



*social sciences*

# Inclusive Research

## Is the Road More or Less Well Travelled?

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Edited by

Patricia O'Brien

Printed Edition of the Special Issue Published in *Social Sciences*

# **Inclusive Research: Is the Road More or Less Well Travelled?**



# **Inclusive Research: Is the Road More or Less Well Travelled?**

Editor

**Patricia O'Brien**

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# Contents

<b>About the Editor</b> . . . . .	vii
<b>Preface to "Inclusive Research: Is the Road More or Less Well Travelled?"</b> . . . . .	ix
<b>Patricia O'Brien</b>	
Inclusive Research: Is the Road More or Less Well Travelled?	
Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 582, doi:10.3390/socsci11120582 . . . . .	1
<b>Danielle Garratt, Kelley Johnson, Amanda Millear, Shaun Picken, Janice Slattery and Jan Walmsley</b>	
Celebrating Thirty Years of Inclusive Research	
Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 385, doi:10.3390/socsci11090385 . . . . .	7
<b>Rachel High and Sally Robinson</b>	
Graduating University as a Woman with Down Syndrome: Reflecting on My Education	
Reprinted from: <i>Soc. Sci.</i> <b>2021</b> , <i>10</i> , 444, doi:10.3390/socsci10110444 . . . . .	21
<b>Alix Herer and Ariel E. Schwartz</b>	
How Being a Researcher Impacted My Life	
Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 127, doi:10.3390/socsci11030127 . . . . .	31
<b>Fionn Crombie Angus and Jonathan Angus</b>	
Exploring My Life Path by Asking 600 People What They Love about Theirs	
Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 551, doi:10.3390/socsci11120551 . . . . .	41
<b>Sofie Sergeant, Henriëtte Sandvoort, Geert Van Hove, Petri Embregts, Kim van den Bogaard and Elsbeth Taminiau et al.</b>	
On the Road Together: Issues Observed in the Process of a Research Duo Working Together in a Long-Term and Intense Collaboration in an Inclusive Research Project	
Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 185, doi:10.3390/socsci11050185 . . . . .	49
<b>Miriam Zaagsma, Mark Koning, Christien van Andel, Karin Volkers, Alice Schippers and Geert van Hove</b>	
A Closer Look at the Quest for an Inclusive Research Project: 'I Had No Experience with Scientific Research, and then the Ball of Cooperation Started Rolling'	
Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 186, doi:10.3390/socsci11050186 . . . . .	63
<b>Isabel Bonello, Sandra Borg, Anne-Marie Callus and Cristina Grech</b>	
Reflections on the Implementation of an Ongoing Inclusive Research Project	
Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 234, doi:10.3390/socsci11060234 . . . . .	79
<b>Greta Westermann, Erin Louise Whittle, Susan Adrian, Suzanne Jessep, Melanie Nolan and Bruce O'Brien et al.</b>	
Being an Inclusive Researcher in a National Consultation Exercise—A Case Study	
Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 164, doi:10.3390/socsci11040164 . . . . .	87
<b>Phillippa Carnemolla, Jack Kelly, Catherine Donnelley and Aine Healy</b>	
Reflections on Working Together in an Inclusive Research Team	
Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 182, doi:10.3390/socsci11050182 . . . . .	97
<b>Susana Rojas-Pernia and Ignacio Haya-Salmón</b>	
Inclusive Research and the Use of Visual, Creative and Narrative Strategies in Spain	
Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 154, doi:10.3390/socsci11040154 . . . . .	109

<b>Catherine de Haas, Joanna Grace, Joanna Hope and Melanie Nind</b> Doing Research Inclusively: Understanding What It Means to Do Research with and Alongside People with Profound Intellectual Disabilities Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 159, doi:10.3390/socsci11040159 . . . . .	<b>123</b>
<b>Carolina Puyaltó, Maialen Beltran, Tània Coll, Gemma Diaz-Garolera, Marta Figueras and Judit Fullana et al.</b> Relationships of People with Intellectual Disabilities in Times of Pandemic: An Inclusive Study Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 198, doi:10.3390/socsci11050198 . . . . .	<b>137</b>
<b>Jeroen Knevel, Jean Pierre Wilken and Alice Schippers</b> Experiences of Inclusive Action and Social Design Research with Social Workers and People with Intellectual Disabilities Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 121, doi:10.3390/socsci11030121 . . . . .	<b>153</b>
<b>Natasha Layton, Em Bould, Ricky Buchanan, Jonathon Bredin and Libby Callaway</b> Inclusive Research in Health, Rehabilitation and Assistive Technology: Beyond the Binary of the ‘Researcher’ and the ‘Researched’ Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 233, doi:10.3390/socsci11060233 . . . . .	<b>165</b>
<b>Caroline Doyle, Sophie Yates and Jen Hargrave</b> Reflecting on the Value of Community Researchers in Criminal Justice Research Projects Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 166, doi:10.3390/socsci11040166 . . . . .	<b>179</b>
<b>Iva Strnadová, Julie Loblinzk and Joanne Danker</b> Sex Education for Students with an Intellectual Disability: Teachers’ Experiences and Perspectives Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 302, doi:10.3390/socsci11070302 . . . . .	<b>193</b>
<b>Robert Hopkins, Gerard Minogue, Joseph McGrath, Lisa Jayne Acheson, Pauline Concepta Skehan and Orla Marie McMahon et al.</b> “Digging Deeper” Advocate Researchers’ Views on Advocacy and Inclusive Research Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 506, doi:10.3390/socsci11110506 . . . . .	<b>209</b>
<b>Patricia O’Brien, Edurne Garcia Iriarte, Roy Mc Conkey, Sarah Butler and Bruce O’Brien</b> Inclusive Research and Intellectual Disabilities: Moving Forward on a Road Less Well-Travelled Reprinted from: <i>Soc. Sci.</i> <b>2022</b> , <i>11</i> , 483, doi:10.3390/socsci11100483 . . . . .	<b>229</b>

# About the Editor

## **Patricia O'Brien**

From 2009 to 2020, Professor Emerita Patricia O'Brien was Director of the Centre for Disability Studies, affiliated with the University of Sydney. Prior to this role, Patricia held respective academic appointments at Trinity College, Dublin, as Director of the National Institute for Intellectual Disability and at the University of Auckland as Dean, Postgraduate Studies and Research.

Patricia's research interests and publications cover deinstitutionalisation, individual supported living, housing, advocacy, inclusive education, community participation, service design, and support. She is known for leading inclusive research initiatives where people with intellectual disabilities are involved as co-researchers. Patricia's work has also seen the development and mentoring of two major Inclusive Research Networks (IRN) one across Ireland and later in Sydney where researchers both with and without disabilities have co-designed areas of research interest with international dissemination of their findings. Also, as a strong advocate for inclusive education within university settings, Patricia introduced the "uni 2 beyond" program at the University of Sydney where students with intellectual disabilities can audit courses. Patricia has co-edited three books that promote the need for value-based inclusion both within education and community based service design. She is a Fellow of the Australasian Society of Intellectual Disability and is active in the non-government disability organisation sector as a Non-Executive Director of both Achieve Australia and The Achieve Foundation.





# Preface to "Inclusive Research: Is the Road More or Less Well Travelled?"

The Preface of the reprint is presented in the form of Robert Frost's poem, *The Road Not Taken*. I offer it as a basis for reflecting on whether we as researchers are on the right road?

The Road Not Taken

Robert Frost, 1916

1. Two roads diverged in a  
yellow wood,  
and, sorry that I could not  
travel both  
and be one traveller, long I  
stood,  
and peered down one as far as I  
could  
to where it bent in the  
undergrowth.

2. Then took the other, as just  
as fair,  
and having perhaps the better  
claim  
because it was grassy and wanted  
wear;  
though, as for that, the passing  
there  
had worn them both about the  
same.

3. And both that morning equally  
lay  
in leaves no step had trodden  
black.  
Oh, I marked the first for  
another day!  
Yet, knowing how way leads on to  
way,  
I doubted if I should ever come  
back.

4. I shall be telling this with  
a sigh

somewhere, ages and ages hence;  
"Two roads diverged in a wood,  
and I  
I took the one less travelled  
by,  
and that has made all the  
difference."

#### Reference

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**Patricia O'Brien**

*Editor*



# Inclusive Research: Is the Road More or Less Well Travelled?

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The purpose of this Special Issue on inclusive research is to capture international insights into the following questions: “How far have we come?” and “Where do we need to go?” Such questions are relevant now that it has been close to two decades since Walmsley and Johnson (2003) first introduced the inclusive research paradigm in their text, *Inclusive Research with People with Learning Disabilities: Past, Present and Futures*. Within this Special Issue, 18 articles promote inclusive research as a paradigm that has succeeded in transferring power to people with intellectual disabilities who were once the “researched” to now being and becoming the “researchers”. The articles draw upon the work of co-researchers, both with and without the lived experience of disability, who have adopted inclusive research as a paradigm to redress the exclusion of people with intellectual disabilities as researchers.

