellectual disabilities in hospital; Building a model for use in clinical practice

J. Russell; F. Gibson; C. Kenten; J. Wray; K. Oulton

Great Ormond Street Hospital for Children, NHS Foundation Trust, UK

Background: This study aims to understand staff perceptions of the capacity of hospitals to meet the needs of children and young people with intellectual disabilities.

Method: Free text from a staff survey (*n* = 2243) conducted in 24 children's and non-children's hospitals in England were analysed thematically to ascertain perceptions of what their hospital does well (*n* = 742) and could do better (*n* = 805) to meet the needs of children and young people with intellectual disabilities. Themes were mapped to an existing model of individualized care, developed from single site research, to understand how staff approach care for this population.

Results: Staff identified personnel characteristics, practices and resources they require to meet the needs of these patients, such as access to training, equipment, specialist advice and flexible or double appointments. The themes mapped closely onto the current model for individualized care, with the exception of one area – focusing on the little things.

Conclusion: The findings suggest increasing staff access to training could have the greatest impact on capacity. The model has potential for use in clinical practice in hospitals, by defining the components of individualized care for this group that will assist the identification of their needs and address barriers to accessing healthcare.

5968 | Associations between intellectual disability nurse provision in children's hospitals and staff perceptions of care

K. Oulton; J. Russell; C. Kenten; J. Wray; F. Gibson

Great Ormond Street Hospital NHS Foundation Trust, UK

Background: Current best practice United Kingdom guidance has highlighted that clinical staff in all children's wards should have access to information, support and advice from a senior intellectual disability nurse. The aim of this study was to identify the extent of intellectual disability nurse provision in specialist children's hospitals in England and associations between provision and staff perception of care.

Method: Using mixed-methods, views about the care of children and young people with intellectual disability were collated from staff in 15 specialist children's hospitals and the results were compared on the basis of whether or not a dedicated children's intellectual disability nurse was in post. Forty-eight senior staff were interviewed and 1681 staff completed an anonymised online survey.

Results: Eight children's hospitals (53%) had dedicated intellectual disability nurse provision in place. Findings suggest that whilst intellectual disability nurse provision may impact staff capability to care for children and young people with intellectual disabilities, this does not appear to be the case for staff capacity, confidence or how children and young people are valued within the hospital, their safety and access to appointments.

Conclusion: The impact of dedicated intellectual disability nurse provision in specialist children's hospitals in England requires further investigation.

5944 | Parents of children and young people with intellectual disabilities: What it means for them to be partners in their child's hospital care

K. Oulton; D. Sell; F. Gibson

Great Ormond Street Hospital NHS Foundation Trust, UK

Background: The aim of this study was to explore the experiences of parents of children with intellectual disabilities during their child's time in hospital. This group of patients frequently experience recurring hospital admissions and/or appointments. Whilst there is some evidence of parents feeling under-utilized or over-burdened by hospital staff, little is known of what their own needs are during this time.

Method: Individual interviews, informal discussions and observation were conducted with twelve parents of nine children and young people aged 4–21 years with intellectual disabilities, as part of a larger ethnographic study.

Results: When asked about their own hospital experience, parents focused predominately on their relationship with healthcare professionals. Poetry will be used to illustrate key themes that emerged from the data: reflecting the importance parents placed on building a genuine partnership with professionals, as reflected by the acronym PARTNER: (1) Preparation, (2) Accessibility, (3) Respect, (4) Trust, (5) Negotiation, (6) Expertise, (7) Reliability.

Conclusion: Involving parents as partners in care helps them feel informed, involved, reassured and valued. Without this, parents experience uncertainty, anxiety, frustration and anger, with the feeling of being expected to provide care rather than being a true partner with professionals.

11. SPORT AND EXERCISE I

5986 | Effects of sports and daily activity on leisure time, mobility and quality of life of adults with intellectual disability

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DE

Background: The main aim of this study (2016–2018) is to highlight the effects of a sports and movement related daily routine, towards independent mobility, leisure time activities and quality of life. The concept is based on low-threshold activities, which do not require a lot of effort to attend to.

Method: The participants are adults with intellectual disability (*N* = 242) and live in different living arrangements (ambulant and stationary). Before, during and after the intervention (18 months), participants of the intervention and control group are (among other components) questioned about their leisure time activities, experienced barriers, mobility as well as their overall quality of life.

Results: First results of this ongoing study show little sports related leisure time activities. Especially people in group homes, which highly depend on the offers provided by the institution, show significantly fewer steps per day (r = 0.233**) and are less mobile (r = 0.240**) than persons in assisted individual living arrangements.

Conclusion: The results show the necessity of such concepts. Taking part in little sports related leisure time activities, the lack of self-determined choices as well as experienced barriers can lead to a rather sedentary lifestyle and therefore to higher health risks and less social interaction.

5739 | Promoting health and wellness: Special Olympics fitness programming

M. Sadowsky

Special Olympics International, USA

Background: One key component of the Special Olympics (SO) global health strategy concentrates on more consistent access to fitness opportunities. In collaboration with local SO Programs and fitness experts, Special Olympics International (SOI) has endorsed three fitness models that have been successfully piloted and developed resources to support individuals with ID to achieve better health and improve their fitness.

Method: Local SO Programs measured participant height, weight, and blood pressure, and collected data on health behaviours before and after the fitness intervention. These results will be presented by age, gender, location, and fitness model.

Results: Data shows evidence of improved health. Among adults who had a hypertensive reading at baseline, 38.4% (*n* = 48) had improved to a normotensive status by the time of the post-test. Results will be updated to include the latest available data.

Conclusion: Special Olympics Fitness programming has a significant impact on individual health outcomes for people with ID. Evidence of lifestyle changes has implications for service providers who work with people with ID, such as clinicians. More fitness programming designed specifically for a person with ID needs to be promoted in communities throughout the world to reduce disparities.

5689 | Physical fitness is predictive for survival in older adults with intellectual disabilities

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Background: The life expectancy of people with intellectual disabilities (ID) is increasing. However, low physical fitness levels of people with ID may negatively impact their life expectancy. Therefore, the aim of this study is to investigate the relationship between physical fitness and survival.

Method: In the Healthy Ageing and Intellectual Disabilities study, physical fitness levels of 900 older adults with ID (61.5 ± 8.1 years) were measured at baseline. Mortality data was collected over a 5-year follow-up period. Cox proportional hazard models were used to determine the association between each physical fitness test and survival, adjusted for age, sex, level of ID, and Down syndrome.

Results: Over the follow-up period, 172 (19.1%) participants died. Better manual dexterity (HR=0.96 [0.94–0.98]), visual reaction time (HR=1.57 [1.28–1.94]), balance (HR=0.97 [0.95–0.99]), comfortable (HR=0.65 [0.54–0.78]) and fast (HR=0.81 [0.72–0.91]) gait speed, grip strength (HR=0.97 [0.94–0.99]), and cardio-respiratory fitness (HR=0.997 [0.995–0.999]) were associated with survival (lower mortality risk). Auditive reaction time, muscular endurance and flexibility were not associated with survival.

Conclusion: We showed for the first time that physical fitness was independently associated with survival in older adults with ID. These results stress the need for being physically fit at older age to reduce mortality risk.

6006 | Health system indicators for use by Special Olympics International in their health programs

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Background: As part of measuring the effectiveness of the variety of health programs and activities that Special Olympics International (SOI) deliver for individuals with ID, SOI is also interested in identifying the system indicators that create opportunities for inclusive health of all people with ID.

Method: A series of 1:1 interviews with SOI staff and a Delphi survey with IASSIDD and AAMDD members were used to identify these indicators. This study was embedded within a social-ecological framework.

Results: Examples of these health indicators included: ID is a mandatory topic in the training of health professionals; people with ID are involved as co-trainers for health staff; policy statements and practice guidelines are available for staff in how to make reasonable adjustments; and feedback is sought from people with ID about their inclusion in the health system. It is unlikely that any one indicator or set of related indicators will produce a tipping point by which a system could be considered to be inclusive of people with ID.

Conclusion: These national health system indicators could be used to measure how successful people with ID are included in healthcare and other systems (housing, education and social welfare systems), as well as included within civil society.

12. SPORT AND EXERCISE II

5876 | Accelerometer counts and energy expenditure during walking in healthy adults with and without ID

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Background: We investigated the usability of accelerometers to measure the intensity of walking in individuals with and without ID, by analyzing the relationship between accelerometer counts and the measured energy expenditure.

Method: Our study included 36 participants, among whom 17 were healthy adults with mild-moderate ID. Energy expenditure and accelerometer counts were measured during three separate 6-minute-walking bouts (over ground comfortable walking speed, and 3.2 km/h and 4.8 km/h on a treadmill).

Results: No significant correlations were found between accelerometer counts and energy expenditure relative to body weight in either group for any of the speeds ($P > 0.05$).

Conclusion: This study used a standardized, reproducible method of evaluating energy expenditure in adults with ID and a control group and compared it to accelerometer counts. We did not find any correlations between accelerometer counts and energy expenditure in either group, potentially due to large variability in both outcome variables. Future research is needed with a larger sample size, to determine the validity of physical activity measurement in individuals with ID. The research leading to these results has received funding from the People Programme (Marie Curie Actions) of the European Union's Seventh Framework Programme (FP7/2007–2013) under REA grant agreement no. °625455.

5690 | Gait of adults with intellectual disabilities, and its association with physical fitness and falls

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Background: We assessed the gait characteristics of adults with ID, and the association of these characteristics with physical fitness and falls.

Method: Gait characteristics of 31 adults with mild to moderate ID (42.77 ± 16.70 years) were assessed with the GAITRite at comfortable speed (CS), fast speed (FS), and while dual tasking (DT). Fitness was assessed (body composition, muscular endurance, strength, balance, Short Physical Performance Battery) and falls were collected over a three-month follow-up period.

Results: Gait characteristics of adults with ID were comparable to those seen in the general older population of on average 20 years older. Adults with ID did have a broader base of support and more variable gait. Gait at CS was associated with body composition, gait at FS with the other fitness components. Dual tasking affected gait. This was not predictive for falls, although medium effect sizes were found (0.31–0.48).

Conclusion: The finding that fitness seems to be more important for gait at more challenging conditions and that dual tasking affects gait, is important for safe community participation. This must be considered while interacting with adults with ID during daily activities. More research is needed to better understand the relationship between gait, fitness and falls.

5791 | Attendance of a resistance-training program in adults with an intellectual disability

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Background: To assess which factors influence the overall attendance of a 6-month whole body progressive resistance exercise training (PRET) program for adults with an intellectual disability (ID) with cardiovascular disease (CVD) risk factors.

Method: Twenty-four adults with a mild or moderate ID with at least one CVD risk factor (diabetes, hypertension, dyslipidaemia, and/or overweight/obesity) exercised twice a week for one hour for 24 weeks. The PRET program consisted of a whole-body workout of seven resistance exercises. After a familiarization phase, the training intensity was increased from novice level to vigorous intensity. Every training session, the attendance or absence was noted, along with the reason for absence. At the end of the program we asked about the participant's experiences with the PRET program with a questionnaire. This information was used to gain more insight in the factors influencing attendance.

Results: The factors influencing the overall attendance or absence of a training session of the PRET-program will be presented. (Results available in May 2018).

Conclusion: The results from this study can be used as a practice based outline for future intervention studies and/or in daily practice when conducting health programs at both individual and group level for adults with ID.

5792 | The reliability of measuring muscle strength in adults with an intellectual disability

S. Weterings[1,2]; A. Oppewal; I. Razzaq; T. Hilgenkamp

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Background: Muscle strength is an important factor of overall fitness. The aim of this study was to assess the reliability of a muscle strength measurement of the leg extension, the maximal voluntary contraction (MVC), for adults with an intellectual disability (ID) with cardiovascular disease (CVD) risk factors.

Method: Twenty-four adults with a mild or moderate ID with at least one CVD risk factor (diabetes, hypertension, dyslipidaemia, and/or overweight/obesity) performed the MVC test of the leg extension twice. Each MVC test contains at least three measurements. If one measurement was >10% lower than the highest measurement an extra measurement was performed, with a maximum of five measurements per test. The MVC was measured with a Handheld Dynamometer (Microfet 2) according to the break-method.

Results: The reliability will be presented as the association between both MVC tests of the leg extension with the intra class correlation coefficient (ICC agreement). Furthermore, the Bland and Altman plot will be presented to display the Limits of Agreement between both MVC tests.

Conclusion: The results from this study can be used when measuring muscle strength in future research or in daily practice in adults with ID.

13. PSYCHOTROPIC MEDICATION I

5962 | Associations of medicine use with falls and bone health in older adults with intellectual disabilities

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Background: Older adults with ID may be exposed to medicines that may contribute to falls/frailty, particularly sedative and anticholinergics, which may be association with falls, antiepileptics, which may be associated with bone loss. To examine associations between higher Drug Burden Index (DBI): a cumulative measure of sedative and anticholinergic medicines and falls and to examine associations between exposure to antiepileptics and bone status.

Method: Medication data (self/proxy report) was drawn Wave 2 (2013/2014) of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA); a representative study of persons >40 with ID. Multivariable regression examined DBI and falls in the previous 12 months. Bivariate analysis examined associations between antiepileptics and objectively measured osteopenia/osteoporosis ($n = 575$).

Results: Of 677 with medicines data, there was no significant association ($P = 0.731$) between higher DBI and falls in the previous 12 months: OR 1.11 (95% CI 0.61–2.05). There was a significant association between antiepileptics ($P < 0.001$) and objective measures of osteoporosis/osteopenia, 52.3% with antiepileptics having objective osteoporosis.

Conclusion: Many older adults with ID are exposed to multiple medicines that may place them at risk of poor bone health and falls. Findings highlight the importance of regular review of medicines for adverse effects.

5999 | Development of a systematic prescription-deprescription tool for adults with intellectual disabilities

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University of Geneva; Geneva University Hospitals, Switzerland

Background: Adults with intellectual disabilities (AWID) suffer from more concomitant somatic and psychiatric disorders than the general population. Although there is limited evidence for the efficacy of psychotropics and standardized procedures for their prescription are lacking, AWID are often poly-medicated during prolonged periods. This can lead to severe side effects, inefficient use of resources and lack of implementation of alternative, more adapted approaches.

Method: After an extensive search of the literature, our group developed a systematic tool for prescription/deprescription in AWID.

Results: The systematic tool is aimed at helping physicians to remove inappropriate treatments, introduce lacking treatments and optimize their administration in order to improve their safety and efficacy. We selected five items for the tool: pain, sleep disorders, gastrointestinal disorders, problem behaviours and deprescription of psychotropic drugs. The items were selected based on their relevance in the population of AWID and on the literature. The choice of the treatments discussed in the tool is based on pharmacological considerations, ease of administration and cost.

Conclusion: The scarcity of the literature on prescription/deprescription procedures in AWID underscores the need for standardized procedures and tools. The next step will be to validate the tool using a Delphi method.

5870 | Patterns of antipsychotic utilization and associations with behaviours, with challenges in older adults with intellectual disability: a cross sectional study.

M. O'Dwyer; N. Galvin; P. McCallion; M. McCarron; M. Henman; J. O'Connell

Trinity College Dublin, Ireland

Background: High-risk medicines (HRMs) may be associated with side effects/significant harm when used in error. Older adults with intellectual disabilities (ID) are susceptible to adverse outcomes associated with HRMS. The aim was to compile an evidence based list of HRMs, evaluate the prevalence of HRMs among older adults with ID, identify associations between HRMs and clinical and demographic characteristics.

Method: Medication data (self/proxy report) was drawn Wave 2 (2013/2014) of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA); a representative study of persons over 40 with ID. HRMs were identified by literature review and stratified into four categories. Bivariate analysis examined associations between HRMs and clinical/demographic factors.

Results: Of 677 with medicines data, 86% (n = 582) had ≥1 HRM, mean (±SD) 2.7 (±2.0). The most common HRMs were antipsychotics, 45.1% (n = 305), medicines with narrow therapeutic index (e.g. carbamazepine, warfarin) (52.4%, n = 305), medicines with risk of toxicity (e.g. paracetamol, lithium) (45.1%, n = 263). There were significant ($P < 0.001$) associations between exposure to 4 + HRMS and older age, severe/profound ID, institutional settings, epilepsy or mental health condition.

Conclusion: Older adults with ID were exposed to HRMs. Education of doctors, pharmacists, nurses, caregivers and adults with ID is required to ensure medication safety.

5993 | Use of high risk medicines among older adults with intellectual disabilities: A cross-sectional study

M. O'Dwyer; N. Galvin; P. McCallion; M. McCarron; M. Henman; J. O'Connell

Trinity College, Dublin, Ireland

Background: High risk medicines (HRMs) may be associated with side effects/significant harm when used in error. Older adults with ID are susceptible to adverse outcomes associated with HRMS. Aim: Compile an evidence based list of HRMsEvaluate the prevalence of HRMs among older adults with IDIdentify associations between HRMs and clinical and demographic characteristics.

Methods: Medication data (self/proxy report) was drawn Wave 2 (2013/2014) of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA); a representative study of persons over 40 with ID. HRMs were identified by literature review and stratified into four categories. Bivariate analysis examined associations between HRMs and clinical/demographic factors.

Results: Of 677 with medicines data, 86% (n = 582) had ≥1 HRM, mean (±SD) 2.7 (±2.0). The most common HRMs were antipsychotics, 45.1% (n = 305),medicines with narrow therapeutic index (e.g carbamazepine, warfarin) (52.4%, n = 305), medicines with risk of toxicity (e.g. paracetamol, lithium) (45.1%, n = 263). There were significant ($p < 0.001$) associations between exposure to 4+ HRMS and older age, severe/profound ID, institutional settings,epilepsy or mental health condition.

Conclusion: Most older adults with ID were exposed to HRMs. Education of doctors, pharmacists, nurses, carers and adults with ID is required to ensure medication safety.

14. PSYCHOTROPIC MEDICATION II

5941 | Psychotropic drug use in older adults with intellectual disabilities who have dementia in Ireland

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Background: There are concerns that antipsychotics and other psychotropics may be prescribed inappropriately in older adults with intellectual disabilities (ID) and dementia. The aim was to determine the prevalence of psychotropic use among older adults with ID and dementia over time.

Method: Data was drawn from Wave 1 (2009/2010) and Wave 2 (2013/2014) of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA); a representative study of persons over 40 with ID. Medication data (self/proxy report) was available and psychotropics examined were antipsychotics, antidepressants, anxiolytics, hypnotics. Participants/proxy reported a doctor's diagnosis of dementia.

Results: At Wave 1, of those taking medicines with data (n = 736), 6.3% (n = 46) reported dementia, after loss to follow-up, of 677 with data at Wave 2, 10.9% (n = 74) had dementia. At Wave 1, of 46 with dementia, 45.7% (n = 21) had antipsychotic use, and at Wave 2 of 74 with dementia, 54.1% (n = 38) had antipsychotic use. Antidepressants were the second most frequently reported class: 43.5% (n = 20) at Wave 1, 39.2% (n = 29) at Wave 2.

Conclusion: A significant proportion of older adults with ID and dementia reported psychotropic use, with antipsychotic use being commonplace. Findings highlight the importance of review of psychotropics to prevent inappropriate prescribing.

5480 | Development of the tool appropriate prescribing of psychotropic drugs (TAPP)

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Background: The aim of this study was to develop a self-report instrument for prescribers to assess the quality of their prescriptions of psychotropic drugs in people with intellectual disabilities (ID). This instrument may enhance the process of reduction of inappropriate psychotropic drug use in this population.

Method: The project group consisting of a pharmacist, a nurse and two physicians developed a draft of the instrument. In a Delphi procedure a panel of psychiatrists, ID physicians and pharmacists consented on the final draft of the instrument. The Research and Development/University of California at Los Angeles (RAND/UCLA) methodology for agreement was used. A second panel assessed the relevance of the domains of the instrument without needing consensus.

Results: In the first Delphi round respondents reached agreement on 47 of 58 statements scored on a 9-point scale, with median values between 7 and 9, controlled for the inter-percentile range adjusted for symmetry (IPRAS). Agreement was reached about the terminology, the age limits of children and elderly and of the domains dose, duration of therapy and duplication. We will present the final draft of the TAPP and the preliminary results of the validity, reliability and usability of the tool.

Conclusion: The TAPP is a promising instrument that will help prescribers to optimize, and not just reduce, psychotropic drug use in people with ID.

5478 | The long-term effectiveness of Risperidone in reducing challenging behaviours: a RCT

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Background: We aimed to study the long-term effectiveness of Risperidone in reducing challenging behaviours in people with intellectual disabilities, by studying the effects of discontinuation of behaviour and side effects.

Method: In this study Risperidone was double blind and placebo-controlled discontinued. In the placebo group, participants discontinued Risperidone stepwise to a placebo in fourteen weeks, followed by an eight-week blind follow-up and eighteen-week natural follow-up. The control group maintained their baseline dosage, but could discontinue after the blinded follow-up. During the study premature de-blinding, behaviour scored on the irritability subscale of the Aberrant Behaviour Checklist (ABC) and side effects (metabolic, neurologic, hormonal side effects) were monitored.

Results: In total, 25 participants were included in the study, of which eleven were in the discontinuation group. Of the eleven participants two were de-blinded prematurely compared to three in the control group. The discontinuation group did not differ significantly on the irritability subscale over time with the control group. However, they did show a worse total ABC score at de-blinding. At de-blinding, only weight was lowered over time in the discontinuation group compared to the control group.

Conclusion: To conclude, discontinuation of Risperidone is possible, despite an increase in challenging behaviours.

5773 | A multicenter double blind, placebo controlled randomized off-label antipsychotic withdrawal trial in people with intellectual disabilities and challenging behaviour

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Background: There is a gap between the available evidence and the policy drive to reduce antipsychotic prescribing to people with intellectual disability (ID) and challenging behaviour. We postulate 3 possible mechanisms for antipsychotic withdrawal failure: (1) The influence of the subjective interpretation of behavioural symptoms. (2) It cannot be excluded that some people with ID might benefit from antipsychotic treatment. (3) When antipsychotics are withdrawn after long-term treatment, withdrawal symptoms might occur.

Method: A multicenter double blind, placebo controlled randomized off-label antipsychotic withdrawal trial (RCT) is currently being carried out in the Netherlands in collaboration with the HA-ID consortium and financially supported by ZonMw (project number: 848016008). Participants are randomized to one of two groups: the withdrawal (placebo) group or the control group.

Results: A summary of our study protocol, including some specific outcome measures and the process of medical ethical review will be presented. Inclusion of participants and obstacles during the setup and execution of the study will also be discussed.

Conclusion: As far as we know, this study is the first multicenter double blind off-label antipsychotic withdrawal RCT investigating possible mechanisms for antipsychotic withdrawal failure in people with ID and challenging behaviour.

15. PSYCHOTROPIC MEDICATION III

5417 | Discontinuation of off-label used antipsychotics; results and determinants for success or failure

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Background: To investigate physicians' considerations regarding their patients' eligibility to discontinue off-label antipsychotics, to study discontinuation trajectories of those who were eligible to discontinue and to identify participant-related determinants for success or failure in discontinuation.

Method: Participants in living facilities of ID service providers were aged >6 year and used off-label antipsychotics >1 year. Antipsychotics were discontinued in a time frame of 14 weeks. Data collection took place at baseline, at 4, 8, 12, 16, 22, 28 and 40 weeks after the first dose reduction in all participants, whether or not they were able to completely discontinue. The primary outcome measure was the Aberrant Behaviour Checklist.

Results: Of 997 antipsychotic drug users 499 were eligible to discontinue; 129 participated in the study and 60% of those were able to discontinue in 14 weeks, with on average no behavioural worsening. At 40 weeks 40% were still completely off antipsychotics. Ill health was associated with failure in discontinuation. Considerations of physicians, differences between those who succeeded and those who failed in discontinuation, and determinants for successful discontinuation will be presented.

Conclusion: Reduction of off-label antipsychotics in people with ID may be improved, when physicians manage ill-health conditions of their clients.

5549 | Trends in antipsychotic and antidepressant prescribing in children and adults with intellectual disabilities, and children with autism throughout Scotland, 2010–2013

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Background: To investigate antipsychotic and antidepressant prescribing in children/young people with intellectual disabilities, and with autism, compared with other children and with adults with intellectual disabilities; and trends over time.

Method: Observational study of all pupils (4–18 years) in Scotland's annual school census (2010–2013), and 25% of Scotland's adults with intellectual disabilities in general practice records (2004–2014); both record-linked to national Prescribing Information System data on en-cashed antipsychotics and antidepressants.

Results: Child/young person analyses are in progress. For adults with intellectual disabilities, antipsychotic use fell from 24.3% (292/1,201) in 2004, to 16.4% (665/4,065) in 2014. However, follow-up of the same individuals (*n* = 549) found similar antipsychotic use of 23.3% in 2004 and 25.9% in 2014, whilst antidepressant use rose from 9.8% to 22.2%.

Conclusion: Adults with intellectual disabilities are unlikely to be withdrawn from antipsychotic drugs once commenced, but rates of new prescriptions are falling. Adult increases in antidepressant use may reflect general population patterns, but further research is needed to understand this. It is important to identify trends in psychotropic use in children/young people, and the at-risk age of onset, given the potential consequences for the developing brain, potential serious side effects and long-term usage.

5418 | Staff-factors related to psychotropic drug use of people with intellectual disability

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Background: Staff's thoughts on effects of psychotropics on challenging behaviour might be related to their clients' drug use. We aimed to investigate whether staff's knowledge of psychotropics and feelings towards challenging behaviour were associated with results of antipsychotic drugs discontinuation, and whether a staff-learning-intervention on this topic was related to decrease of inappropriate psychotropic drug use.

Method: We used a self-designed questionnaire in a survey on knowledge of support staff and in a prospective open label, off-label antipsychotics discontinuation study. Here we studied the influence of staff-related variables on success or failure in discontinuation. Also, we investigated the influence of a learning-intervention on the appropriateness of their clients' psychotropic drug use.

Results: Of 194 support professionals, 6% had sufficient knowledge, a majority had false beliefs on the effects of psychotropics on clients' behaviour and 60% indicated they were in need for education. When clients attempted to discontinue their drug use staff's feelings of depressive mood and anger were associated with less and more knowledge with more chance of successful discontinuation. Effects of the learning-intervention will be presented.

Conclusion: Staff's thoughts on effects of psychotropics on clients' behaviour should be taken into account in attempts to reduce inappropriate psychotropic drug use.

16. GENETIC OR RARE CONDITIONS I

6068 | Learning from facial expressions of emotion among persons with Down syndrome, Williams syndrome and autistic spectrum disorder

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Israel

Background: Socio-emotional adaptation facilitates well-being and communal belonging. In this study we compared the use of facial expressions of emotion as sources of information to facilitate adaptive responding among individuals with Williams syndrome (WS), Down syndrome (DS) and autistic spectrum disorder (ASD), functioning in the range of ID.
Method: A feedback-learning task incorporating two levels of difficulty was administered to 12 participants with WS, 19 with DS, 18 with ASD and comparison groups of typically developing children at similar developmental levels. After choosing one of two objects, participants received feedback in the form of facial expressions (happy or angry) or in non-social form (icons) and then repeated or corrected their choice.
Results: Participants with WS responded accurately when using facial expressions as feedback, but only when cognitive demands were low. The accuracy rates of those with ASD were slightly lower, but less affected by an increase in task demands. Participants with DS responded correctly to the happy face, but only half responded accurately to the angry face.
Conclusion: Adaptively responding to facial expressions of emotion involves the interplay of emotion recognition with cognitive abilities and style. Differences between the three groups in the nature of this interaction will be discussed.