In introducing the Special Issue with its title, “Inclusive Research: Is the Road More or Less Well Travelled?” I am reminded of the whakataukī or Māori proverb, “I walk backwards into the future with my eyes fixed on my past” where the past, present, and future are intertwined. The Māori perspective emphasizes that “the past is central to and shapes both present and future identity” (Rameka 2017, p. 387). Interpreted within the context of the title of the Special Issue, it is therefore not surprising that many of the articles have cited the work of Walmsley and Johnson (2003) as foundational to what they have researched and written. All 18 articles have an eye on the future, and to help the reader to walk backwards into the future of inclusive research, a brief introduction to each article is provided as follows. The issue is bookended by two articles in which inclusive researchers of long standing reflect on how to continue to walk forward on the road that, aided by this issue, will become more well-travelled. The articles are sequenced across the following themes: the individual impact of being and becoming an inclusive researcher; building inclusive research relationships as a duo; being part of an inclusive research network; and using inclusive research to push boundaries and facilitate issues of importance identified by people with disabilities.

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## 1. The Opening Bookend

The opening article, “Celebrating Thirty Years of Inclusive Research” (Garratt et al. 2022), finds Kelley Johnson, Amanda Millea, and Janice Slattery, who work in Australia, being joined by Danielle Garratt, Shaun Picken, and Jan Walmsley, who live and work in the UK. They each share a brief life history on how inclusive research has brought about change, both in their lives and for people with intellectual disabilities (learning disabilities). They stress that even after 30 years of working together, there is still the need for activist and academic researchers to learn together about the way disability is viewed. The article models how to walk and write together as co-researchers in a way that is both accessible and inclusive.

## 2. The Individual Impact of Being and Becoming an Inclusive Researcher

Three articles then follow on what being an inclusive researcher has meant to individual authors with the lived experience of disability, illustrating a range of approaches that have worked for them. In the second article, entitled “Graduating University as a Woman with Down Syndrome: Reflecting on my Education” (High and Robinson 2021), the

work of Rachel High, supported by Sally Robinson, illustrates how using autoethnography enabled Rachel to tell her story of being the first person with Down Syndrome to complete an undergraduate degree at an Australian university. She writes of how such inclusion raised her confidence and enabled her to feel more a part of society, while at the same time overcoming the confrontation of being the only person with a disability in her class. Doing research inclusively led her to document her journey for others to gain inspiration from.

In the third article, “How Being a Researcher Impacted My Life” (Herer and Schwartz 2022), Alix Herer, supported by Ariel Schwartz, relates how she engaged in inclusive research that led her to identify her communication strengths, be professional, and tap into her own creativity. By being and becoming an inclusive researcher Alix participated in studies associated with both peer mentoring and disclosure, where she supported others with disabilities as both an advocate and a leader.

What distinguishes the fourth article entitled, “Exploring My Life Path by Asking 600 People What They Love About Theirs” (Crombie Angus and Angus 2022), is that Fionn Angus co-researches with his father, Jonathan, whereas for Rachel and Alix, their co-researcher partners were academic researchers. For Fionn and Jonathan, the core principle of inclusive research is the research question being owned and activated by the person with disability. They achieved this through Fionn’s street style of interviewing, challenging traditional research methods.

### 3. Building Research Relationships as a Duo

The scope of the Special Issue now moves from listening to the voice of individuals with disabilities to articles where duos of co-researchers discuss how they have built their working relationships. The fifth article, entitled “On the Road Together: Issues Observed in the Process of a Research Duo Working Together in a Long-Term and Intense Collaboration in an Inclusive Research Project” (Sergeant et al. 2022) is part of a national research project from The Netherlands where Sophie Sergeant, Henriette Sandvoort, Geert Van Hove, Petri Embregts, Kim van den Bogaard, Elsbeth Taminiau, and Alice Schippers examine the working relationship between the first two authors, one who had the lived experience of disability. Analysis of personal data collected about their collaboration led to the identification of six necessary conditions for diversity-sensitive work in inclusive research: experiencing belonging, empowerment through competency-building and self-awareness; reflection; sharing power; finding the needed time; and mutual engagement.

Correspondingly, in the sixth article, “A Closer Look at the Quest for an Inclusive Research Project: ‘I Had No Experience with Scientific Research, and then the Ball of Cooperation Started Rolling’” (Zaagsma et al. 2022), Miriam Zaagsma, Mark Koning, Christien van Andel, Karin Volkers, and Alice Schippers also co-explore the work of the first two authors once again, with one identifying as a person with a disability. Over five meetings Miriam and Mark reflected on their collaboration and concluded that time is the essential element needed to: get to know one another deeply to ensure that the person with a disability has voice and can exercise control; adequately manage the implementation of research strategies; reflect on ongoing research issues with one another and all other project stakeholders. As a result of these qualifiers, they concluded that doing inclusive research was not for everyone.

### 4. Being Part of an Inclusive Research Network

The journey of inclusive research now moves to that of four inclusive research teams reflecting on their journeys. The seventh article, “Reflection on the Implementation of an Ongoing Inclusive Research Project” (Bonello et al. 2022), comes from Malta with Isabel Bonello, Sandra Borg, Anne-Marie Callus and Cristina Grech outlining how they as a group of four with two members with the lived experience of disability addressed unemployment through making video CVs. The synergy between the four authors is strongly portrayed in both the development stages of the project as well in its evaluation.

The eighth article moves to an inclusive research network that operates out of the University of Sydney, where nine authors, the majority with intellectual disabilities, present the dynamics captured in the title, “Being an Inclusive Researcher in a National Consultation Exercise—A Case Study” (Westermann et al. 2022). Here, Greta Westermann, Erin Louise Whittle, Susan Adrian, Suzanne Jessep, Melanie Nolan, Bruce O’Brien, Jasamit Pannu, Elizabeth Young, and Mary-Ann O’Donovan document the resilience of the network in adapting the planned data collection method of face-to-face focus groups to online zoom in response to COVID-19. What the group learned was that regardless of the external circumstances brought about by COVID-19, it was important to debrief regularly on their data collection techniques, which enhanced their further learning.

The ninth article, *Reflections on Working Together in an Inclusive Research Team* (Carnemolla et al. 2022) finds Phillippa Carnemolla, Jack Kelly, Catherine Donnelley, and Aine Healy forming an inclusive research partnership within a Faculty of Design, Architecture and Building in an Australian university to explore how local governments could be more inclusive. The article offers five tips that could be used by other teams to set up inclusive research within university settings. A core tip is that of “recognising that inclusive teams can work in all learning and research spaces, not just disability-specific ones”. Collaboration, learning, and leadership were evidenced in the write up of the inclusive study.

A tenth article, “Inclusive Research, and the Use of Visual, Creative, and Narrative Strategies in Spain” (Rojas-Pernia and Haya-Salmón 2022), finds Susana Rojas-Pernia and Ignacio Haya-Salmon working with eight co-researchers with and without intellectual disabilities, where they illustrate a range of accessible data collection strategies. These include mediated reflection using objects, image theatre, and body mapping. Such strategies created inclusive research spaces where dialoguing together built relationships between members.

## 5. Pushing the Boundaries through Inclusive Research

There are seven articles that exemplify how inclusive research has pushed boundaries through including people with profound disabilities as researchers; expanding the original intent of inclusive research beyond collaborating only with people with intellectual disabilities; growing methodological approaches; and validating the relationship between inclusive research and advocacy.

The eleventh article, entitled “*Doing Research Inclusively: Understanding What it means to Do Research with and Alongside People with Profound Intellectual Disabilities*” (de Haas et al. 2022), brings together the positions of Catherine de Haas, Joanna Grace, Joanna Hope, and Melanie Nind, a group of researchers experienced in working with people with profound disabilities, as professionals, practitioners, and family members. Brief stories and photographs are used to bring alive the agency, personhood, and relational autonomy of people with profound disabilities, indicating that they do have a place in doing research.

The two articles that pushed the boundaries around methodology were intent on engaging co-researchers in having a voice associated with their need for social inclusion. The twelfth article, entitled “*Relationships of People with Intellectual Disabilities in Times of Pandemic: An Inclusive Study*” (Puyaltó et al. 2022), was undertaken by an inclusive research team in Girona, Spain, involving Carolina Puyaltó, Maialen Beltran, Tania Coll, Gemma Diaz-Garolera, Marta Figueras, Judit Fullana, Cristina Gonzalez, Maria Pallisera, Joan Pujolar, and Ana Rey. Each stage of the research was rethought in how to recruit, collect data, analyze, and write the findings arising from the restrictions of COVID-19. The study captured the socially isolating impact that the pandemic had on the lives of people with intellectual disabilities, indicating nevertheless how doing inclusive research was sustained throughout.

Reinforcing the need for social contact, the thirteenth article, “*Experiences of Inclusive Action and Social Design Research with Social Workers and People with Intellectual Disabilities*” (Knevel et al. 2022), Jeroen Knevel, Jean Pierre Wilken, and Alice Schippers demonstrate how inclusive research can merge the different methodologies of participatory action research and social design. The combination of approaches comes together in the



development of a Community of Development (CoD) as differentiated from a Community of Practice (COP).

The relevance of inclusive research to other disciplines beyond that of intellectual disability is reported in two articles. In the fourteenth article, “Inclusive Research in Health Rehabilitation and Assistive Technology: Beyond the Binary of the ‘Researcher’ and the ‘Researched’” (Layton et al. 2022), Natasha Layton, Em Bould, Ricky Buchanan, Jonathon Bredin, and Libby Callaway illustrate the relevance of inclusive research using co-design and co-production in assistive technology and allied health. They draw upon three co-design stories, leading them to introduce a revised ladder of inclusive research ranging from a person being a research participant to a person commissioning research and directing research method design and dissemination.