5735 | Vagus nerve stimulation for the treatment of problem behaviour in people with Prader-Willi Syndrome

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Background: Prader–Willi Syndrome (PWS) is a genetically determined neurodevelopmental disorder characterized by intellectual disabilities and problem behaviours alongside severe hyperphagia. These behaviours have a significant effect on the quality of life of those with PWS and those who support them. An earlier study found unexpected anecdotal reports of beneficial effects of vagus nerve stimulation (VNS) on problem behaviours in two people with PWS; we investigate this further.
Method: Five individuals with PWS wore an external VNS device for four hours per day. The numbers of problem behaviours were recorded monthly and semi-structured interviews conducted twice in both the baseline and active phases.
Results: We observed a reduction in number of problem behaviours as a result of VNS. Caregivers in semi-structured interviews also noted a beneficial effect where improvements in temperament, social functioning and problem behaviours were reported. These improvements suggest that VNS may have potential as a novel treatment for problem behaviour in PWS.
Conclusion: We offer insight into the mechanisms underpinning behavioural problems faced by people with neurodevelopmental disorders, suggesting that changes in these behaviours may be mediated via vagal projections and their effects on specific neural networks and functioning of the autonomic nervous system.

5779 | Iceberg alert: undetected health problems in adults with Prader-Willi syndrome – multidisciplinary care could prevent “unexplained deaths”

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Background: In Prader-Willi Syndrome (PWS), up to 4% of young adults die every year. PWS is a complex genetic disorder, characterized by hypotonia, intellectual disability (ID), hormone deficiencies and hyperphagia. The mean age of reported deaths is 29.5 years. Mortality is often unexpected. In some cases, cause of death is related to rapid consumption of food. In half of the patients, the cause of death turns out to be cardiovascular origin or obesity-related respiratory failure. These severe complications can be prevented if PWS-associated obesity is managed effectively in a multidisciplinary setting.
Method: The multidisciplinary outpatient clinic (MOPC) for adults with PWS aims to prevent complications and reduce mortality in PWS. We have analysed the clinical data.
Results: Untreated diabetes, hypothyroidism and obesity were frequent findings, among the first 90 patients visiting the MOPC. Although 43% was obese (BMI above 30 kg/m^2), 23% exercised less than 30 min/day and 29% were not on a diet. 50% had untreated hypogonadism, and 65% had insufficient dairy intake.
Conclusion: We detected a striking number of untreated health problems among adults with PWS. The MOPC for adults with PWS will prevent painful and expensive complications and reduce mortality in this vulnerable patient population.

5967 | Social behaviour among adults with Down syndrome: Is it mediated by psychopathology?

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Background: The first aim of this study was to develop a new tool to measure social behaviour skills among adults with intellectual disability (ID) and second was to examine the possible mediation effect of psychopathology between Down syndrome (DS) etiology and social behaviour skills.

Method: Five hundred eighty adults with ID participated in this study. For each participant, the referent caregiver completed the Social Behaviour Questionnaire (SBQ) and the Reiss Screen for Maladaptive Behaviour. Data of the whole sample on SBQ were analysed in order to test the factor structure of this new tool. Mediation analyses involved two subgroups of participants: participants with DS (*n* = 92) and participants with ID of non-specified etiology (*n* = 328).

Results: Factor analyses suggested retaining a four-factor structure of the SBQ. Down syndrome was associated with a higher level on SBQ global and subscales scores, showing more preserved social behaviour skills in this group. However, this association completely disappeared when the mediation effect of psychopathology was controlled.

Conclusion: These results suggest that higher social skills commonly associated to persons with DS are actually due to the lower level of psychopathology of these individuals.

17. GENETIC OR RARE CONDITIONS II

5978 | Beneficial effect of betaine treatment in 2 adult patients with creatine transporter deficiency

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Background: Creatine transporter deficiency (CTD) is caused by mutations in SCL6A8 and causes intellectual disability. No approved treatment exists. We describe 2 half-brothers both suffering from CTD and intellectual disability, both improving after betaine treatment: A 36-year old male with ID and epilepsy developed progressive speech loss, feeding difficulties, weight loss and motor disturbances. Supplementation with a commercial product reportedly containing cyclocreatine showed improved balance, speech and feeding. After the product became unavailable after 11 months, his condition deteriorated. Later, an analysis showed that the product contained betaine 79,2% and creatine 17,7%, but no cyclocreatine. Treatment with betaine, increasing to 10 grams daily, started, and his balance and feeding improved. At age 31 the other patient showed lack of energy and feeding difficulties with a considerable weight loss. He was treated with betaine 8 grams daily, and after 2 months he had gained weight and was able to resume his protected work.

Conclusion: Betaine supplementation is a possible new treatment for CTD patients. In our patients the treatment was effective and well tolerated, although the mechanism of its effect is unclear. Further studies with betaine supplementation in this patient group seem warranted.

5936 | Natural course in Dutch adult patients with Angelman syndrome

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Background: Angelman syndrome (AS) is a neurogenetic disorder characterized by severe cognitive impairment, ataxia, speech impairment and characteristic appearance. Data on natural course in adulthood are scarce. The aim of this study is to describe the evolution of AS in adulthood.

Method: Data was collected through questionnaires, physical examination and medical records. Eighty-seven patients (43 males, 44 females, median age 33 years) (range 18–83 years) with genetically confirmed AS were included. Six patients from one large family are reported separately.

Results: Sleeping problems (55%) and behavioural problems (86%) persisted in adulthood in a considerable number of patients. Epilepsy was a continuous concern in 53% of patients, with 10% of adults suffering from poorly controlled epilepsy. 71 patients were able to walk independently, however a decline in mobility was observed in 52% of patients. Besides 54% of adults had scoliosis and over 50% appeared to visual function problems. Constipation was a problem in 88% of patients.

Conclusion: This is the largest cohort of clinically studied adult patients reported to date. Adults with AS have many debilitating health problems. Mean areas of focus are epilepsy, scoliosis, vision, constipation, behaviour, sleep and mobility.

5921 | A novel UBE3A micro deletion in a large family

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Background: Angelman syndrome (AS) is a rare genetic disorder, clinically characterized by intellectual disability, lack of speech, ataxia and facial characteristics. Mutations in the maternally inherited UBE3A gene are known to cause AS.

Method: Clinical symptoms and genotype of Dutch adult patients was studied. Questionnaires, physical examination and medical records were used. For two patients deceased at the time of the study, interviewing legal representatives retrieved clinical data. Eight patients from one large family were found to have a novel maternally inherited UBE3A micro deletion.

Results: Affected members from this family exhibited a phenotype which does not meet the clinical criteria of AS. Although all affected family members were cognitively impaired, they were able to a large extent to speak in sentences. Facial appearances were not characteristic of AS. Mild ataxia was observed in 2 patients only and 2 patients suffered from epilepsy. Behavioural problems were only present in one patient and sleeping problems were not found.

Conclusion: We are reporting on a large family with several family members affected by a novel maternally inherited UBE3A mutation. Phenotypes in these patients did not match clinical criteria of AS. Affected patients did however all have a moderate to severe cognitive impairment.

18. GENETIC OR RARE CONDITIONS III

5830 | Growing up with Fragile X Syndrome – concerns and care needs in young adulthood and implications for transitional care

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Background: Little is known about the worries and the healthcare needs of young adult male and female patients with Fragile X Syndrome and their caregivers. More information on care needs will assist in providing optimal transitional and adult care for this vulnerable patient group.

Method: A qualitative study was performed using semi-structured group and individual interviews with young adult patients aged 18–30, and parents of young adults. Concerns and healthcare needs in medical, psychological and socio-economic domains were discussed. Themes were organized using the International Classification of Functioning, Disability and Health (ICF).

Results: In total, 33 parents (20 of males, 1 of a female) and 5 patients (1 male, 4 females) participated. Results indicated many and diverse worries, with different outcomes for males and females. In both groups parents reported high stress levels, difficulties with their parental role, and a lack of knowledge of FXS in care providers.

Conclusion: The concerns and care needs of young adults with FXS and their parents revealed concerns on various domains, requiring gender-specific, multidisciplinary transitional care and adult follow-up for patients with FXS. Additionally, parental stress requires more attention from care providers.

5823 | The relationship between emotion regulation and temper outbursts in individuals with neurodevelopmental disorders

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Background: Temper outbursts are prevalent in several neurodevelopmental disorders and have a negative impact on wellbeing. Here, we explored the relationship between such outbursts and emotion regulation, which has been widely proposed but rarely examined. 31 individuals with a neurodevelopmental disorder (NDD group; Down syndrome or ASD; mean CA 14.9y, range 8–22; mean MA 7.8y, range 4–15; 58% male) and 459 typically developing (TD) individuals were recruited. Following cleaning, data from 410 TD children remained (mean CA 10.2y, 6–17y, 46.8% male). Participants played a modified ultimatum game (UG), in which decision-making drew on emotion regulation and self-reported on habitual emotion regulation. Non-parametric bootstrapping was applied to individually match NDD participants to two sub-samples of typical peers based on mental and chronological age. Parents reported on NDD participants' temper outbursts, allowing classification according to associated negative impact. Comparison of groups based on more or less negatively impactful outbursts suggested less effective emotion regulation in those with more impactful temper outbursts. However, there was substantial individual variability in which UG parameters indicated most emotion regulation deficit.

Conclusion: Further work must unpick differences in how emotion regulation is achieved by different individuals with NDDs and the impact of this on clinically important behaviour.

5712 | The association between emotional dysregulation and mental health outcomes in Rubinstein-Taybi syndrome

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Background: Anxiety and mood disorders have been reported in over 65% of adolescents and adults with Rubinstein-Taybi syndrome (RTS). Emotional dysregulation has been implicated in the development of mental health difficulties in the general population, including anxiety and low mood. This study combines cross-sectional and longitudinal analyses to examine associations between emotional dysregulation and mental health outcomes in RTS.

Method: 48 parents of individuals with RTS completed a cross-sectional questionnaire study in 2010. The Mood, Interest and Pleasure Questionnaire (MIPQ) and Behaviour Rating Inventory of Executive Function (BRIEF-P) were employed. These measures, along with the Anxiety and Depression and Mood Scale (ADAMS) were repeated in 2017.

Results: In the cross-sectional analysis, low mood was associated with poorer inhibitory control ($R = -0.43$, $P = 0.002$) and poorer emotional regulation ($R = -0.42$, $P = 0.002$) on the BRIEF-P. Low mood was not associated with any of the other BRIEF-P subscales, or ability level. This finding is consistent with the longitudinal data.

Conclusion: Emotional regulation is important to consider in the aetiology of mood disorders in people with RTS, as well as other rare genetic syndromes that have a heightened prevalence of mental health difficulties.

5590 | Behavioural dysregulation in children with tuberous sclerosis complex (TSC) and associations with caregiver well-being

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Aim: TSC associated neurodevelopmental disorders (TAND) include intellectual disability, ADHD, challenging behaviour and autism spectrum disorder. Caregivers of children with TSC report elevated stress, which is associated with features of TAND. This study examined behavioural dysregulation in children with TSC, and its association with anxiety and depression symptomatology in caregivers.

Method: Thirty-one children with TSC (4–14 years) participated. A delay of gratification task, go/no go task and The Activity Questionnaire assessed impulsivity and overactivity and the Challenging Behaviour Questionnaire measured self-injury and aggression. Caregiver well-being was assessed using the Hospital Anxiety and Depression Scale. Scores are contrasted to 29 typically developing (TD) children (3–15 years).

Results: Children with TSC were more impulsive and overactive, showed more challenging behaviours and performed less well in the delay of gratification task, than TD children of comparable chronological age or ability. No differences were found on the go/no go task. Greater caregiver-reported impulsivity was correlated with increased depression and anxiety scores in TSC caregivers (but not TD caregivers).

Conclusion: We found evidence of broad behavioural regulation difficulties, supporting existing descriptions of TAND, including novel evidence from direct behavioural assessment. Impulsivity in particular, may be associated with poorer caregiver well-being.

19. GROWING OLDER I

5505 | Health status and health disparities experienced by individuals with intellectual disability who are aging

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Background: Individuals with ID are living longer, and according to national official statistics, 32,500 individuals with ID aged 45 years and over are living in Spain. The main goal of this project is to provide basic knowledge about their health characteristics by using a self-designed questionnaire.

Method: 6,147 individuals aged 44 years or older have been identified from 76 different organizations through a multi-stage sampling procedure. A complete examination of healthcare needs and disparities is being carried out with 973 individuals.

Results: On 590 persons with ID aged 44 and older are presented. Some results point out that 31.5% rate their health as bad, and 59% present some chronic health condition. 49.7% present a mental health issue, being disruptive impulse control and conduct disorder the most frequent (16.9%) closely followed by mood disorders (16.6%). Only 32.4% of those with a dual diagnosis are receiving psychological services apart from medication. Access to specialized health services is rated as problematic by 40% of the sample.

Conclusion: Research has the potential to identify medical conditions that are more likely to occur in aging persons with ID. This information would be very useful for reducing costs associated with secondary or tertiary prevention efforts.