The fifteenth article, “Reflecting on the Value of Community Researchers in Criminal Justice Research Projects” (Doyle et al. 2022), further expands the relevance of inclusive research, where Caroline Doyle, Sophie Yates, and Jen Hargrave initially relay a story of issues experienced by women with disabilities, where a community researcher (inclusive researcher) had the lived experience of being a woman with a disability. They then critiqued a study associated with prisoners relocating to the community which did not involve the principles and practice of inclusive research. As a result, there is an argued case for ex-prisoners to be included as community researchers in ongoing research associated with the criminal justice system.

A sixteenth article included under this theme of pushing boundaries, “Sex Education for Students with Intellectual Disability Teachers Experiences and Perspectives” (Strnadová et al. 2022), also exemplifies how inclusive research can bring the focus to sensitive topics. Here, Iva Strnadova, Julie Loblinzk, and Joanne Danker call for related goals in sex education to be part of the school based Individual Learning Plan (ILP) development. This article, like several others in the issue, is written by an inclusive research team whose members have worked together across multiple projects, leading them to embed inclusive research principles into their practice as a matter of course. The road that has been travelled by those with a long history of performing inclusive research has moved the milestones from innovation to accepted praxis, welcoming newcomers to walk beside them in posing and answering questions of importance identified by people with disabilities and their allies.

A final article in this theme of confronting boundaries is the seventeenth article, entitled “‘Digging Deeper’ Advocate Researchers’ Views on Advocacy and Inclusive Research” (Hopkins et al. 2022), which comes from the Clare Inclusive Research Group in Ireland, where Robert Hopkins, Gerard Minogue, Joseph McGrath, Lisa Jayne Acheson, Pauline Concepta Skehan, Orla Marie Mc Mahon, and Brian Hogan detail what has driven them on their journey of research and advocacy. They conclude their article with five recommendations arising from their long journey as advocate researchers, covering the need for equal relationships with academic researchers, government funding, career paths for advocate researchers, development of national and regional advocacy and research bodies, and the academic community accommodating the need for accessible language.

## 6. The Closing Bookend

The final eighteenth article has enough in common with the first article, looking back over 30 years and into the future, to be a paired bookend, with the title, “Inclusive Research and Intellectual Disabilities: Moving Forward on a Road Less Well-Travelled” (O’Brien et al. 2022). Here, Patricia O’Brien, Edurne Garcia, Roy Mc Conkey, Sarah Butler, and Bruce O’Brien, who have worked together over many years, walk backwards through both successes and challenges of inclusive research, leading to a series of recommendations for moving forward. These cover raising awareness of key disability stakeholders to the value of inclusive research; training in inclusive research; jobs for co-researchers with disabilities; adopting a bottom-up approach to involving people with intellectual disabilities in the development of research proposals; policy makers to partner with people with intellectual disabilities evaluating disability policy and commissioning research; funding to be made

available for people with intellectual disabilities to present and attend conferences; and inclusive research to have an impact on the overall disability research community.

## 7. A Final Comment

The development of the Special Issue has been a long journey, and I would like to thank all who have participated in giving their precious time to consider the role that they and their team of co-researchers have played in moving along a road that has gathered momentum since its opening in 2003. Nearly 20 years later, the road is “much more travelled”, and it is my hope that walking backwards through those early years will allow the push forward to continue so that all research becomes inclusive of all.

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## Article

## Celebrating Thirty Years of Inclusive Research

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**Abstract:** Inclusive research has been an important way of increasing the understanding of the lives and issues of people with intellectual (learning) disabilities for 30 years. Three authors of this paper, Amanda, J and Kelley, are Australian and have been conducting inclusive research for much of this time. The other three, Danielle, Shaun and Jan, are English. Jan has been doing it for a long time, while the others are relatively new to it. In this paper, we explore together what inclusive research has achieved in its original aims of supporting people with intellectual (learning) disabilities to have a heard voice and in working towards changing attitudes, policies and practices in relation to supporting them to lead good lives. Fundamental to achieving these aims was the need for active participation by people with intellectual (learning) disabilities in conducting research relevant to them. We record what we have done, how we did it and why it was important to do this work together. We focus on what inclusive research has meant to us and how it has been used to get positive change for people with intellectual disabilities. We end with a summary of what we think inclusive research can achieve and where we think it needs to go next.

**Keywords:** inclusive; research; learning/intellectual disability; impact; life history; rights; community

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## 1. Introduction

This paper is by six people. Kelley Johnson, Amanda Millea and Janice Slattery live and work in Australia. Danielle Garratt, Shaun Picken and Jan Walmsley live and work in England. All of us work as inclusive researchers, and four of us have been doing inclusive research since the 1990s—or even earlier.

In this paper, we tell the story of inclusive research as we have experienced it, and end with some ideas about where it might go next. The paper consists of six brief life histories which provide an account of the meanings inclusive research have had for us and what has been achieved. The life histories include references to published inclusive research by each of the authors. We aimed for this paper to provide an example of how inclusive research can be done in ways that make it as accessible as possible.

### 1.1. What Is Inclusive Research?

Two of the paper authors, Jan and Kelley, came up with a definition of inclusive research which has been cited many times since it was published in 2003.

Here it is:

- The research problem must be owned (not necessarily initiated) by disabled people.
- It should further the interests of disabled people; nondisabled researchers should be on the side of people with learning disabilities.
- It should be collaborative—people with learning disabilities should be involved in the process of doing the research.

- People with learning disabilities should be able to exert some control over its process and outcomes.
- The research question, process and reports must be accessible to people with learning disabilities.

(Walmsley and Johnson 2003, Box 3.1, p. 64)

Almost 20 years on, Learning Disability England, a charity representing self-advocates, families and service providers encouraged its members and others to adopt these principles, which are listed below.

We will work alongside self-advocates and/or families to decide what to research.
We will prioritise research which matters to self-advocates and families.
We will involve self-advocates and/or families in doing the research, as advisors and/or as co-researchers at all stages.
Nobody should be excluded from research. We will work hard to make sure that people with different needs and from different backgrounds are included in our research.
We will pay self-advocates and family members (and/or their organisations) for their work. We will make sure our systems make payment possible in fair and flexible ways.
We will learn together how to do research. We will support each other. We will invest in developing people's skills as we learn to work together.
We will share what we find out in accessible ways. We will consult with our partners before we publish and we will recognise the work of self-advocates and families in our publications and other outputs, as well as co-authoring (writing) together. We will budget for co-researchers to present at conferences, too. We will make sure we have a plan for how the work will make a difference. We will use our research findings to help people with learning disabilities and their families get better lives.

Other than the requirement to pay co-researchers and others, these principles are very similar to those written 20 years previously. However, while the principles may not have changed very much, in the intervening time, inclusive research has become more widely practised and in many more parts of the world.

### 1.2. The Words We Use

When writing about inclusive research the words we use matter, but they are often difficult too. We use 'inclusive research' to refer to research where people with learning/intellectual disabilities play an active part. But there are other ways to describe this, such as 'participatory research' or 'co-production'.

The words we use to label people as having a learning or intellectual disability are also difficult. In Australia, and in this Journal, intellectual disability is used. But in England and Wales where three authors live and work the term is 'learning disability', and we know some self-advocates really dislike 'intellectual disability' (Armstrong et al. 2022). In this paper, we use the terms with which the authors in each country are most comfortable.

Finally, what to call the different partners in inclusive research? Co-researcher is quite commonly used to refer to the researcher with a learning or intellectual disability. Some people say everyone is a co-researcher, so that will not do. Are there alternatives that do not use lots of words? Jan worked a lot with Alan Armstrong, and he called her an 'academic researcher' and himself an 'activist researcher'. (Armstrong et al. 2022). In this paper, we use different terms according to how people choose to describe themselves.



## 2. How We Wrote This Paper

We wrote this paper with difficulty. Jan and Kelley each invited two people with whom they had conducted research to write it with them. Everyone was enthusiastic to take part. But it was not easy. Not only were we working across the world, we were also working during a pandemic which, for long periods, forbade us to meet face to face. When the work started, Jan had not even met Danielle in person, despite having done a lot of work together over the previous year. In spite of these challenges, commitment, phone calls, Zoom and Skype all made it possible to collaborate.

We prepared for the paper by agreeing on some questions to address, with some support when necessary, about our experiences of inclusive research. Jan talked through the questions with Shaun, recorded the conversation, then wrote his answers. Kelley met with Amanda and Janice to build their stories. Danielle preferred to write her piece and then to respond to written comments and questions.

Once we had done this preliminary work, the highlight was a meeting of the six people on Zoom in December 2021. The time difference made this a challenge. At the time, Melbourne was 11 h ahead of the UK. It meant that a meeting had to be early in the UK morning while the Aussies had to stay up late. But we did it, after careful preparation, and everyone had a great time, lots of laughter and camaraderie.

Then, we all went away and worked on our personal accounts. Jan and Kelley had to make lots of changes because their language was not accessible. It was interesting that the Australian researchers were not familiar with the term ‘co-production’ which is used very widely in UK. And sadly, other than Kelley and Jan, no one knew the meaning of normalisation, social role valorisation, or the social model of disability, even though these are big ideas that have shaped the way we think about disability over the past 50 years. Jan and Kelley then wrote the beginning and end of the paper and shared it with everyone. And this paper is the result.

The next section of this paper consists of two sets of reflections, one from the UK and one from Australia. There are three reflections in each section. Essentially, these are life stories which seek to capture the importance of inclusive research in each of our lives.