6026 | Ten years of data: The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing

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Aim: To assess achievement of successful ageing over 10 years.

Background: The intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) is designed to gather data to identify the principal influences on and contributors to successful ageing.

Method: Three waves to date of interviews with a nationally representative sample of people with ID from across Ireland. Use of descriptive statistics and regression to describe, pinpoint predictors and measure incidence and prevalence of chronic conditions as well as to ascertain the social and person-centred lives and living situations of people aged 40 years and older with ID.

Results: High levels of access to health care professionals, and uptake of screenings has been found that now match or exceed general population levels. There are also concerning levels of dementia, osteoporosis, constipation and other chronic conditions as well as high levels of polypharmacy. Levels of community engagement and realization of person-centred community living also need improvement.

Conclusion: The data being gathered and monitored by IDS-TILDA is providing the tools to both advance public policy and practice goals for people with ID as they age and offers an opportunity to systematically measure both success and continuing or expanding concerns.

5819 | Tracking utilisation of health services by people with Intellectual Disability as they age

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Background: A correlation between ageing and increased health service use (HSU) by general older population is well documented and increasingly challenges health care delivery. Increased longevity of people with ID means similar trends in health service use may arise.

Aim: Examine HSU by older people with intellectual disability in Ireland over a 10-year period and compare to Ireland's general older population.

Method: HSU data from three waves of the Intellectual Disability Supplement to the Irish Longitudinal study on Ageing (IDS-TILDA) were examined for changes in utilisation during the period 2007–2017 as was the association with age of participants. Comparisons were made to similar time period data available from the general population ageing study (TILDA).

Results: Use of GP services was relatively stable across waves and similar rates found for general and ID older population. However, for the 65–69 years age group there was a decrease in GP use increases in emergency department and hospital admissions.

Conclusion: Managing upward trends in emergency department and hospital admissions for people with ID aged 65–69 years may require greater investment in community based primary care.

20. GROWING OLDER II

5639 | Defeating dementia together

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Background: UK ethics committees define those with intellectual disabilities (ID), including the Down Syndrome (DS) population, as a vulnerable group. This often results in automatic exclusion of those with DS in research with the assumption they lack capacity to consent. Our research group aims to actively engage participants with DS to increase and maintain our current cohort for collection of important longitudinal data.

Method: To recruit participants and their families, an experienced ID Research Nurse is employed. To gain meaningful consent, researchers developed accessible information to aid participant's decision making whilst monitoring fluctuating capacity over time. For engagement researchers created newsletters for caregivers and participants, video interviews with participants about their research experiences and incentives such as a 'passport' allowing participants to track their research journey.

Results: DS participants have repeatedly taken part in multiple studies since 2011. One current study recruited 28 participants from previous imaging studies with a low withdrawal rate (4/32 invited). Participants independently promote dementia research through magazine articles, charity fundraisers and local news interviews.

Conclusion: Although prioritising participant engagement is demanding, it allows this 'vulnerable group' to feel valued through developing resourceful relationships with researchers whilst contributing to dementia research together.

5636 | Genotype and phenotypic association of TREM2 and Tau in Down syndrome dementia

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Aim: In Down syndrome (DS) the amyloid precursor protein (APP) is encoded in triplicate and Aβ accumulation plays a key role in the pathogenesis of Alzheimer's disease (AD). However, other genes including tau, TREM2, Apolipoprotein E and HLA-DR allelic variants, also affect dementia pathology. The aim was to understand the influence of specific genetic haplotypes on DS dementia pathology. Methods Using serum samples from a well-characterised cohort of people with DS ($n = 47$) we genotyped TREM2, Tau, ApoE and HLA-DR by SNPs analysis and investigated protein expression and its co-relation between inflammation and disease pathogenesis. Two DS participants had the AD-associated TREM2-R47H mutations, and a morphologically extreme phenotype of erythromyeloid cells. Using post-mortem derived DS brain tissues ($n = 18$) and age matched controls, we also investigated tau and TREM2 pathology.

Results: Those with high-risk haplotypes (TREM2 C/T, Tau H1/H1 and ApoE e4) were more prevalent among participants with DS with an earlier age of onset of dementia. Serum TREM2 levels were found to decreased with age (~35%) whereas phosphorylated-Tau (p-tau) levels increased. In the temporal cortex Tau accumulation initially presenting as neuropil threads (NTs) and later as neurofibrillary tangles.

Conclusions: We provide evidence that peripheral TREM2 originating from erythromyeloid cells significantly determines AD neuropathology in DS.

5958 | A 10-year longitudinal follow-up of dementia in persons with Down syndrome

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Aim: To examine dementia characteristics, age at onset in persons with Down syndrome (DS) over a 10-year period.

Method: All people with DS included in the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) were followed since Wave 1, in 2009. Cognitive tests included the Test for Severe Impairment and the Brief Praxis Exam. Adaptive behaviour was measured using the Daily Living Skills Questionnaire. All Participants were asked if they received a doctor's diagnosis of dementia.

Results: in all three Waves of IDS-TILDA, the prevalence of dementia increased from 15.8% in Wave 1, to 29.7% in Wave 2 (2014) to 35.5% in Wave 3 (2017). The incidence of dementia was 22.5% between Wave 2 and 3, with a mean age of onset of 52.3 years compared to people with ID of other aetiologies with a mean age of onset at 65.5 years in this study.

Conclusion: The risk of dementia in people with DS is lower than previously reported in other research, however, of those with DS and without a diagnosis of dementia, 47% had never had a dementia assessment. Longitudinal follow-up appears effective in supporting early identification of dementia in this population.

5858 | Patterns of dementia and epilepsy in adults with Down syndrome in Ireland: data from IDS-TILDA

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University of Dublin, Trinity College, Ireland

Aim: To examine patterns of onset of dementia and of epilepsy in adults with Down syndrome in Ireland over a ten year period. Method Data from 3 waves of the IDS-TILDA study were collected with 149 participants with Down syndrome in Wave 1, 135 in Wave 2 and in 109 Wave 3. Data was collected on diagnosis of dementia and of epilepsy across the 3 waves along with data on level of intellectual disability, functional limitations, and scores on objective cognitive tests.

Results: In Wave 3, 35.5% (n = 38) of people with DS had a doctor's diagnosis of dementia, which rose from 15.6% in Wave 1. Of those without a diagnosis of dementia, 47% had never had a dementia assessment. For those with Down syndrome, prevalence of epilepsy without dementia was low at 13.7%, however among people with Down syndrome with dementia, the prevalence of epilepsy rose to 54.8%.

Conclusion: This data confirms the high rates for both dementia and epilepsy in this population and that one appears to influence the other. Of concern, however, was the high number of those with DS who had never had a dementia assessment.

21. GROWING OLDER III

5774 | Mental health disorders in an older, Irish population with Intellectual Disability – results from Wave 3 IDS-TILDA

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IDS-TILDA, Trinity College Dublin, Ireland

Aim: To report the findings on mental health status in an older, Irish, intellectually disabled (ID) population.

Method: Six hundred and nine older individuals with ID participated in this third wave of IDS-TILDA. A computer assisted interview included items on areas including health, social circumstances, medication and associated factors. The Glasgow Depression Scale (GDS-LD) and the Glasgow Anxiety Scale (GAS-LD) were completed by the individual or in association with their proxy.

Results: Over half of participants (51.9%) reported a diagnosis of a mental health disorder; anxiety being reported by a third and depression by 15.8%. The prevalence of mental health disorders in those with Down syndrome (DS) was half that (26.2%) of the overall group. Two thirds (77.5%) reported their emotional and mental health to be good, very good or excellent. The GDS-LD indicated that 10% had symptomatology consistent with a depressive disorder and 15.1% reported above threshold scores for anxiety on the GAS-LD.

Conclusion: Mental health disorders are prevalent in older people with ID; anxiety and depression being most commonly reported.

5781 | Overweight & obesity and, interrelated chronic health conditions in older adults with an Intellectual Disability: results from Wave 2 IDS-TILDA

J. Ryan

Trinity College, Dublin (IDS TILDA), Ireland

Aim: To explore the relationship between overweight/obesity and interrelated chronic health conditions in older adults with an intellectual disability (ID).

Method: Data for this paper was drawn from the second wave of the IDS-TILDA study. A longitudinal study examining health determinants among older adults with intellectual disability in Ireland. Data included objectively measured (OM) BMI and waist circumference, which were examined in relation to doctor's diagnosed obesity related disease. Chi-squared automatic interaction detector analysis was applied to identify the most influential variable on overweight/obesity.

Results: A prevalence of 66.7% of overweight/obesity was identified with 69.6% identified as at risk of cardio-metabolic conditions according to their waist to hip ratio. Higher levels of overweight/

obese were identified among women (69.9%), those with a mild ID (84.9%) and those under 50 years (69.5%). Cardiovascular disease, for example 18% OM with hypertension, 9.3% with diabetes and over 7% reporting stroke/TIA were evident.

Conclusion: Obesity is recognised as one of the most pressing societal challenges of the 21st century. From this study it can be seen that those who are overweight/obese have increased risk of multiple health consequences.

5861 | Changing chronic health conditions among older adults with ID: results from 3 waves of IDS-TILDA

M. McCarron; E. McGlinchey; R. Carroll; P. McCallion
University of Dublin, Trinity College, Ireland

Aim: To examine changes in the incidence, prevalence and patterns of multimorbidity in adults with ID, to better understand how the numbers and type of chronic health conditions change as people age.

Method: Data was collected for 609 individuals over three waves of IDS-TILDA on diagnoses of chronic health conditions, specifically 12 chronic health conditions identified in the Charlson Comorbidity Index.

Results: Rates of multimorbidity increased slightly to 74.2% in Wave 3, from 71.05% in Wave 1. The highest number of chronic conditions experienced by an individual was 7. Multimorbidity increased from 60.6% in those under 50, to 72.7% in those aged 50–64 and 83.9% in those aged 65 and over. Mental Health was the most common condition at 52.2% followed by gastrointestinal disease 47.4%, and neurological disease at 39.6%. Disease patterns were different than those found in Wave 1 where eye disease was the most common condition. The presence of several chronic conditions at baseline were predictive of the onset of additional chronic conditions over time.

Conclusion: Multimorbidity remained high in this population with increasing complexity in patterns of co-morbid conditions.

5399 | Is mental health status affected by chronic diseases in older people with intellectual disability?

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Australian National University, Australia

Background: Authors explore the impact of certain chronic diseases/disorders which are linked with poor mental health amongst older people with intellectual disability (PwID).

Method: Cross-sectional face-to-face survey of 392 adults aged > 60 years living in community settings in urban and rural regions of Australia. Mental health composite score (MCS) was derived from MoS-SF12, a QoL instrument with high internal and external validity.

Results: Mean age was 65.2 years (SD 4.4); males = 62.7%. MCS values were close to population norm (X = 50.4, SD 9.9) but showed a wide range (18.1–70.8) indicating very poor mental health for some study respondents. MSC values did not differ significantly between urban and rural residents. Prevalence of chronic diseases/disorders was: arthritis (40.4%), diabetes (25.6%), asthma (16.1%), coronary disease (14.8%), chronic pain (26.9%), sleep disturbance (22.3%), and falls (29.2%). MCS values were significantly lower for chronic pain, sleep, and falls; whereas, mean MCS was lower for coronary disease and hearing loss, but not statistically significant. Respondents with multiple co-morbidity had lower MCS.

Conclusion: Primary care management of chronic diseases/disorders for older PwID is important. The clustering of certain chronic conditions calls for health promotion strategies to improve mental health of older PwID.

22. GROWING OLDER IV

5883 | A comparison of drug burden measures on physical function scores in a cohort of older adults with Intellectual Disabilities

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Aim: To measure the association between two measures of drug burden, Drug Burden Index (DBI) and Anticholinergic Cognitive Burden (ACB) on two physical function measures in a cohort of older adults with intellectual disabilities (ID).

Method: Data for this study is drawn from Wave 2 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA), a representative study of older adults with ID in Ireland. DBI and ACB scores were tested as dichotomous (no exposure, any exposure) and ordinal variables (no exposure, low exposure, high exposure) to measure associations with grip strength (kg) and timed up and go (seconds).

Results: Grip strength was not significantly associated with exposure to DBI or ACB medications ($P = 0.778$, $P = 0.618$) after adjusting for confounders. Similarly, there was no association between adjusted timed up and go and exposure to DBI or ACB medications ($P = 0.808$, $P = 0.594$).

Conclusion: There was no association between DBI and ACB exposure and grip strength or timed up and go measurements, which is different to evidence in older adults without ID. This could be a result of low levels of physical activity and the effect of ageing.

5924 | Using chi-square automatic interaction detection modelling to identify predictors of osteoporosis among adults with Intellectual Disability

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School of Nursing and Midwifery, Trinity Centre for Ageing and Intellectual Disability, Trinity College Dublin, Ireland

Aim: To identify predictors of osteoporosis among older adults with intellectual disability.

Method: The sample was drawn from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA). Bone quality was measured by quantitative ultrasound (QUS) as part of an objective health suite of assessments. CHAID analysis was performed to determine the significance of literature supported predictors for poor bone quality drawn from the data of the IDS-TILDA study including physician diagnosed chronic health conditions, dietary intake and frequency, medication use and activity levels.

Results: In total 575 participants completed QUS. The prevalence of osteoporosis was 41%. Three major predictor variables reached significance to be included in this model, difficulty walking 100 yards (P-value < 0.0001), taking AED medicines (P-value = 0.004) and taking proton pump inhibitors (P-value = 0.043). This model had an overall classification accuracy of 70.8% with its ability to classify osteoporosis at 72.5%.