## 3. Reflections from the UK

This section consists of three reflections or life stories about the involvement of Jan, Danielle and Shaun in inclusive research.

### 3.1. *Personal Reflections on Inclusive Research*

Jan Walmsley

In writing this, I want to say how much I owe to people who have worked with me. Kelley, one of the co-authors of this paper, has been alongside for much of the journey. Alan Armstrong, who tragically died of COVID-19 in February 2021, really pushed me to work out my position as a researcher. He was not going to be fobbed off with slogans such as ‘Nothing About Us Without Us’ when it did not mean anything in practice, while working with Danielle has given me confidence because she can make videos and I cannot.

It is a matter of awe and wonder to me that by inventing the words inclusive research I made my name, and it gave me a passport to many exciting places and people.

Now, over 20 years later, inclusive research is not only in the English speaking world but way beyond it. Frankena et al.’s (2018) paper is an example of a truly international collaboration on inclusive health research. I wrote a paper with some friends from Norway who are trying to start inclusive research there (Chalachanová et al. 2020). Japanese colleagues are really keen to get started (see Tilley et al. 2020). Furthermore, inclusive research has gained strength from people with learning disabilities. For example, some self-advocates in England and Wales now say all journal papers about research should be written with a researcher with a learning disability—or for there to be a good excuse if they are not.

I came up with the term ‘inclusive research’ at a dark period in my life. Divorce, my father had died, my daughter had had a serious head injury and my mother had breast cancer—and our beloved dog too had died. This provided me with the space to do some deep thinking about the contrasts and contradictions inherent in normalisation/srv<sup>1</sup> and the social model of disability<sup>2</sup>. I remember wrestling for days to get my ideas straight, and they were published in the journal *Disability and Society* in 2001—the best thing I have ever written (Walmsley 2001).

Research as a ‘valued social role’ was one of the things I wrote about. It remains true that sometimes people are included because it looks good rather than adds to the project. The Social Model of disability, in particular Mike Oliver’s powerful argument for disabled people to control the research agenda (Oliver 1990), was also a strong influence. It left me and other equally sensitive souls floundering, wondering how to justify our continued professional existence.

It became important to work through these ideas, something I did with Kelley, which emerged as our 2003 book (Walmsley and Johnson 2003). I am proud that that book has stood the test of time. It continues to be read and used by lots of people. Since then, I have become more certain that it is not enough to justify inclusive research just to make research look good and inclusive. A few years ago, I wrote about the ‘added value’ of inclusive research, meaning that working alongside self-advocates in a research project has to bring something extra to the table (Walmsley et al. 2017). It has taken many years to work out what that added value might be, and I still think there is a way to go in identifying it. But here is an attempt.

Most certainly access is one area where working together pays off. When approaching self-advocacy organisations or individuals, it helps if self-advocates are part of the team.

Activist researchers (Alan Armstrong’s term) can draw attention to what matters to people with learning disabilities. For example, helping self-advocacy groups evaluate their own projects, something we wrote about together (Armstrong et al. 2019). Activist researchers can advise on what is accessible and can also explain answers which might seem surprising. The best example of this that I know of was the high number of people saying they had a direct payment in the 2003 England National Survey (Emerson et al. 2005). The People First team members who were activist researchers in the project explained that people did not understand ‘direct payment’ as being a type of benefit, such as NDIS in Australia, but rather saw it as simply getting money out of a bank or post office!

A recent example of working with self-advocates in planning research was to ask for feedback from three different groups on the value of a widely used set of questions to measure self-esteem for a project on self-advocacy and well-being. We paid each group a small sum to evaluate the questions. We received very strong advice not to use it from all three groups.

*‘The risk of emotional harm is too high’ said one. ‘I feel a lot of the questions have a negative aspect to them.’*

Another:

*‘The questions confused me. They’re asking about how I felt generally about myself, what I can do, what I’m worth. Since my feelings about all this can vary so much day to day I had to answer neutrally to all of them.’*

A third person pointed out that his situation is fluid.

*‘As of right now the survey is not allowing me to give straight answers that will stay accurate.’*

You might argue that these answers are so obvious as to merely be good research. True, but our ability to obtain these honest responses was built on long-term partnerships with the groups concerned. Anne Collis, my friend, and Alan’s too, argues that inclusive research is the only tool we have to address the exclusion of people with learning disabilities from universities and other places that conduct research. If people like Alan want to carry out research, it is the only avenue open to them. Furthermore, it also addresses what Ann calls

hermeneutic injustice, which means that people are unable to comment upon or interpret their own lives. Inclusive research opens the door to change this (Armstrong et al. 2022).

I am still learning how inclusive research can challenge things we take for granted. For me, the most exciting development is *In Response*, an initiative by journal editor Melanie Nind to give self-advocates a platform to respond to an article in every issue of *The British Journal of Learning Disabilities*. It started as a well-boundaried initiative, and one that has been widely welcomed, even by the academics whose work has been looked at, often critically, by a self-advocacy group (See for example Blackley et al. 2021). It is developing into something more. An online public meeting in autumn 2021 between the groups who did the first three In Responses and the Journal editor produced these ideas:

- Change the questions referees (who make decisions about whether research will be published) are asked to answer.
- A request that self-advocates have their own special issue of the journal.
- A suggestion that journal paper *titles* should be in plain English.
- An insistence that accessible summaries really are accessible.

The doors are opening in all sorts of directions, and though I am not naïve enough to think the world will change overnight, it is indeed exciting to watch inclusive research challenging established norms—as it has from the start.

### 3.2. *Respect Us as We Respect You*

Danielle Garratt

Hello, my name is Danielle, and I am a learning disability voices project worker at Brighton and Hove Speak Out in England. Speak Out is a self-advocacy organisation that lets people with a learning disability speak up and take action about things that matter to them. My first ever research project was at the beginning of the pandemic, I did not know what my job would include. I started doing social media and posting things on there until one day in July 2020 my colleague was talking about how it would be a good idea to create a video series on how people with learning disabilities are coping with the pandemic and to give advice to other people about how people have coped. The project's name was called *Speak Out with Danielle*. I started thinking about who I would like to interview and started thinking about how to create a video. I started to get into recording people and interviewing people over Zoom, and it sparked an interest of wanting to conduct more research. In this research, I think that being able to talk to people in this particular time was hard, as everyone's emotions were up in the air, and they did not know what was going to happen and how long we were going to be stuck indoors. Another thing that was hard was relying on Zoom and if the internet went down or buffered, it was even harder. Being able to talk to people and being there for them to chat went really well. This is where I fell in love with creating videos and also conducting research. I want to do more to try and help people with learning disabilities and get across to others how hard it was for people who do not have internet and do not know how to read and write.

For my next research project, I stepped in and helped Jan with *50 years of Speaking Up in England towards an important history* (Walmsley et al. 2022). This was a project to interview people who remembered the early days of self-advocacy in England. This project had started already, and I was asked to help out as Ian Davies, who had started it, could not help anymore, so I stepped in as everything was set up ready. This project was really interesting as I was a part of hearing other people's stories about the institutions where they had lived and seeing how they coped with it. This research project made me really think about the history of people with learning disabilities, and being able to tell their history to someone was a real pleasure to listen to and ask questions about. Having someone else with me to help ask more in-depth questions to obtain more answers out of them was really helpful as this was my first proper research with it being written down as well. I think doing the interviews online got in the way, even though it was during the pandemic, because it was more difficult to engage with people than it would have been in person.

Diving in the deep end with this research was a bit scary as I had not spoken to any of the people before, so I had to get to know them a bit while doing the research.

Doing these two different research projects has made me realise that I want to conduct more research and find out more about people with a learning disability and the history of people as, if we do not do it now, the older people will not be about for the younger generation to learn from them about how the institutions were for people and how they were treated compared with now.

The current research project I am helping out with is called *COVID Stories*. This is a project speaking to people that have not been able to get online during the pandemic. In this project, I was asked some questions by my boss that she thought would be good for this project, and I responded with how I coped with the pandemic, and then a few weeks later I interviewed someone, and while I was hearing her answers to the same questions, I found she had completely different responses of how she coped during the pandemic. This really opened my eyes up to see how other people coped and how much they struggled. I am hoping this project will make people think about what people with a learning disability felt during the pandemic: not being able to know what is going on and not being able to go to groups that they used to go to.

Becoming a researcher has really opened my mind up to all things that need to be researched about people who have a learning disability, and being able to spread awareness is one thing I am going to focus on by conducting research.

I have not had training to conduct research. I have trained myself to create videos, and also I have some training of video editing to help me edit the videos for the Speak Out with Danielle series on YouTube. I would like some training on being able to get people to elaborate on their answers and to be able to get them to dive deeper.

### 3.3. *Do Not Sweep Us under the Carpet*

Shaun Picken

I am Shaun. I work for My Life My Choice. My Life My Choice is a self-advocacy organisation based in Oxford, England (<https://www.mylifemychoice.org.uk/>). I am a consultant, which means I am paid for the work I do. I have a zero-hours contract, I only get paid for the jobs I do; I do not have a regular wage.

Research is important to me. We—My Life My Choice—do a lot of campaigning, evaluations and consultancy work. A total of 25% of my time is spent on research.

The best thing about research is what I am doing right now. Doing the epilepsy project. It is about helping people with epilepsy and their carers to know what are the triggers, how you can manage and the medication and its impact and side effects. We know all this, it is about putting it in an easy framework that people can use. It is basically me and a couple of others from My Life My Choice. Only 7% have photo-sensitive epilepsy. It used to be called grand mal. It is no longer politically correct to use that term.