Conclusion: The findings support a need for robust risk assessment and for clinical practitioners to not only consider the obvious risks but also specific concerns for people with ID in order to better target preventative strategies to decrease future risk of fragility fractures.

5627 | Thicker retinal structure in Down's syndrome and its relationship with ageing

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University of Cambridge, UK

Aim: To investigate retinal thickness in people with Down's syndrome (DS) in relation to ageing, cognitive abilities and dementia status and in comparison to age-matched controls. Alzheimer's disease (AD) research has found reduced retinal thickness in patients with AD compared to age-matched controls. People with DS have very high prevalence of early-onset AD. Retinal changes have the potential to be a biomarker of AD, which could be used as a proxy outcome measure in clinical trials.

Method: 50 adults with DS completed optical coherence tomography examinations of the retinal nerve fibre layer (RNFL).

Results: Results were compared to 36 age-matched control participants. Neuropsychological tests were also completed in the DS group. Results: Results showed significantly thicker retina across almost all areas in people with DS compared to age-matched controls. This result was consistent across all age groups and correlations with age showed that the DS group did not show typical age-related RNFL thinning, as was seen in the control group.

Conclusion: The results of this study suggest that there are underlying pathologies which may be influencing the thickness of the retina in people with DS, this could be related to amyloid-beta depositions and associated factors, including inflammation and cell death.

5612 | Protocols to detect and initiate assessment and treatment of dementia in people with intellectual disabilities

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Aim: The number of elderly with intellectual disabilities (ID) will increase significantly, and more people with ID will experience dementia in the future. Research shows that in Norway, 8 out of 10 people with ID who are suspected of suffering from dementia are not assessed. The aim of this study is to identifying protocols that should be established in municipal health services to detect and initiate assessment and treatment of dementia in people with ID.

Method: Employees representing the municipal health services from all the health regions in Norway participated in a qualitative interview survey.

Results: The survey shows lack of implementation of protocols, a lack of knowledge by service providers in identifying early symptoms of dementia, and a lack of involvement by GPs, may be some of the main reasons for the failure to make assessments and for not receiving the appropriate treatment and care.

Conclusion: To detect early signs of dementia, a comprehensive and systematic approach should be established and include observation, documentation, information, and intervention. With the correct diagnosis, municipalities will be better prepared to provide appropriate resources, avoid malpractice and reduce constraints for the individual with ID, their relatives, and the health services concerned.

23. DEATH AND DYING I

6046 | Expecting the unexpected. Awareness of impending death among adults with Intellectual disabilities and paid carers in social care settings in the UK

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Aim: To determine the proportion of deaths of adults with ID where either the dying person or direct care/support staff (CS) were aware death was likely. To examine the effect of awareness on place of death and CS satisfaction with End of Life Care (EOLC).
Method: Providers of social care for adults with ID in the UK supplied data on deaths over an 18 month period and contact details of a staff member who had known the deceased person well. Data from a CS-completed VOICES LD and a questionnaire designed for this study were obtained for 157 deaths.
Results: A minority were aware, partly reflecting different causes of death. Of 157 deaths in the study period, staff believed 17 were aware they were dying. Staff were aware that 67 had an illness that might lead to death. 28% of deaths followed less than a week's illness. CS awareness was associated with home deaths and with higher levels of overall satisfaction with EOLC.
Conclusion: Possible reasons for the low levels of awareness are explored. Research and practice in EOLC for people with ID must include unexpected deaths. Better identification of those at risk might allow earlier access to curative and EOLC.

5704 | Hidden lives and deaths: people with ID living in generic care settings

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Aim: To investigate the nature of death of people with ID living in non-ID adult care settings.
Method: 70 non ID care settings in the UK participated in the study. Within this population, 162 people (8.8%) were reported to have ID. Demographic and health data on those people with ID were obtained. This was repeated within 12 months and data also obtained on deaths that occurred within this time period.
Results: Preliminary analysis suggests that the people with ID were almost 20 years younger than other people in those settings. Almost one quarter were identified as being at likely risk of dying within 6 months. At Time 2, 22 people (17.6%) with ID had died. Their average age of death was 71.7 years (SD=7.97). Of those perceived to be at likely risk of death, 25% had died. Data on end of life care for this population are currently being analysed.
Conclusion: People with ID living in non ID settings maybe be amongst the oldest of older people with ID. It is conceivable that although not a predominant provider of carer, such services may be playing a significant role in end of life care to people with ID.

5697 | Talking about dying with people with ID who have experienced a bereavement: a UK survey of support staff

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I. Tuffrey-Wijne

University of South Wales, UK

Aim: To investigate the extent to which people with ID who have experienced a bereavement are informed about it.
Method: Support staff in supported living and residential settings completed an online survey (*n* = 724, 64% response rate), supporting over 6,000 people with ID across the UK. Those answering "yes" to the question whether any of their clients had experienced a bereavement during the past 12 months (*n* = 693) were asked further questions about this.
Results: In 33% of cases, the person with ID was not told that the person was dying. Most respondents recognised the benefits in preparing a person with ID for the death of a significant other in their life. Almost two third of people were told of the eventual death within 24 hours (66.3%) and were involved in the subsequent funeral (64.5%). Most reported that they felt confident in dealing with the bereavement experiences of people with ID.
Conclusion: The data suggest that there has been a major shift in practice concerning the bereavement experiences of people with ID. Most were told beforehand that a significant other would die soon, informed about the death soon after it occurred and participating in grief rituals.

5587 | Talking about dying with people with ID who have a terminal illness: a UK survey of support staff

J. Bernal; J. Finlayson; C. Lam; L. Taggart; S. Todd;
I. Tuffrey-Wijne

University of South Wales, UK

Background: To investigate the extent to which people with ID who have a terminal illness are informed of their diagnosis and prognosis.
Method: Support staff working in supported living and residential settings completed an online survey (*n* = 724, 64% response rate), supporting over 6,000 people with ID between them. Recruitment was through contacting managers of ID service providers from all four UK countries (*n* = 25). Those answering "yes" to the question whether any of their clients had died during the past 12 months, or was currently terminally ill, were asked further questions about this.
Results: Over a quarter of respondents (*n* = 205) had experienced death or terminal illness among their clients during the past year, reporting 199 deceased (of which 114 were non-sudden deaths) and 76 terminally ill clients. Over half of people with ID whose death was expected were told about their illness, but only 20% were ever told that they would die of it. However, 36% of respondents thought that the person "definitely" or "probably" realised that they were going to die.
Conclusion: People with ID whose deaths are expected by staff are mostly uninformed about their own impending death. This has implications for their involvement in end-of-life decision making.

24. DEATH AND DYING II

5425 | Validity and reliability of an advance-care planning tool for people with IDs

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Aim: Research shows that people with ID are hardly involved in end-of-life decisions. The goal of this study was to use a person-centred future-planning tool to explore the usefulness, validity and reliability of advance-care planning (ACP) for people with IDs.

Method: A volunteer sample of 60 persons rated the capacity to consent to treatment of 4 persons with ID's. Sensitivity, specificity and percentages of agreement were calculated, and inter-rater reliability was assessed using Fleiss' kappa and Krippendorff's alpha.

Results: The sensitivity value was 62%, the specificity value was 95%. The percentage of agreement (P(a)) for all participants was 69.75%, Fleiss' kappa was $k = 0.396$ and Krippendorff's alpha was $\alpha = 0.395$. Finally, 72% of the participants found the tool very or partly useful for ACP for people with IDs.

Conclusions: Documented interviews help persons with IDs to declare their wishes and values regarding end-of-life issues. The interviews help carers and relatives to identify those individuals who had the capacity to consent to treatment. It is useful for physicians, caregivers and relatives to interview people with IDs about end-of-life decisions and to document these interviews systematically.

5928 | Where you live and die?: A comparisons of end of life outcomes for expected deaths in people living in social care ID settings

S. Todd; E. Jones; K. Lower; R. Forrester-Jones; J. Shearn; R. Worth

University of South Wales, UK

Aim: To investigate factors that shape end of life care outcomes for people with ID.

Method: 53 deaths of people with ID were identified from a larger representative sample of deaths in the UK ($n = 156$). These 53 deaths were deaths that had been expected for three months or more. They were evenly distributed between care homes and support living settings. Data were obtained on individual an setting characteristics, and end of life care outcomes.

Results: Decedents living in care homes were significantly more likely to die in the setting in which they lived than people living in smaller supported living settings. There were few demographic differences between decedents across these two settings. Setting factors, in particular staff: client ratio and size of staff group explained most of the variance in outcome.

Conclusion: Although supported living services offer enhanced opportunities for ordinary living, they seem less well able to support people with ID at the end of life. There are suggestions that staff development is a major area for improving EoLC outcomes for people with ID. The results in this paper suggest that resources may be just as or more important.

5810 | Predictors of mortality in Down Syndrome: results after 15 years of follow-up in a longitudinal cohort study

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Aim: During the last decades the life expectancy of people with Down Syndrome (DS) has increased to an average of 60 years in developed countries. Knowledge of factors influencing mortality in older people with DS is limited. The aim of this longitudinal population based study on older people with DS is to study determinants of mortality.

Method: Therefore we conducted a study of 506 persons with DS, aged 45 years and older, who were enrolled from December 1, 1999 to December 1, 2003 in a community-based study on DS and ageing. All participants were monitored until they died (76%), up to the reference date of January 1, 2017 (mean follow-up survivors 15 years). We studied the prevalence and incidence of dementia as well as mortality in the demented and the non-demented.

Results: The high risk levels for dementia among people with Down syndrome was confirmed in these data.

Conclusion: Age and dementia were found to be the most important predictors of mortality in this study cohort.

25. MENTAL HEALTH I

5504 | Prevalence of mental health conditions and relationship with general health in a whole country population of 26,349 people with intellectual disabilities, compared with the general population

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Aim: To determine (1) prevalence of mental health conditions and, (2) relationships with general health in a total population with and without intellectual disabilities.

Method: Data were drawn from Scotland's Census, 2011, on intellectual disabilities, mental health, and general health. We calculated prevalence of mental health conditions, and conducted logistic regressions on intellectual disabilities predicting poor mental health, and on general health status predicting poor mental health, adjusted for age and gender.

Results: 26,349/5,295,403 (0.5%) had intellectual disabilities; of whom 12.8% children, 23.4% adults, 27.2% older adults had mental health conditions compared with 0.3%, 5.3%, 4.5% general population. Intellectual disabilities predicted mental health conditions: OR=7.1 (95% CI 6.8–7.3). General health was associated with mental health conditions within the intellectual disabilities population; fair health OR=1.8 (95% CI 1.7–1.9), bad/very bad health OR=4.2 (95% CI 3.9–4.6), but to a lesser extent than within the whole population. Female gender reduced the likelihood of mental health conditions: OR=0.89 (95% CI 0.89–0.95); and increase in age group up to 64 years predicted mental health conditions.

Conclusion: This large-scale, whole-country study findings are important, given the previously stated lack of confidence in comparative prevalence results with the general population, and the need to plan services accordingly.

5538 | The role of social support in posttraumatic coping in people with Intellectual Disabilities

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University of Vienna, Austria

Aim: In the general population, positive social support is a main protective posttraumatic factors. There are only two studies aiming at replicating this effect in people with Intellectual Disabilities (ID). So far, a mediating protective effect of social support has not be found. One possible explanation is that the type of social support that people with ID receive is disadvantageous. Our hypothesis is that people with ID receive a high amount of unsupportive acknowledgement. We aim to assess the role of posttraumatic social support.

Method: We will assess social reactions to disclosure of traumatic events and the type of posttraumatic social support received in qualitative interviews with ten people with ID. Their influence on symptoms of trauma sequelae will be assessed.

Results: Preliminary results are expected before July 2018. Reported posttraumatic social support will be categorized in 'turning against', 'unsupportive acknowledgement', and 'positive reactions'. We expect that there is a mediating effect of social support on symptoms of trauma sequelae.

Conclusion: This study will identify which types of social support are perceived as helpful by people with ID and gain an understanding on the mechanisms by which they mediate trauma sequelae. These results have implications for designing training for professional carers.

5461 | A pilot randomised control trial of Eye Movement Desensitisation and Reprocessing (EMDR) vs. Waiting List Control for DSM-5 Posttraumatic Stress Disorder (PTSD) in adults with intellectual disabilities

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Aim: The present study reports on the first ever pilot trial of EMDR versus WL for DSM 5 PTSD in people with IDs.

Method: A total of 29 participants were randomised to either EMDR (*n* = 15) or WL (*n* = 14). Participants were assessed at pre-post – and 3 – month follow – up on measures of traumatic stress, depression, anxiety and general distress. Qualitative interviews were also conducted with completers and non-completers on treatment experience.

Results: Participants in the EMDR group received a mean of 6.8 (Sd = 1.4) sessions. A proportion of 40% dropped out from the EMDR + WL group and 29% from the WL group. At post – treatment 60% in the EMDR group were diagnosis free versus 27% in the WL group. At 3 – month follow – up 47% in the EMDR group and 27% in the WL group were diagnosis free. Qualitative findings confirmed that EMDR is an acceptable treatment for people 1 with IDs and DSM 5 PTSD.

Conclusion: A definitive trial on EMDR for DSM 5 PTSD is recommended.

5393 | A multicentre randomised controlled trial for bright light therapy in adults with intellectual disabilities and depressive symptoms: first results

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Aim: There are only a few options to treat depressive symptoms in adults with intellectual disabilities (ID), especially in the severe/profound ID population. As pharmacological treatments are not always desirable or usable, this study investigates the effect of Bright Light therapy (BLT) in adults with ID and depressive symptoms.

Method: A multicenter randomised controlled trial (RCT) was carried out in the Netherlands. Participants were randomised over three groups. Group I received two weeks of BLT in the morning (10,000 lux), additional to their care as usual. Group II: received two weeks of BLT in the morning (< 499 lux), additional to their care as usual. Group III: only received care as usual (control group). Depressive symptoms measured at baseline, right after the end of BLT and four weeks after the end of BLT were our main outcome measures.

Results: Data collection of this study ended in November 2017. In total, 41 participants have been included in the past two years. The first results on its effect on depressive symptoms will be presented for each intervention group.

Conclusion: As far as we know, this study is the first multicenter RCT investigating BLT to decrease depressive symptoms in adults with ID.

26. MENTAL HEALTH II

5654 | Psychologists' adherence and carer experiences with best practice in Intellectual Disabilities and co-morbid mental Ill health – oral presentation research report

J. Man

Macquarie University, Australia

Aim: This PhD research explored Australian psychologists' perceptions of best practice in dual disabilities and its alignment with practice guidelines and carer experiences.

Method: The first study explored assessment practices, training needs and barriers to evidence based practice implementation of Australian psychologists via an online survey. Study two involved focus groups with psychologists exploring their perceptions of best practice, adherence to practice guidelines and impact of organisation factors. The final mixed method study explored carers' experiences with mental health and disability services, carer mental health literacy and barriers to seeking help.

Results: Overall, findings suggest psychologists were aware of best practice principles and reported clinical practices that aligned with international and Australian practice guidelines. Psychologists reported limited confidence in mental health diagnosis with individuals with intellectual disabilities and the need for further training. Carers also displayed high mental health literacy and few attitudinal barriers to help seeking.

Conclusion: Further clinician training and addressing organisational barriers to best practice implementation are needed. Findings also have implications for service models of care, policy and practice based evidence.

5617 | Feasibility of tandem-delivered psychoeducation for service users and staff: a case series of a tablet-based intervention

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Bielefeld University, Germany

Aim: People with intellectual disabilities may have a limited cognitive understanding of mental health problems and mental well-being. We aimed to explore the feasibility of a brief tablet-based psychoeducational intervention for use by people with ID and their care-givers.

Method: Five participant pairs were formed by adult service users with mild to moderate ID living in residential facilities and a nominated care-giver. Service users, supported by their care-giver, completed four weekly 30-minute sessions of the psychoeducational programme. The intervention introduced four concepts: self-concept, community participation, behavioural activation, and cognitive restructuring.

Results: Quantitative within-subjects analyses evaluated self-reported and proxy-reported quality of life, behaviour problems, mood, and self-efficacy. Qualitative analysis of the acceptability and feasibility of the intervention, using the client change interview, yielded recommendations for further development of the intervention.

Conclusion: The findings suggest that tablet-based psychoeducation may be feasible and acceptable to people with ID. Further development of the intervention would benefit from a collaborative approach with both service users and staff is desirable prior to evaluating its efficacy in a larger sample.

5592 | A pilot study to evaluate a group intervention for boys with Autism Spectrum Disorder (ASD) bullied in mainstream school

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Independent practitioner, Greece

Aim: This presentation describes the development and evaluation of a cognitive behavioural anti-bullying group programme.

Method: The intervention was directed at 11–16 year old boys with ASD who were being bullied within mainstream school. The group programme aimed to teach youngsters strategies to manage bullying and improve their confidence and resilience. A pre-test/post-test single group design was utilised. Primarily qualitative methods were used to evaluate the impact of the intervention 6–24 months post completion.

Results: Qualitative analysis of semi-structured interviews with 8 youngsters and their parents was completed. Both the participants and their parents reported benefits of attending the group, including bullying-related positive changes (e.g. improved self-awareness, reduced isolation and enhanced ability to cope with incidents of bullying) and high levels of user satisfaction with the service.

Conclusion: Young people with ASD attending mainstream school are at risk of experiencing bullying and the associated long-lasting negative effects on their well-being. Group programmes promoting self awareness and self management may have a useful role in empowering youngsters to build resilience and manage these experiences effectively. Within societies that value diversity, it is vital that bullying behaviour is addressed in schools so that truly inclusive cultures are established within education establishments.

5771 | Promoting carers' well-being using acceptance-based interventions for carers of children with intellectual disabilities; a pilot project

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Central and North West London NHS Trust, UK

Aim: It is well known that carers of children and young people, whose behaviour is deemed as challenging, experience high levels of stress. In an attempt to promote greater resilience to the carers we are working with, and to ensure the integrity of our interventions, we run workshops for carers based on the principles of Acceptance and Commitment Therapy (ACT).

Method: Participants were parents of children with intellectual disabilities, accessing specialist tier 3 CAMHS Learning Disability services in the UK. The workshops involved two 4-hour group sessions on consecutive weeks. One follow up individual appointment 4–6 weeks following the group took place, to measure progress and obtain feedback.

Results: To assess the outcomes of our intervention, we used a qualitative feedback form, a general measure of psychological acceptance and a goal-based outcome. The preliminary analysis of the qualitative feedback of a small group of participants suggests that parents found the workshops useful, and an acceptance-based intervention may positively affect their psychological adjustment.

Conclusion: This intervention appears to promote carers' well-being and may also offer an important contribution to the wider implementation of the Positive Behaviour Support (PBS) framework.

27. MENTAL HEALTH III

5915 | The setting of a specialised service for people with intellectual disabilities and mental health

E. Guaia

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Aim: Setting up a new service for people with intellectual disability and mental health requires building a network between the existing services. With the introduction of National Disability Insurance Scheme, the support for people with a learning disability has moved to a new system where each person needs are offered with an individualised access and with provisions that are based on needs and individual preferences.

Method: The mental health component otherwise has always required a specific approach that involved not only the specific support to the individual with Id and Mental Health problem as these in people with ID are three times more common and require a tailored approach that involves a holistic approach.

Results: Due to the historic divide between health and support services in Australia, the mental health component has not been fully developed and psychiatrists did not have the opportunities to be specifically trained and as well this has happened to mental health professionals.

Conclusion: This presentation will highlight the experience of the author on setting up a new service from the beginning providing the preliminary framework and the progress since the early setup and as well the challenge relevant to establish a new model of service.

6016 | Relations between social and emotional competence and mental health problems in adolescents with intellectual disabilities (ID)

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Faculty for Education and Rehabilitation Sciences, University of Zagreb, Croatia

Aim: 1. To determine relations between social and emotional competence and mental health problems in adolescents with ID 2. To determine relations between social and emotional competence and mental health problems in adolescents without difficulties 3. To analyze differences in structure of canonical factors between two samples.

Method: Participants: sample of adolescents with ID (100); sample of adolescents without disabilities (100) Procedures: Special teachers will assess socio-emotional competence and mental health with two scales. Data processing: Descriptive analysis, Canonical correlation analysis, Multivariant regression analysis Measurement instruments: Scale of emotional development—Short (Spook at all., 2016) and Scale for developmental-psychiatric diagnosis in persons with ID (SRPD, Došen, 2002).

Results: There are statistically significant correlation between social and emotional competence and mental health in sample with ID, but not in typical sample. There are significant differences in canonical structure between two samples. There are different predictors of mental health problems between two samples.

Conclusion: This research plan is implemented for the first time in Croatia and enrich scientific knowledge as we find out specific factors and predictors which can contribute to better socioemotional competence and better mental health in adolescents with ID in relation with adolescents without disabilities.

5368 | Substance abuse among outpatients with ID: adapting treatment methods through multiprofessional collaboration

P. Björne; A. Edvardson

City of Malmö, Sweden

Aim: The frequency of drop out among clients with cognitive disabilities such as ID, borderline intellectual functioning and/or autism at an outpatient care centre for persons with substance abuse, aroused questions. The manager and therapists at the centre wanted to develop the treatment methods, thus making them more accessible. The aim of the study was to explore how, through multiprofessional collaboration with a cognitive scientist, treatment methods could be modified for clients with cognitive disabilities.

Method: The manager and therapists collaborated with a cognitive scientist during one year. The therapists presented client cases and jointly explored possible adaptations of methods with maintained method integrity. Between meetings, therapists adjusted client sessions and documented the impact on clients.

Results: The therapists found that clients with ID, BIF and/or autism were able to engage in the therapeutic partnership when context changes were supported, visual aids were provided and time for client sessions was adapted to individual needs. Continued collection of statistics will show if the adapted treatment methods will affect drop outs among clients with ID/BIF or autism.

Conclusion: Multiprofessional collaboration with a researcher can be an efficient way of adapting client work, making treatment methods more accessible to clients with ID/BIF.

5716 | Results of a multi-component walking programme for children with intellectual disabilities: a randomised feasibility study

L. Taggart; A. Johnston

University of Ulster, Northern Ireland, UK

Background: We developed a 12-week multi-component walking programme for children with ID (9–13 years) based upon COM-B behaviour change model and the social ecological model. Components of the programme included: the use of peer role models with ID (15–19 years), incremental walk programme, use of paedmoeters and creating walk zones within the school.

Aim: To undertake a randomised feasibility study of the walking programme compared to routine school input targeting physical activity.

Method: Two school in N Ireland were randomly allocated to receive the walking program and one school acted as the control group.

Results: There was minimal attrition (7%) and adherence to the 12-week multi-component walking program was 78.5% across the 2 schools. There was poor compliance to accelerometer wear time however all other outcome measures were appropriate and acceptable. There were positive trends in vigorous physical activity, increase in step account and in physical fitness. **Conclusion:** It was feasible to deliver this 12-week multi-component programme within a school setting. This is the first study to develop and test a school-based multi-component walking programme for children with ID.

28. MENTAL HEALTH IV

5975 | Enhancing staff knowledge of positive behaviour support for adults with Intellectual Disability in Hong Kong

P. King Shui Wong

The Chinese University of Hong Kong, Hong Kong

Aim: Positive behaviour support (PBS) is increasingly viewed as the preferred service approach for people with intellectual disability (ID),however knowledge and skills are insufficiently widespread in Hong Kong. This paper reports findings from a PBS project carried out with a Disability Service Agency in Hong Kong, as part of a wider study evaluating effectiveness of PBS training. The current study aims to examine changes in staff knowledge after the tier one staff training.

Method: In total, 238 participants from various positions (both direct support workers and professionals) who work with adults with ID attended the PBS training workshop. A pre-test/post-test design was adopted. Participants rated their knowledge on the author-constructed 3-item scale before and after the training.

Results: Showed that participants achieved statistically significant positive changes in the domains of perceptions of challenging behaviours ($P = 0.000$), active participation in PBS intervention ($P = 0.014$) and the total score ($P = 0.000$).

Conclusion: The findings provided initial evidence of the effectiveness of staff training that enhances PBS knowledge of Chinese rehabilitation personnel of various positions. The content and pedagogy of the staff training will be discussed.

6017 | Effective occupational therapy with young people with complex mental health / learning disabilities

M. Avantaggiato-Quinn; S. McAnelly

Northumberland Tyne & Wear NHS Foundation Trust Northumbria University, UK

Aim: This relativist research enhances understanding of the phenomenon of effective occupational therapy with children and young people (CYP) with complex mental health needs/learning disabilities, in the lived experience of occupational therapists.

Method: Assuming an interpretivist epistemological perspective, a Heideggerian (1962) interpretive phenomenological methodology guided a reflexive relational approach (Finlay and Evans, 2009) to in-depth interviews carried out with eight OTs working in specialist CYP services in England. Using threefold analytic.

Method: Thematic (Van Manen, 1997), metaphorical and Lifeworld (Ashworth, 2003), results were contextualised using an occupational perspective of health (Wilcock and Hocking, 2015).

Results: Effective OT identified issues of occupational injustice and child centredness. Primarily supporting the development of the young person's sense of occupational being through having an authentic relationship and time and space during occupational therapy. Opportunities to improve health through occupational doing were created through micro-grading of activity-based interventions. Grading the environment enabled OTs to facilitate CYP to set and reach personally meaningful goals to become the experts in themselves and develop a sense of self-hood and occupational belonging.

Conclusion: Enhancing understanding of occupational therapy with CYP, offering recommendations to refine OT practice with CYP to celebrate diversity through improving participation in meaningful occupations.

6024 | Using hidden Markov models to better understand transitions in both depression and loneliness

P. McCallion; A. Wormald; E. Cleary; M. McCarron

Temple university, USA

Aim: To understand transitions in both depression and loneliness.

Background: Depression and loneliness in older adults with intellectual disabilities are reported as somewhat higher than for the general population but the transition to depression or to loneliness and the reverse transition from depression to no depression or from loneliness to no loneliness have not been fully explored.

Method: This study uses the longitudinal data from the first three waves of the intellectual Disability Supplement to The Irish Longitudinal Study on Ageing to examine the transition to depression, reverse transition from depression to no depression and also repeated transition from no depression to depression after experiencing a reverse transition during a study period. Covariate-dependent Markov models used the logistic link function based on the Chapman-Kolmogorov equation.

Results: Similar to prior reports for the general population, differences by age and by gender appeared to influence transitions in both loneliness and depression.

Conclusion: Depression and loneliness have emerged as major health concerns with the potential to have long-term impact in terms of risk for chronic conditions and lower life satisfaction. The findings here help to further identify those at risk and the times in one's life when risk may be greatest.

29. CHALLENGING BEHAVIOUR

6033 | Intervention MOMENT: developing family resources to cope with challenging behaviours

E. Kontu; J. Virtanen; V. Tyyskä-Korhonen; R. Pirttimaa

University of Helsinki, Finland

Background: Intellectual and developmental disabilities are often linked with behavioural challenges, for which families seek solutions. Several programmes are available to support positive behaviours. The project MOMENT (Hetki) a resource-driven model is being developed. The aim is to develop a model for intervention to support family resources. Understanding siblings' behaviour is also promoted. The model includes individual guidance for the family members and intense co-operation in peer-group activities, with the aim to increase the family's means of solving problems.