I feel I am really making a difference. Epilepsy Action (<https://www.epilepsy.org.uk/>) is running the research. They are a charity who offer support and advice to people with epilepsy.

I did not have any training to conduct research. I do not think you really need it. You are used to it from the other things you do. If you have not carried it out before you might need it. But you get the knack quite quickly. I have been on computers since I was 5 years old. If I want to know something, I use Wikipedia. But I have never conducted research interviews. With the epilepsy research, we were given the questions to answer. If I was conducting research interviews, I would welcome some training. But I have never performed that. For the epilepsy research, it is me answering the questions.

I do get paid sometimes if I am working for My Life My Choice. But it has never been about money for me. I have done work with the Open University. I have been on advisory groups for projects about self-advocacy. One was about how they worked during the COVID-19 pandemic, all the things they did to keep people going. And the other one was about how self-advocacy is funded. One is called '*Filling the Gap*' (Tilley et al. 2021)

and the other one '*Funding the Gap*' (Tilley et al. 2022). I helped by suggesting ways to get the messages out there using social media.

I also told my story for a video in a course. The course is called Exploring Learning Disabilities—Supporting Belonging, and you can see my story on this link below. Thousands of people have studied it. It makes me very proud<sup>3</sup>.

Research is both my hobby and my job. I have been able to conduct my own research such as looking at how many countries are pro LGBTQ. It is growing by the year. Western Europe is high.

At the moment, half my time is on the epilepsy research and half is on the *Don't Lock Us Away* campaign. It is a campaign to stop people being locked away in hospitals when all they need is support to live a good life in their own communities. I tell you more about it on this link: <https://www.mylifemychoice.org.uk/pages/20-don-t-lock-us-away>. That one has been lingering a bit too long, maybe it needs more research.

Why do we need inclusive research? That is a really hard question. It is about better lives. Valuing People<sup>4</sup> did it, but that was 20 years ago.

My friend says, 'Don't sweep us under the carpet'. I think that is the big message.

#### 4. Reflections from Australia

Kelley, Amanda and Janice were able to meet twice together to discuss our experiences of researching together, and then we Zoomed twice to develop our reflections further.

##### 4.1. *Living and Working for Change*

Kelley Johnson

I used this title as a starting point for this brief history of my involvement in inclusive research because it is what made me start doing it so long ago and what motivates and excites me still after more than 25 years of researching inclusively with people with intellectual disabilities. Change means many different things to me when I think about inclusive research. It has changed me in many ways, helping to create who I am and what inspires me. I think too it has through its processes led some people with intellectual disabilities to view their lives and those of others, differently. And finally, it has, not as often as we would like, led to changes, or at least supported them, in disability policies and in the power and participation which people with intellectual disabilities have in their communities and their lives.

So, starting with me. I came to inclusive research through working with a man who had a commitment to participatory action research, which involves community members and is strongly about getting change to happen. As a young researcher, I worked with him as he evaluated services and undertook community development in Melbourne. I changed from seeing research as something which only trained researchers conducted to one where it was self-evident that people about whom research was conducted, should be involved in carrying it out if it were to lead to wider social change. From this work, I went to London and spent 12 months at the Tavistock Institute, then the home of action research. I loved the experience and came back to Australia excited by what I had learned. From then on, I began, as a research consultant, to conduct research that always included people about whom the research was undertaken. Gradually, through changes in my life and concern about what I saw as injustices, my research focused more on undertaking research with people with intellectual disabilities. However, I did not then use the term inclusive research. It is thanks to Jan that my views of this kind of research developed further, and our discussions, writing and friendship have been extremely important in my research since our first meeting. Watching and participating in the growth of inclusive research since our book on it was published (Walmsley and Johnson 2003) has been in a way like being a parent. I have been part of its growth and learned enormously from my involvement, and I have seen inclusive research go in directions that I would not have thought of in the beginning of the work. The use of computers and social media, photographs and film and the growing links between self-advocacy and research by people with intellectual



disabilities have transformed the processes and impact of inclusive research. I learn new things each time I work with people on research that is important to all of us.

Sometimes I do think inclusive research is written about as if its primary importance is change that may happen in the lives of individuals with intellectual disabilities who are researchers. One does not read very much about how conducting inclusive research may have changed those who do not identify as having an intellectual disability. I think my argument would be that all of us involved in such research experience change. For example, I found it interesting that the stories written for this paper by my colleagues all tended to pick out common themes: new learning, confidence, changing attitudes and new skills and sometimes a recognition of skills yet to be learned. When I think of this mutual learning I remember back to the beginning of a project in Ireland where I was co-ordinating the development of inclusive research (Johnson 2009). I went to talk with a group of people with intellectual disabilities who used a service in the country Ireland. I was excited at the possibility of developing an inclusive research project with them, but our first meeting was a disaster, as I talked about what research was and suggested possible topics which were met with silence. I almost fled back to Australia. At our second meeting, I asked them to talk in pairs about things which were important to them or which they found to be problems. The discussion was lively and went on for a long time. At the end, we all talked about what had been discussed. Topics included: I want to know how to make my coffee shop better; I want to stop being bullied because I am afraid to leave my house; I want to stop the service from closing the garden where I have worked for 20 years; and I want to talk about poetry. All of these topics were taken up by the group (except for the poetry, unfortunately) and became research projects (Hogan et al. 2007; Minogue et al. 2007; Johnson 2009). All of them led to some changes in the issues raised. For example, in relation to bullying, a small research project led to a commitment by a manager of Dublin buses to reduce bullying; researchers in this area went on radio to talk about the issues, and a national anti-bullying project gradually developed from smaller ones. People in the original group began to speak out about what they wanted, and they developed ideas for how the research would happen. Some of these people have now taken up strong roles in self-advocacy, have travelled overseas to talk about their work or to teach other people about conducting research (Johnson et al. 2014). I learned to listen and to find ways of supporting people to conduct research that they saw was important.

So, inclusive research can lead to change for individuals. And it gains value in the contributions which all those involved make to it from life experiences, formal and informal learning and commitment. However, inclusive research does also have at least three goals: one is to better understand the issues and concerns of people with intellectual disabilities and the part that people not identifying as disabled play in them and, secondly, to support and advocate for changes in the community, which becomes clear from the research findings. The third goal is one which is achieved when we work together as a team. There are now numerous instances where the impact of research findings has supported or led to change. For example, a national inclusive research network in Ireland has developed, with a strong focus on rights (Johnson et al. 2020). People with intellectual disabilities for the first time have been consulted about changes to a law which made it very difficult for them to have sexual relationships. In Australia, people with intellectual disabilities involved in inclusive research have used peer education to teach others in different local government areas to run their own workshops on sexuality and relationship rights for people living in their areas (Frawley and O'Shea 2018). I could go on for a long time and I could also record those disappointing times when good inclusive research has not been taken up or led to the recommended change.

But the research goes on and it remains an exciting adventure for those people committed to it. Furthermore, it now can lead to positive changes in the lives of all those researching inclusively and in the ways people with learning disabilities live their lives in their communities.

#### 4.2. *A Link in a Chain*

Amanda Millear

This story is just a few drops of water from the enormous glass full of my life.

For me, research is a link in a chain. I have been a self-advocate since the 1980s and have conducted research since the late 1990s. Research for me is finding out information I want to know, working with other people to find out about things that are important to people with disabilities, talking with people about what we have found out and trying to get them to see us. So, research and self-advocacy are mingled, for me, they are knotted together. Research, self-advocacy, sharing information and telling our stories are all links.

From conducting research, I have got knowledge and skills. It has helped me with other things in my life. I became more observant. Research allowed me to explore things a lot more deeply, seeing things I have never seen before. For example, when we carried out a research project looking at the history of self-advocacy (Frawley and Bigby 2014) there were things I had not thought of before, such as how to work in a group. I had not been able to work in a group before, but I learned to do it in a research way.

I look up information now on Google. Getting an ipad has been great. Sometimes I just put in a word and dig deeper from 1–6 and it just depends on what turns up on the screen. Since 2012, I have had my ipad, and now I am on my second. By conducting research, I think about different things and now, with the ipad, I know how to find out more about them.

I have kept a record of what we do. I learned to do this in our research. I take photographs of things that are important to me and the research we have conducted. I keep them in files at home.

From doing research, I learned about public speaking or ‘barking’. I have been doing that since 1981. I would do preparation for talks and sometimes I would read up on the thing I was going to talk about, but ad lib is my best style. You have to know what you are supposed to be talking about and you have to conduct research so that you know this.

For 11 years, I went and taught medical students at Monash University about what it is like for people with disabilities to go to the doctor. In doing this, I shared my experience. I had to be flexible and know the topic. I have learned to use photos and flash cards to talk with people. I learned you have to start at the bottom and work your way up to the top when you are talking. Sometimes, I have flown by my pants or my imagination, but I do try to have a plan B if there are problems. You have to be flexible, alert, observant, willing to change if the situation changes, adapting to the situation. It is important to find ways of telling a story from a clear beginning through to the end so that people can understand it. Hopefully, they can see the picture from what I am describing to them.