Method: The intervention and the developmental work are carried out through action research, and the usefulness of the intervention is evaluated through family and group interviews. In addition, information is obtained through observations. In addition, the behaviour of a single child is monitored. Data are also collected during professional discussions. Thirty-three families are involved in the development of the intervention and the research.

Results: Results will be collected throughout 2018.

6004 | Reestablishment of the Institutional Model? Organisational and individual aspects regarding services for persons with challenging behavior

M. Reichstein

Germany

Background: Following the ratification of the UN CRPD the support systems for persons with intellectual disability undergo substantial changes in many countries. While many persons with intellectual disability can benefit from the recent development certain groups seem to bear a higher risk of being excluded from newly developed service models. In this context persons who show so-called challenging behavior appear to be especially vulnerable. Support models for persons with intellectual disability are being intensively discussed in Germany at the moment.

Method: The presentation will refer to results from a recently finished research project on services for the aforementioned group. In this context, both structural aspects and the individual situation and quality of life were covered with a mixed-methods approach. A representative quantitative study among service providers in North Rhine-Westfalia (Reichstein & Schaedler 2016) showed a wide acceptance of custodial measures up to closed accommodation with legal approval among service provision organizations. In this context, there might be a risk of restrictive institutional models to become reestablished with a drastic impact on individual quality of life. Those negative impacts have been found in interviews with the target group.

Results: Results have been structured referring to the quality of life model by Schalock and Verdugo (2002).

5684 | Self-injurious behaviour and service receipt in young adults with autism: a ten year longitudinal cohort study

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Aim: Autism spectrum disorder (ASD) is a risk marker for self-injurious behaviour (SIB). However, despite the deleterious consequences of self-injury, there are limited data describing the trajectory of self-injury over time in this high risk group. Thus, the present study aimed to describe the course of self-injury in individuals with ASD over ten years, assessing correlates of poor outcome and associated access to services and intervention.

Method: Parents and carers of 67 individuals with ASD (median age = 20.5) completed questionnaires relating to self-injury at T1 and ten years later at T2. Analyses were conducted to evaluate the persistence of SIB and behavioural and demographic characteristics associated with persistence. At T2, data were gathered on service and intervention access in the preceding ten years.

Results: Self-injurious behaviour was significantly persistent over ten years ($P < 0.01$) and persistence was predicted by higher levels of impulsivity and overactivity at T1. Persistence in self-injury over ten years was not associated with increased access to service or appropriate interventions.

Conclusion: Self-injury is persistent in ASD and predicted over ten years by reliable, observable risk markers. However, despite the availability of evidence-based interventions, service receipt is not matched to the level of need in this group.

5471 | Knowledge translation intervention with supervisors to reduce injuries to DSP

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Aim: The main aim of this study was to evaluate the effectiveness of an educational knowledge translation intervention with supervisors of community homes to reduce injuries.

Method: The participants were 7 supervisors of community homes, with responsibility for at least 20 staff. The intervention with supervisors comprised self-study of 4 modules and a workshop. The intervention group was compared to the rest of the population of supervisors. The direct support staff was surveyed regarding their satisfaction with the support they received following an injury related to challenging behaviour and the support for use of the training they received to prevent injuries, as well as a measure of workplace engagement. The supervisors evaluated the usefulness of the modules and the usefulness in their ability to support their staff.

Results: Overall, the supervisors felt that the modules were valuable resources and that all people working in their roles should receive this education. The final survey results of the group homes from the intervention group and comparison homes will be described.

Conclusion: Supervisors are in an ideal position to emphasize the training that is provided to direct support staff to prevent challenging behaviours and support their staff who have been injured.

30. AUTISM I

5574 | Children and young people with autism – observational study of general health status in a whole country population

E. Rydzewska; L. Hughes-McCormack; A. Henderson; S.-A. Cooper

University of Glasgow, UK

Aim: To investigate 1) identified prevalence of autism by age and gender, 2) general health status and its relationship with age and gender in a whole country population of children and young people aged 0–24 with and without autism.

Method: The data source was Scotland's Census 2011. We calculated the percentage of children/young people identified with autism by age/gender. We described their general health ratings, and calculated odds ratios (OR: 95% confidence intervals) of autism predicting poor (fair/bad/very bad) general health in the general population. We then calculated OR of age and gender predicting poor general health within the autism cohort.

Results: Of 25,063/1,548,819 (1.6%) children/young people with autism, 19,880 (79.3%) were males and 5,183 (20.7%) females. Identified prevalence rose with age, peaking at 11 y (2.9%). 21.9% with autism, and 1.9% without autism had poor health; autism had an OR = 11.3 (11.0–11.7) for predicting poor general health. Girls with autism had poorer health than boys (OR = 1.6: 1.5–1.8).

Conclusion: Autism diagnosis is improving at younger ages, but children may still not be identified until late primary or secondary school age. Identification is important given educational needs, and for vigilance/awareness of substantially poorer general health so that suitable managements are provisioned.

5577 | Children and young people with autism – observational study of comorbidity in a whole country population

E. Rydzewska; L. Hughes-McCormack; A. Henderson; S.-A. Cooper

University of Glasgow, UK

Aim: To investigate prevalence of comorbidities and their relationship with age and gender in a whole country population of children and young people aged 0–24 with and without autism.

Method: The data source was Scotland's Census 2011. We calculated the percentage of population with autism, and their extent of comorbidities. We calculated odds ratios (OR: 95% confidence intervals) of autism predicting comorbidities, adjusted for age and gender. We then calculated OR for age and gender in predicting comorbidities within the cohort with autism.

Results: 25,063/1,548,819 (1.6%) had autism; 19,880 (79.3%) males and 5,183 (20.7%) females. Autism had an OR = 5.4 (5.0–5.8) for predicting deafness/partial hearing loss, OR = 1.6 (1.5–1.6) for blindness/partial sight loss, OR = 49.7 (47.5–52.0) for intellectual disabilities, OR = 15.7 (15.0–16.5) for mental health conditions, OR = 15.8 (15.1–16.6) for physical disability, and OR = 3.9 (3.8–4.0) for other conditions. Females with autism were more likely to have each additional condition than males.

Conclusion: Children and young people with autism are more likely to have health problems than their peers without autism, substantially so for intellectual disabilities, mental health conditions, and physical disability. Females with autism may have more severe autism than males.

5576 | Adults with autism – observational study of general health status in a whole country population

E. Rydzewska; L. Hughes-McCormack; A. Henderson; S.-A. Cooper

University of Glasgow, UK

Aim: To investigate general health status and its relationship with age and gender in a whole country population of adults aged 25+ with and without autism.

Method: The data source was Scotland's Census 2011. We investigated general health status in adults aged 25 + with and without autism. We calculated odds ratios (OR: 95% confidence intervals) of autism predicting poor (fair, bad, or very bad) general health in the general population, and OR of age and gender predicting poor general health within the autism cohort.

Results: Of 6,649/3,746,584 (0.2%) adults aged 25 + known to have autism, 4,610 (69.3%) were males and 2,039 (30.7%) females. 46.8% with autism, and 23.7% without autism reported poor health; autism had an OR = 5.1 (4.9–5.4) for predicting poor general health, or OR = 7.5 (6.9–8.2) when the interaction with age was included. Poor health was common across the entire life course for adults with autism; in the population with autism, females and older people had poorer health.

Conclusion: Poor general health merits attention across the full life course for adults with autism. There has been little previous research on this topic, and our findings suggest more is needed in order to accurately plan for appropriate service provision and supports.

5578 | Adults with autism – observational study of comorbidity in a whole country population

E. Rydzewska; L. Hughes-McCormack; A. Henderson; S.-A. Cooper

University of Glasgow, UK

Aim: To investigate prevalence of comorbidities and their relationship with age and gender in a whole country population of adults aged 25 + with and without autism.

Method: The data source was Scotland's Census 2011. We investigated the extent of comorbidities in the adult population with and without autism. We also calculated odds ratios (OR: 95% confidence intervals) of autism predicting comorbidities in the general population, and OR of age and gender predicting comorbidities within the autism cohort.

Results: There were 6,649/3,746,584 (0.2%) adults aged 25 + known to have autism in Scotland, of whom 4,610 (69.3%) were males and 2,039 (30.7%) females. Autism had an OR = 3.3 (3.1–3.6) for predicting deafness or partial hearing loss, OR = 8.5 (7.9–9.2) for blindness or partial sight loss, OR = 94.6 (89.4–100.0) for intellectual disabilities, OR = 8.6 (8.2–9.0) for mental health conditions, OR = 6.2 (5.8–6.6) for physical disability, and OR = 2.6 (2.5–2.8) for other conditions. Contrary to findings within the general population, female gender predicted all conditions within the population with autism.

Conclusion: Adults with autism are substantially more likely to have comorbidities than other adults. Clinicians need heightened awareness of comorbidities to improve detection and suitable care, particularly given the added complexity of assessment in people with autism.

31. AUTISM II

5880 | Female experiences and behavioural presentations of Autism Spectrum Conditions: a systematic review

E. Gale; J. Bradshaw; F. Gullon-Scott; Peter E. Langdon

University of Kent, UK

Aim: Females are typically diagnosed less and later than males. There is little consensus regarding female presentations of autism. This research explored the presentation of autism in adolescent and adult females, with particular focus on experiences and behavioural presentations.

Method: A systematic review of the literature was conducted. Four databases were searched. The search terms included "autis*, female, women and girl". Inclusion criteria: Adult/Adolescent participants, all research designs (except case studies), peer-reviewed, focusing on experiences or behavioural presentations. Papers on genetics and cognition were excluded.

Results: Twenty-three papers were included. Differences in diagnosis and presentation were explored. As females are generally expected to be more socially skilled than men, autistic women reported less acceptance of their social difficulties. Camouflaging and imitation were specific coping strategies that developed. Females were reported to have fewer identified repetitive/restricted interests but it remains unclear whether repetitive/restricted interests are present but less likely to be identified. Females reported higher levels of mental health difficulties.

Conclusion: Improvement in awareness of female presentations, and access to diagnostic pathways may improve with screening tools that are designed to identify people (including women) who are more difficult to diagnose, taking into account issues identified above.

5743 | A Feasibility randomized clinical trial (RCT) of a manualized intervention targeting elopement (running away) in children with Autism Spectrum Disorder

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Marcus Autism Center, Emory University, USA

Aim: Elopement is an incredibly prevalent concern among individuals with autism spectrum disorder (ASD) and can be incredibly dangerous. There are examples of successful treatments, but most use single-subject design or summaries of clinical data. This study had two primary aims to advance research elopement treatment: (1) evaluate the feasibility of a RCT of a manualized behavioral intervention for elopement and (2) determine initial efficacy of the intervention in reducing elopement, decreasing caregiver stress, and improving home-safety.

Method: We enrolled 24 children with ASD who frequently eloped. The manual was implemented across 12 weeks in a home setting. It included psychoeducation, instructions for home safety, a functional behavior assessment, and a function-based treatment.

Results: Primary outcome measures of feasibility were adequate: > 80% completion and integrity and adequate acceptable. Preliminary efficacy showed improvement on the irritability subscale of the Aberrant Behavior Checklist, the child-domain of the Parenting Stress Index, and home safety Results from the clinical global improvement scale are also discussed.

Conclusion: Results suggest that an RCT with this population is feasible and the intervention shows promise for future larger sample efficacy trials.

6010 | Review of the efficacy of sensory integration therapy in autism through the practice of occupational therapy

E. Maglari
Pediatric Institute, Ltd, Greece

Aim: 42–88% of individuals with ASD present Sensory Processing Disorders (SPD) (Baranek, 2002). A common type of SPD is sensory modulation difficulties which cause and/or contribute to behaviors such as self-stimulatory, stereotypical, self-injurious, and/or sensory avoiding behaviors in an effort to control, avoid and exert meaning from sensory overload (Roberts et al. 2007). Hyperactivity, aggressiveness, poor attention, dyspraxia and high arousal levels are also associated with SPD (Tomchek & Dunn, 2007).

Method: Sensory Integration theory and practice developed by Dr. A. Jean Ayres, focuses on the neurological processing of sensation and how dysfunction impacts on the organization and expression of functional behaviors and actions. (Schaaf & Miller, 2005, Watling & Diaz, 2007).

Results: Sensory Integration treatment targets the enhancement of the sensorimotor foundations of attention, regulation, learning, praxis, social, and emotional skills through active participation in meaningful activities and appropriately orchestrated sensory environments (Schaaf & Nightlinger, 2007). Since sensory integration therapy is widely used in ASD, it is necessary to investigate its efficacy (Yell et al. 2008).

Conclusion: This presentation will focus on the efficacy of sensory integration in autism as implemented by the profession of occupational therapy.

5987 | Occupational and speech language collaboration using sensory integration in individuals with autism spectrum disorder

E. Maglari
Pediatric Institute, Ltd, Greece

Aim: Sensory Processing Disorder (SPD) affects all aspects of speech-language and feeding skills in people with ASD. (Willems et al. 2007) Children with ASD and Speech Language Impairment (SLI) frequently present vestibular, tactile and visual-auditory sensory processing difficulties, as well as sensory modulation difficulties that affect attention, imitation, comprehension and production of language (Guenther, 2006). Difficulties in auditory discrimination and/or hyper-responsiveness, oral tactile hyper-responsiveness, sensory-based dyspraxia and in multisensory processing develop and/or contribute to lesser or greater problems in receptive and expressive language, articulation, and feeding skills as well as in communication and social abilities (Pfeiffer et al. 2011). Dr. A. Jean Ayres developed the theory and practice of Sensory Integration.