I was the founder member of a programme named *Raising Our Voices* on community radio. I got the idea sitting in a café and did most of the work, with some support, to get it going. The first show was on 17 August 1987. We now have a team which meets to plan each show that is coming up. Over the years, this programme has raised important issues that people with disabilities want to know about. Some have been touchy subjects where we have shared life experiences or sexuality and our research. Other topics have included housing, transport, pensions and closing large institutions. There are many other issues we have talked about. I have been on *Raising our Voices* talking about topics that I am involved in for 35 years.

I learned that my work was valuable, and I could be paid for it. Some research you do not even get paid for, and that is not right in my book.

I learned to speak up. I do not let things go. I bark loudly. I do not like jargon. I hope that people will see past the disability and give us a go, and not just look at the things we cannot do but the things we can do. I might walk around with a white cane, but I am still a person and need to be recognised as one. I want to lay down a path that the people who come after me can use, such as our research on sexuality that changed the laws about people with disabilities being able to have sexual lives (Johnson et al. 2000).

When you do research, you start small and grow bigger like a tree.

#### 4.3. Why Research Is Important

Janice Slattery

Research has been important in my life. It has made me feel proud of conducting research and proud of passing it on to other people. A highlight of my life was in 2018 when I received the Lesley Hall Life Time Achievement Award, which celebrated my work in research and advocacy.

It is important to know what happens to research that we conduct.

In conducting research, I learned lots of different things. When I was involved in the research, *Living Safer Sexual Lives* (Johnson et al. 2000) and the later project *Sexual Lives and Respectful Relationships*, (Frawley and O'Shea 2018), I learned from the life stories we collected about sexuality and abuse of women. I learned that abuse happens to others (not just me), both single and married women. It took courage but I shared my story with other people and helped women in workshops and in talking with them.

As part of the *Living Safer Sexual Lives* research, I was involved in reading the life stories that were collected from people with intellectual disabilities about their sexual relationships. I acted in one of the films that we made where we read the life stories so that people with intellectual disabilities and other people could see and hear what we had found out in the person's own words.

After *Living Safer Sexual Lives* was finished, people on the reference group were asked to meet with people in the government for about 12 months, and they used what we had found out to get a change to the Victorian law which gave people with disabilities more rights about sexual relationships.

As part of the *Sexual Lives and Respectful Relationships* research in which I was a researcher from 2009–2019 (Frawley and O'Shea 2018), I interviewed peer workers at six different sites in Australia and trained them how to run their own groups with people with intellectual disabilities about sexuality. They were able to go on doing this in their own areas.

I have taught medical students about what it is like going to the doctor if you have a disability and particularly what women may experience about things such as breast screening. The students were interested in what we had to say. They asked a lot of questions, and we taught them that when people with intellectual disabilities go to the doctor, the doctor needs to listen to them, understand them and be a little bit patient with them.

Because of being a researcher, I have travelled lots: Seattle, England, Iceland and Sweden. I gave papers at conferences about our research. Travel gave me confidence in giving papers overseas. People at the conferences were excited that people with disabilities could stand up and give research papers. They were most interested. They did not know much about Australia or Australian research, so it was good we could go over it. And we did not know much about their cultures either, so I learned a lot.

I think it is important for people to know about research. I am the editor of the *Reinforce* (self-advocacy organisation) newsletter, which goes out every three months to members and workers. It tells them about research that is happening. For example, when we were doing the history of *Reinforce* (Frawley and Bigby 2014), we talked about the history research project and told people what we had found out in the newsletter. I know that self-advocacy groups get a little more funding now, and I hope it had something to do with our research. But it is still not enough!! I also have been involved with a community radio programme for people with disabilities called Raising Our Voices. I used this to talk about the history of the self-advocacy project, giving people information and telling them where they could get the book. The newsletter and community radio tell people about things they may not know about.

Because of my work, I was asked to sit on the National Disability Advisory Committee for people with disabilities. It was a national government committee and was about housing, employment and pensions for people with disabilities. It was tough sitting on the committee. Half of the information went over my head, and I stood up and told them

so, but they did not listen. That is the thing with government people, they do not listen to people with disabilities!! I was disappointed that it did not really change things and was not accessible. (I did stay at a fancy hotel though!)

Some of us have been involved in a lot of research. I think because of us some of the research has been conducted differently because we taught other researchers how to conduct it better. We can do that because we are part of the research, and we are the history of people with intellectual disabilities. We have been here since the 1980s, and we know more about our history than other people.

Conducting research, we have all learned things we never knew.

## 5. Inclusive Research: Where to from Here

Our reflections are a starting point for thinking about where inclusive research might go from here. We consider some themes which came out of our work together, and what the future might hold.

### 5.1. Learning

All six reflections in this paper show how inclusive research has helped to develop our learning. Amanda and Janice talk of the confidence gained from conducting research and the skills of working with others either as a member of a team or in sharing difficult experiences. Shaun is aware of his own skills in undertaking research but also expressed the need to learn how to conduct interviews with others, something he has not done before. Danielle has learned about issues which are important to people with learning/intellectual disabilities and recognises a need for training to conduct interviews. Jan and Kelley celebrate the long and continuing learning curve they have experienced in conducting inclusive research.

Everyone agrees that learning while doing is important because it supports us to gain confidence, to identify the important issues, apply skills in new contexts and gain new knowledge. But we also recognise that people need opportunities to develop their skills and knowledge further. There have been some opportunities for some activist researchers to learn skills to help them conduct inclusive research, including at Iceland's University of Reykjavik, University of Sydney Australia, the Open University in the UK and Trinity College Ireland (High and Robinson 2021; Rillotta et al. 2020; Stefánsdóttir and Björnsdóttir 2015). But our reflections suggest there needs to be more. New opportunities should include courses which allow activist and academic researchers to learn about inclusive research together and opportunities to learn about the big ideas—such as normalisation and the social model of disability—which have shaped the way disability is viewed.

### 5.2. Breaking Down the Barriers

All the authors of this paper have been involved in advocacy in relation to people with intellectual/learning disabilities. Some have been long-term members of self-advocacy organisations, others had been more recently involved as employees or as members of management committees. All had undertaken research about histories of self-advocacy organisations or issues relating to their work. Everyone saw it as important to use research to work for social change or to support people with disabilities to live good lives. Unfortunately, it is still the case that much research relating to issues which are important to people with disabilities remains inaccessible to them, in academic journals behind a paywall. We applaud the initiative of *The British Journal of Learning Disabilities* for In Response, a forum for people with learning disabilities to critique articles submitted for publication. This journal is considering more active roles for self-advocates, in co-producing papers, refereeing articles and becoming involved in journal management. These are ideas that could be taken up by other academic publications.

More could be done. Self-advocacy organisations know many of the issues affecting people with disabilities. University research centres could include their members as paid representatives on advisory groups. This would enable more funded research to be under-

taken which reflects their needs and aspirations. We also believe it is important to have academic researchers available to self-advocacy organisations if they see a need for research to be conducted and to offer advice on funding, methods and practical support.

### 5.3. *Communicating and Social Change*

The importance of finding ways to communicate about research was emphasised by all six authors. Our joint meeting on Zoom revealed anger from all the activist researchers about the use of ‘jargon’ in research. Amanda and Janice wrote about this in their contributions. There is increasing diversity in ways to share research. Academic books and articles about inclusive research were cited by Kelley and Jan, but these were not accessible easily to people with learning/intellectual disabilities. More accessible ways to communicate were mentioned by the authors of this paper. The founding and development of a community radio programme for people with disabilities, which included references to research and its findings, had involved Janice and Amanda. Danielle, amongst others, has pioneered the use of photographs, videos and social media to both undertake research and share its findings, which was seen as important for people with intellectual/learning disabilities. In our view, these different forms of communication should be considered as a matter of course by academic researchers undertaking inclusive research. BJLD’s encouragement to authors to add a video abstract to published papers is a small step in this direction. Thinking about the forms of communication that best suit the people who will be involved in the research and those who will be interested in it needs to be considered at the beginning of the research and planned for to make sure as many people as possible can benefit.

## 6. Conclusions

Like other inclusive research projects, the writing of this paper has been an interesting, if at times, difficult journey. Our meetings in either the UK or Australia led to a sharing of experiences at a personal level but also in terms of how important inclusive research is in changing attitudes and policies. Frustration at not being heard was there for all of us whether this was in national consultations or in workplaces. For all of us, there were shared experiences of excitement and a sense of being involved in work that was important and that could lead to change in all our lives.

If readers of this paper would like to pursue the themes we have aired, we leave you with two important questions:

What would it mean to be working as an inclusive researcher from your perspective?

How can inclusive research be used to have an impact on the lives of people with intellectual/learning disabilities?

There is plenty to be done.

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## Notes

- <sup>1</sup> Normalisation and social role valorisation are ideas that were around in the late twentieth century. People who believe in it say that we can change things by giving people with learning disabilities ‘valued social roles’ such as being a researcher and having friends who are not disabled.
- <sup>2</sup> The social model of disability is the idea that people are not disabled by their impairment but by the way society is organised. If everyone was deaf, deaf people would not have a hard time. So the answer is ‘change society’.
- <sup>3</sup> <https://www.open.edu/openlearn/health-sports-psychology/exploring-learning-disabilities-supporting-belonging/> (accessed on 20 May 2022).
- <sup>4</sup> Valuing People was a policy launched in England and Wales in 2001, promising better lives.

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## Article

# Graduating University as a Woman with Down Syndrome: Reflecting on My Education

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**Abstract:** This paper reflects on the experience of being a woman with Down Syndrome who completed an undergraduate degree at an Australian university. This autoethnography is based on a year-long research project completed as part of my studies. I did a literature review about the experiences of other students with an intellectual disability at university. Then, I wrote about my own university experience. I found that the parts of my own educational journey were linked to each other like stepping-stones. Four main things came from my research: the importance of the journey before going to university; the isolation experienced by students in this situation; how stereotypes might affect students; and teaching methods that can be used to support students during their time at university. This experience changed me as a person. I gained skills and confidence whilst being at university, as well as the ability to see where I am going in life. This experience made me feel more part of society. While there were many wonderful parts, it was not an easy journey. People with an intellectual disability have a right to have an education. What makes the biggest difference is the way we are treated by other people. It would be good for students with an intellectual disability to be accepted and treated with respect. People may have a different way of learning, and it would be good if this was recognised.

**Keywords:** university; higher education; intellectual disability; inclusive education; autoethnography; Down Syndrome

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## 1. Introduction

This paper is an autoethnography of a woman with Down Syndrome who has recently completed an undergraduate course at Flinders University, South Australia. This paper is a reflection on my own experience of being a student at university.

This paper was written from work I did in a year-long research project as part of my studies. Sally helped me by supervising this project and writing this paper with me. First, I did a literature review about the experiences of other students with intellectual disabilities at university. Then, I wrote about my own university experience.

In this paper, we talk about how I completed this project, and some of the important things about my experience of university. I found out four main things in my research through both my own experience and by learning from other people's experiences at university. In this paper, the following are discussed:

- The importance of the journey before going to university;
- The isolation experienced by students in this situation;
- How stereotypes might affect students; and
- What teaching methods can be used to support students during their time at university.

## 2. Materials and Methods

The methodology used for this project was autoethnography. Autoethnography is a relatively new qualitative research approach which involves researchers critically analysing



their experiences and providing an understanding of how these compare to the experiences of others from a similar social group (Chang 2016). By collecting personal accounts and reflecting critically on the social meanings of these experiences, it allows researchers to develop an understanding of their own experiences and how they have shaped them (Liggins et al. 2013). Autoethnography also asks the researcher to think about how analysing their experience can help them understand other people's experiences by thinking about social and cultural meanings (Chang 2016).

At first, I found it hard to think about this unfamiliar word and how it related to my own life and experiences. So, I broke it into parts. I thought about it as *auto*—referring to yourself; *ethno*—looking at your own journey; and *graphy*—referring to the research. Therefore, for me this word described the study of my own 'journey of learning' when compared with those of other people.

### *Methods*

This research was conducted in stages. Firstly, I did my literature review. The aim of the literature review was to find out about the experiences of people with intellectual disability at university and their ideas for improving university education. Sally conducted the first review, using university databases. The review set terms to search for qualitative research; literature about the views of students with intellectual disability themselves; and research in university settings. To make the project manageable, we reduced the scope of the literature review and selected the most relevant nine articles for me to read in full. Some of the papers were hard to read because they were very long, and it was difficult to find the information needed. The Read Aloud program on the computer was useful. I am a visual learner, so I worked with my mother to help me understand the main ideas in the papers. She drew diagrams of the ideas, and we talked about how the ideas affected the people who were in the research. I then looked for information which might answer some of the questions. These were selected and recorded on to templates under the heading of the questions. Each author's comments supporting the discussion was combined to relate to the question.

I had a student mentor, Kathryn, who helped by summarising some of the reading for me too. We were interrupted by COVID-19, which made it very hard. We had to go online, which made it very hard to work together when we did not know each other well. When the lockdown had eased, we were able to all meet face to face in the university. This was better because we exchanged easier conversation together, and there was a warm feeling between us. For example, with Sally, we were looking at the paper together and trying to figure out which sentence should go where, and she could write instructions straight on to the paper. This was helpful because we worked as a team. I also audio-recorded the sessions so that I could listen to them again.

All of this work helped us when it was time to start the next stage—my autoethnography. The first step in my autoethnography was that I related the educational story of my life in conversation with Sally. I found that the parts of my own educational journey were linked to each other like stepping-stones. The next step was to write in more detail about each of the stepping-stones on my education pathway. This took a long time and a lot of energy—I worked very hard. I conducted a series of interviews with people who were involved in my education, and I did a lot of personal reflection.

I needed to work out how these ideas fitted together. Once I had words written down in each of my main stepping-stones, we looked together for things that came up more than once, and where my experiences connected to the big ideas that were in my literature review. This is how we came up with the themes.

With the same kind of assistance as I used for the literature review, I critically analysed the themes and compared my experiences of university with the information I found in the literature review. This allowed me to identify the importance of the themes and how they contribute to new ways of thinking about the social world of university education for people living with intellectual disability.

### 3. Results

In this part of the paper, I have written about the major ‘stepping-stones’ in my education. These are about my high school education, the Duke of Edinburgh’s award, starting university life, film studies, the foundation course, and the Bachelor of Arts degree. They are all important because each one opened a door to the next opportunity.

#### 3.1. High School

I lived in a South Australian country town until I was 28 years old, and all my formal schooling was there. In primary school, I was in a special small class but in regular classes for some of my subjects.

When it was time to go to high school, I wanted to be with people I already knew, not just people with a disability. I had the choice of two high schools, and I visited them both to see which one was the best for me. When I arrived at the second one, my friends from primary school rushed over to meet me; so I decided this was the school I wanted to go to.

In high school, I was included in mainstream classes for subjects like English, history, and drama. For other subjects, I went to the learning centre and had a Student Support Officer to help me with the more difficult lessons.

I learnt some other skills: one was using the computer and another was in the drama class. I learnt about work experience and some sports. I learnt how to play basketball, hockey, as well as weightlifting. I felt comfortable with these lessons and enjoyed gaining self-confidence. Some of my friends in high school were Indigenous Australians and they involved me in an Indigenous Australian school club.

In the last years of school, the principal allowed me to go to Adelaide every Friday as one of my school days to go to dance workshops with a well-known inclusive dance organisation.

I had a great time when I went with the school to Mount Hotham in Victoria, during a week’s holiday in July. There was snow everywhere, I had a whale of a time being on the snow and having an instructor teaching me how to ski.

When I left school, I was very pleased to get my modified SACE (school leaver’s) certificate. I then went to TAFE (technical college) for computing and mathematics.

#### 3.2. Duke of Edinburgh’s Award

From ages 14 to 21, as well as schoolwork I was doing the Duke of Edinburgh’s Award Scheme for people with special needs. The purpose of the Duke of Edinburgh’s Award is about expanding people’s vision and introducing them to a wider knowledge of what is around them.

There are four different areas: (1) Volunteering; (2) Physical; (3) Skills; and (4) Expedition, with levels of Bronze, Silver, and Gold.

I volunteered with the Salvation Army and the special needs program where I did secretarial work, copy typing, and photocopying. I helped the teachers by playing with the children, reading them stories, and helping with hydrotherapy. I took up physical exercise and went to line dancing and swam in the Special Olympics.

I wanted to learn how to play the piano and study some classical music. I took some sessions in culinary arts, as well as poetry and theatre. The expedition was about going camping, lighting a fire, putting up a tent, learning to use a compass, bushwalking, horse trekking, and safety precautions if ever we got lost. The last project for my Gold Award was talking to Prime Minister Mr John Howard about the value of arts for people with disability. He was very friendly.

It did a lot for me. It was a lot of fun; I had to learn how to find people in the community to help me with each project. So, I met new people and learnt many new things. I had to meet up with my mentors regularly to work on the project, and I had to write it up and present it to a panel.

### *3.3. Starting University Life*

After I received my Gold Award at Government House, the Duke of Edinburgh's Award director asked me what I was going to do next. She then introduced me to the idea of applying for the Up the Hill program at Flinders University. This program includes people with disability in classes, with support from student mentors. They participate in the learning by auditing subjects and gain the experience of being at university. People learn what the atmosphere is like and how the student feels by stepping into higher education. So, it was the link for me to the next experience in my life.

I was invited to the university for afternoon tea. I had a conversation with the director of the program, where he asked what subject I was interested in. I said I was interested in drama. I later learnt that the conversation had been my interview for the program. I was incredibly happy to be offered a place.

Over the three years in the Up the Hill program, I audited many subjects—English, Creative Writing, Drama, Poetry, Cinema and Fantasy, Film Appreciation, and Screen Studies. I was totally included in the classes and I was involved in the discussion groups. The film studies class went on location to make a short film. I enjoyed being part of the team and to be included in a filmmaking experience. I helped with the lighting and I played the voice over in the film.

When the three-year course was finished, I crossed the stage in a graduation ceremony with beautiful music playing. I was very proud because some of my teachers from my secondary school came to the ceremony. It was a wonderful experience and I enjoyed it. The program was an inspiring experience for me. Later, some of my friends followed me in enrolling in the program.

### *3.4. Film*

During my time in the Up the Hill program, I met the lecturer of screen studies, a man named Tom Young. He found out I wrote stories and suggested that I could make a film out of one of them. He said he would mentor and guide me to direct the film. It took me a while to write the film script, it was much more complicated than just writing the story.

After the Up the Hill program, it took me a further two years to do film production. During this time, there were some media students who were involved with me in the making of the film. We were all learning what the filmmaking industry was like. The lecturer worked with me on characters, costumes, music, finding a site, and everything else that was needed to make a film. This film was shown in the cinema and went to film festivals in different parts of the world. The film was shown on television at Christmas time.