Method: Review of 16 articles between 1981 and 2011.

Results: The findings support that sensory integration treatment can benefit the development of speech, language and social skills in ASD (Case-Smith & Holland 2009; Atchison 2007).

Conclusion: This presentation focuses on the role of the speech language pathologist in identifying ASD individuals with SPD and the importance of the co-treatment with occupational therapists trained in sensory integration for the development and improvement of speech language and feeding skills.

32. CRIME AND OFFENDING BEHAVIOURS

5615 | Young people with intellectual and other developmental disabilities who display harmful sexual behaviour: a case series report

A. Malovic; G. Murphy

Tizard Centre, University of Kent, UK

Aim: Up to 40% of adolescents within specialist services for harmful sexual behaviours (HSB) are thought to have IDD. Hackett's Research to Practice Review (2014) found access to services, especially for those with IDD, to be inadequate, resulting from poor recognition of the offence, lack of care pathways and services (Fox, 2013). Part of the reason for this is our lack of knowledge and understanding of those young people with IDD (NSPCSS, 2016) and how they might be distinguished from the neurotypical cohort.

Method: Data were accessed from a case series of a cohort of young people with IDD who have been referred to specialist services for HSB, run by a major UK national charity based in London.

Results: Up to 20 case reports were reviewed, with 6 main themes identified and analysed. These pertained to the adolescents' demographics, family constitution, nature of HSB, victims, own victimisation and other risky behaviours.

Conclusion: Overall, the adolescents in this cohort had wide-ranging experiences of abuse and neglect in their own histories. They were most likely to display impulsive HSB towards people and family members in their immediate environment.

5614 | Keep Safe: the development of a manualised group CBT intervention for adolescents with intellectual disabilities who display harmful sexual behaviours

A. Malovic; R. Rossiter; G. Murphy

Tizard Centre, University of Kent, GB

Aim: A significant proportion of adolescents within specialist services for harmful sexual behaviours (HSB), are thought to have IDD. UK national reports have highlighted the need for the development of specialist programmes as there is a lack of evidence or practice-based interventions. This study focuses on the development of Keep Safe, a manualised CBT group intervention for adolescents with IDD who display HSB.

Method: An expert-consensus methodology based on the Delphi method was used. The iterative process for the manual draws on the slim practice-based evidence from UK, North America and Australasia. Keep Safe comprises six modules distributed through 36 term-time young people's sessions, alongside 18 concurrent parental/ carer sessions (some joint).

Results: Four initial sites volunteered as feasibility leads, and 2 more were added as recruitment was more difficult than foreseen. Only a small number of young people (n = 7) have engaged in the group programme so far. However there were improvements in sexual knowledge and attitudes, and fewer harmful sexual behaviours amongst the young people who completed the Keep Safe programme.

Conclusion: The main focus of Keep Safe is to enhance well-being and reduce harm. It appeared successful as a pilot study and a larger trial is needed.

5534 | Adapted sex offender treatment programmes for men with autism spectrum conditions: clinician views

C. Melvin; G. Murphy; Peter E. Langdon

University of Kent, UK

Aim: Clinicians working with individuals with autism spectrum conditions (ASC) who display sexual offending behaviours can face challenges during treatment, potentially as a result of the cognitive and behavioural profile associated with ASC. This research explored the views and experiences of those running adapted sex offender treatment groups with men with ASC.

Method: Semi-structured interviews with group facilitators (n = 13) focused on engagement and response to the core components of the treatment programme (e.g. increasing victim empathy, addressing cognitive distortions), and gathered the experiences of those working with men with ASC who display sexual offending behaviours.

Results: Grounded Theory was used to develop a model conceptualising the potential impact of ASC on treatment outcomes and future risk. Benefits of attending a group included: the presence of other group members, a forum to develop pro-social roles and relationships, and increased opportunity for monitoring. Challenges regarding empathy, specifically emotional empathy, and shifts in cognitive distortions were felt particularly pertinent to those with ASC, as well as questions over internalisation of therapy.

Conclusion: Despite identification of a number of challenges, adapted sex offender treatment programmes were considered beneficial for men with ASC, especially in light of a dearth of evidenced-based alternatives.

5481 | The face validity of an initial subtypology of adults with Autism Spectrum Disorders Detained in Hospital

M.-F. Barnoux; R. Alexander; S. Bhaumik; J. Devapriam; C. Duggan; Peter E. Langdon

Tizard Centre, University of Kent, UK

Aim: We have previously proposed that individuals with ASD detained within hospitals may be categorised into eight subtypes distinguished across three factors (i.e., psychopathy, psychosis, and behavioural problems). The aim of the current project was to investigate the face validity of these subtypes.

Method: Using both a focus group and consensus rating exercise with clinicians, people with ASD, and family members/carers the validity of the subtypes were examined.

Results: Our findings indicated that these subtypes possess face validity.

Conclusion: Further findings and the implications for future research will be considered, along with the clinical and forensic risk implications.

33. SEX AND SEXUALITY

5953 | "Sexual education of children with intellectual disability and autism at school age"

N. Apteslis

Greece

Background: Parents are particularly concerned about the sexual development and sexual behavior of their children. The aim of our research was to investigate and compare the views of parents of children with and without mental disability/autism regarding the sexual education of children with intellectual disabilities/autism at school age.

Method: The target population was considered to be the parents of children with and without mental disability/autism in school age who are attending educational structures of the Greek state (school age for children with mental disability 6–22 years). The participants in our survey were 308 parents of children without disabilities and 306 parents of children with disabilities.

Results: The results of our research revealed that parents' beliefs depend mainly on age, older parents of children with and without mental disability were more positive in the sexual education of children with intellectual disability and the educational level, the higher, greater acceptance was shown in the sexual education of mentally disabled children by the parents of both groups.

Conclusion: Both groups of parents believe that sexual education will help mentally disabled young people make correct sexual decisions and develop healthy interpersonal relationships.

5470 | Sexuality and relationships education for people with ASD – pilot programme implementation

M. Brown; G. Murphy; M. McCarthy

Tizard Centre, Cornwallis North East, University of Kent, Canterbury, Kent, UK

Aim: Sex and relationships education (SRE) has been integrated into the National Curriculum for UK schools for the past two decades, but tends to be mainstream orientated. There has been a limited amount of research into the appropriateness of present SRE programmes for pupils with ASD. This study has involved the development of an SRE programme for ASD pupils, based upon information gained through previous studies in order to reduce participant vulnerabilities.

Method: The development of a 9 sessions pilot programme, cognisant of the views of ASD pupils and teachers, was undertaken. The programme accessed a range of materials from different sources which were adapted further for individuals with ASD. Two pilot sites allowed recruitment of pupils with ASD (from those schools who took part in previous two studies.) Pre and post intervention data obtained using two measures (Sex-K-ID and SAKS).

Results: Results for both schools indicated significant gains in respect of sexual and social knowledge relating to sexuality. Pupils in both schools (n = 9; n = 13) showed significant gains on the Sex-K-ID after the pilot programme. One school also showed significant gains on the SAKS.

Conclusion: Further roll-out of the pilot programme is planned to evaluate its effects more widely.

5469 | "I wish I had learnt to keep myself safe" – Sexuality and Relationships Education (SRE) for People with ASD-Pupil Views

M. Brown; G. Murphy; M. McCarthy

Tizard Centre, Cornwallis North East, University of Kent, Canterbury, Kent, UK

Aim: Sex and relationships education (SRE) has been integrated into the National Curriculum for UK schools for the past two decades, but tends to be mainstream orientated. There has been a limited amount of research into the appropriateness of present SRE programmes for pupils with Autistic Spectrum Disorder (ASD). This study has explored the views of pupils with ASD regarding SRE programmes.

Method: Focus groups incorporating pupils with ASD were performed to gain pupil insight into the SRE programmes they had received and the areas they felt were required to keep them and others safe that were not present in the programmes.

Results: Thematic analysis of focus groups identified themes, including: lack of appropriate mainstream SRE programmes for pupils with ASD, issues relating to social and relationship aspects of sexuality, inconsistency in implementation of SRE resulting in insufficient levels of skills being learnt by pupils with ASD to keep safe.

Conclusion: A new SRE programme is needed specifically adapted for pupils with ASD to effectively cover the areas highlighted by pupils with ASD.

5468 | Sexuality and relationships education for people with autistic spectrum disorder – staff perspective

M. Brown; G. Murphy; M. McCarthy

Tizard Centre, Cornwallis North East, University of Kent, Canterbury, Kent, UK

Aim: Sex and relationships education (SRE) has been integrated into the National Curriculum for UK schools for the past two decades. SRE aims to teach about the emotional, social and physical aspects of growing up, relationships, sex, human sexuality and sexual health. Such a curriculum tends to be mainstream orientated, taught in large classes, with limited exploration and clarification for those who need it. There is concern that the development of incomplete knowledge and skills places the pupil with Autistic Spectrum Disorder (ASD) in a difficult, and potentially vulnerable, position.

Method: A literature review performed in relation to SRE and ASD formed the background to the study. Face to face semi-structured interviews occurred with head teachers or PSHE co-ordinators from 15 schools for pupils with ASD in London, Surrey and Sussex. These were analysed for common themes.

Results: Results highlighted a number of themes, including: programme implementation difficulties, attitude issues amongst staff, carers/parents, and individuals with ASD impacting upon programmes, staff support and training.

Conclusion: Development of an appropriate SRE programme is needed. Pupils with ASD will be involved in the next phase of the study.

34. PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES

5785 | Catalysts and barriers to school staff responsivity toward students with significant intellectual and developmental disabilities (SIDD)

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Aim: Children with SIDD are characterized by substantial language delays and depend on pre-symbolic and early symbolic means for communication. The way and the extent of the communication partners' response to a child's communication (responsivity) has been recognized as a key component in language development. The purpose of the study was to examine two models that would map possible catalysts and barriers to school staff's responsivity towards communication of students with SIDD. The models included staff member, student and environmental variables.

Method: Interactions between 120 school staff members and 43 students ages 9 to 16, with SIDD, were videotaped, during 258 routine school sessions. Staff behaviors were coded qualitatively and quantitatively. Staff and student variables were collected using questionnaires.

Results: Individual encounters and group encounters models were analyzed using exploratory path analysis, revealing different variables involved in each of the two types. In the individual encounter model student's verbal ability were the main predictor for responsivity. In the group encounter model, correlation between variables and responsivity were mediated by a latent variable- 'availability'.

Conclusion: The models present two extremities of communication environments involving different variables. Discussion will address the variables that serve as catalysts and barriers across both models.

5371 | Assessing engagement and responsiveness of children with profound/multiple disabilities

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Aim: To examine the extent to indices of engagement/responsiveness of five, 9–13-year-old, children with profound/multiple impairments varied in relation to differing levels of environmental stimulation.

Method: Each child was observed across three different environmental conditions that varied in terms of the amount and type of stimulation provided. The child's level of engagement/responsiveness was rated under each condition from videotapes using the Pittsburgh Participation Scale.

Results: A number of potential indices of engagement/responsiveness varies reliably and consistently in relation to the amount and type of environmental stimulation being provided. Indices of engagement/responsiveness were more frequent under conditions of higher levels of environmental stimulation.

Conclusion: These results suggest that children who appear largely passive and unresponsive can show subtle, yet reliable and consistent, signs of engagement/responsiveness in response that vary in relation to different levels of environment stimulation. The presence of these indicators might signal times when the child is actively engaged and thus perhaps more likely to be responsive to instruction.

5674 | The relation between physical fitness, activity and motor development in children with intellectual disability

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Aim: The purpose of this study was to determine the relationship between physical fitness, physical activity and motor development in children and adolescents with moderate to severe intellectual disabilities (ID).

Method: Children and adolescents (2–18 years) with moderate to severe ID, attending specialised day care centres in the Netherlands, were invited to participate. Data on physical fitness, physical activity and motor development were collected by respectively the modified 6-minute walk test (6 mwt), accelerometry, and the gross motor scale of Bayley Scale of Infant Development (BSID). Linear regression analyses were used to study the association between physical fitness, physical activity and motor development, corrected for age, sex and level of ID.

Results: For 59 participants (38 boys, age 9.4 ± 4.2 yrs) data on all three variables (6 mwt, accelerometer, BSID) were collected. Increased fitness was positively associated with physical activity and motor development ($\beta = 0.34–0.48$, $P < 0.01$). No significant association was found between physical activity and motor development.

Conclusion: Both motor development and physical activity are associated with physical fitness in children with moderate to severe ID. Further research should focus on the effect of increasing physical activity and motor development for the improvement of physical fitness, and thereby health.

5494 | Evaluation cognitive polyhandicap or cognitive evaluation for people with PIMD

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Description: Person suffering from PIMD confronts the professional with questions whose complexity can lead the latter either to a form of relinquishment, and/or to abandoning any evaluative approaches whatsoever in the field of cognition or emotional life. ECP (Evaluation Cognitive Polyhandicap or cognitive evaluation for people with PIMD) is an assessment tool that enables the psychologist, in cooperation with other professionals and the parents, to contribute to a better understanding and evaluation of competences and deficiencies and analyse the signs of mental suffering. This avenue allows an intervention to be implemented based on a scientifically validated method and tools.

Contribution: The aim is to avoid three pitfalls: 1. Overestimating the skills and so being led to offer her activities she cannot make her own. 2. Underestimating her skills and, in that case, leading to her being deprived of help in terms of education and care. 3 Abstaining from any assessment. The ECP was validated in 130 cases. It addresses children, adolescents and adults and encompasses the emotional and affective dimensions. The present communication sets out the methodology for construction of the tool, its indications, its advantages and limits.