### *3.5. Foundation Studies Course*

It was after this experience that coordinators from the program suggested the idea of me taking the Foundation Studies Course. This course is the beginning of academic study at university. At first, I was not sure if I could do it; however, I gave this a try. I asked permission from the course director for my parents to come with me to the classrooms so that they could help me with the course. The tutors agreed with this, and I went to the classes three nights a week. Some of the topics were Mathematics, the Ecology of the River Murray, and English. There was also a survey on Nuclear Power Stations. I interviewed some people on that topic, hearing their point of view. I also did a topic on China and how it was building up bases in the China Sea.

The study was hard and all very new to me. I learnt a lot about tutorial work as well as having to write assignments. This felt different to going to the Up the Hill program because, when I was auditing topics, I did not have to do any assignments. Now I was working to get a pass in my studies. There was also a lot of homework. At the end of the course, I was pleased to learn that I managed to gain enough marks to apply for a Bachelor of Arts Degree.

### 3.6. Bachelor of Arts Degree

I began attending Flinders University as an Arts Degree student when I was 35 and have undertaken one, or sometimes two, topics each semester. Coming to university as a student became a great thrill to me, but daunting at the same time. From this experience I feel I have learnt so much during these semesters and about so many different topics.

The topics I enrolled in were Drama for my Major and Screen Studies for my Minor. There was the Stanislavski Workshop, this involved about learning the history of the dramaturge himself. He taught that acting is something you do instead of something you show. This motto gave me the inspiration to understand not only myself but to understand the techniques of theatre. There were acting workshops and learning about the history of the stage, including from different nationalities such as Asian Dramatic Traditions, the way both the Japanese and the Chinese use their craft theatrically including the way they use their body movements. These styles of movement are called 'Noh' and 'Kabuki'. This influenced me in my own dance movements. I also learnt about stage and film directors and had to make some short films myself.

In Aboriginal Studies I learnt about the children being taken away, and how much I related to their sadness. I learnt about the history of the Aboriginal Australians, including what they struggled with over the years through their historical art. What stories they brought out whilst crafting their baskets and how the DNA of the original people is connected to these baskets. Some of this I did not know before. Another subject I studied was English. I was very fascinated with writing at the time.

Studying at university was very different to being part of the Up the Hill program, or even the Foundation Studies Course. Now I was studying to gain results, working towards an actual degree. Before the beginning of the first semester, I went to the Disability Office to find out what support was available. I was informed that I could have an access plan towards my studies, for example extra time for assignments and exams. With this, I could have a room of my own to take the exam and have somebody with me to assist me to understand the questions. When I queried about having a mentor, they said they could not provide that. They did not do it for people with intellectual disability, only for people with physical or visual disabilities.

I soon found that at university I was on my own and it was all very different. As a student I was by myself. I had to learn how to get to the university on the bus, and I had to try to find the rooms where lectures and tutorials were located. This became extremely hard for me because I felt very lonely on the campus, and I did not know anyone. People did not talk to me, and every so often I could not find the class or felt too shy to go in. So, I missed some lessons. Being on my own around the campus, at times I felt that I wanted to go home and not come back to university.

Some of the activities I had done in the Up the Hill program with a mentor were going to orientation week, dancing with people at a community fair in the university hub, and trying out the wonderful food they had there. I learnt how to socially interact with mentors outside of the university environment, as an example taking a mentor to a show. Now, I felt very lost without this contact.

The university did not fund mentors for students with intellectual disability. For me to have support at university, my family and circle of support had to raise funds. It took a lot of effort to organise. With this support, I was able to pay a student in the class to be my buddy. This made all the difference to me being at university, I got to know the student as well. I met their friends and I felt happier being safe at university. We also worked on the topics together. We sometimes went to the library to look at my studies, and we enjoyed having lunch together. On a social aspect, we went out either watching a show or just hanging around talking about anything we wanted.

## 4. Discussion

My journey through education has been very rewarding, but it has not always been easy. In the next section of the paper, I reflect on the isolation I felt once I got to university,

how the stereotypes about people with disability affected me, and what helped me in my studies. In this section, I am also using the literature to draw on the experiences of other students who have been in my shoes and have been involved in research projects.

#### *4.1. The Importance of the Journey before Going to University*

From my experience, something that stands out to me is how important it has been for me to have had lots of activities and experience before I went to university.

I have been involved in many community projects as well as drama for many years. Through this I have met lots of people and learned lots of new things. My parents and other people were always finding new activities for me to get involved in. This was fun and it always led onto the next exciting thing to do. Being involved with the Up the Hill program where I was auditing topics and had a mentor with me helped me to get ready for university life.

Other people have said they felt like this too. Philip and Heidi shared their views in Wilson et al. (2012), saying that their early experiences were important in building their confidence and readiness for university study: "They felt that these were difficult but important years in their development during which they matured, volunteered in the community and maintained entry-level jobs" (Wilson et al. 2012, p. 40).

Like me, both Heidi and Philip were supported by their parents to become included in community activities. They both felt that it was extremely important to state how significant the advocacy of their parents had been in their development, especially in preparing them to succeed at school, to access opportunities and supports at work, to participate in the community, gain access to post-secondary education, and to feel 'normal'. I agree with Philip and Heidi about how lots of experiences in the community can be very helpful before you go into higher education. For me, it was the same.

They thought their opportunities reflected a combination of what their parents wanted for them, what was available, and what they enjoyed and interested them (Wilson et al. 2012). For me, it was the next thing I was introduced to. If something I was interested in came my way, people guided me along that pathway. For me, it was my parents, but also my teachers at school, people from the Up the Hill program, and other friends and family. So, each of the things I did led me on to my journey to university.

#### *4.2. The Isolation Experienced by Students in This Situation*

When I first started attending university, I found it was different to going to the Up the Hill program. On my first day with Up the Hill, I was introduced to my mentor who helped me to find my way around and build friendships with other students. The mentor attended classes with me, helping me to understand what was being said by the tutor, and supported me with the end of semester presentations. Rillotta et al. (2020) explained that mentors attend university classes with students, and they also support them with social activities inside and outside the classroom. They help them learn their way around the university. Other students with intellectual disabilities also said they felt they developed more confidence when they were supported by mentors (Rillotta et al. 2020).

In her research with nine college students with intellectual disability, Paiewonsky explained how certain aspects of being new to college affected students: "feeling different, adjusting to new expectations, having a new identity, transportation, new routines, self-determination and new relationships" (Paiewonsky 2011, p. 37). All these aspects needed to be dealt with by the student. This has been a common experience for students, and several studies have shown that students with intellectual disability feel unsure about what to expect, find it stressful, and find it hard to concentrate (Rillotta et al. 2020; May and Stone 2010; Wilson et al. 2012). This was also the situation for me, because all these things affected me in this new experience. I found it to be rather hard without a mentor to guide me. Even though I had been in the Up the Hill program and knew the university well, now being on my own turned out to be a big challenge for me. I also found it hard to concentrate.

Other students have also found this support to be important for feeling more comfortable in the classroom (Kubiak 2017) and for encouraging tutors and lecturers to be more confident in supporting students with intellectual disability (Plotner and May 2019). This individual support was found to help people find their way around the campus and get settled in, as well as start to discover what their strengths are and what they prefer as a subject (Paiewonsky 2011).

#### 4.3. *How Stereotypes Might Affect the Students*

It is extremely derogatory for people to say negative things about people with disability. This topic matters because to be unkind to others is the wrong thing to do. It is hurtful and makes them feel like a knife stabbed them in the heart. It makes them feel they are the worst thing around, and that they are not important. This affects them emotionally and they feel useless. In my experience when you are new to university and trying to fit in, these comments and being ignored makes people feel very low. I felt alone when this happened to me and I felt I could not speak. I could not concentrate because these feelings made me so unhappy. I did not feel I wanted to be there. I still find this very hard to talk about. It makes me feel ashamed.

Being harassed or possibly overlooked is not a helpful thing to go through in life. This would scare the person with disability, who may not know what to do and would not know where to find the guidance to do something about it. This is not a good way to go for people with disability, feeling alone and as though they are not allowed to be there.

Other students with intellectual disabilities have experienced stereotyped thinking and discrimination as well. These damaging views include thinking that people with intellectual disability are stupid, cannot learn concepts, and are lower achievers (May and Stone 2010); and that they are not able to learn or even to think for themselves, so may not be able to learn at university (Lightner et al. 2012). Some people have the idea that people with a disability sometimes scheme to get extra support so that they can ask for special privileges and pity (May and Stone 2010). These negative attitudes have a strong impact on students with intellectual disability. It is very hard for students with intellectual disability when other students were judging them and behaving badly towards them (Kubiak 2017), and when tutors talked down to them (Stefánsdóttir and Björnsdóttir 2016). Wilson et al. (2012) relate how one student's mother introduced her to the class and as a result she was teased or ignored by other students. Other students agreed that it was not good to point the disability out to the rest of the class, as it highlighted differences, not similarities (Rillotta et al. 2020).

There were some great times when I did not feel dismissed by the students or by the tutors. This was in media. I felt so much involved in this subject because there were people I was teamed up with and we became very friendly: they did not look or seem fazed about me at all. The conversations we all had were basically getting to know each other, and to help each other with the technological areas about the camera. Here I felt I became part of the group; we were learning together.

The positive experience of being on the stage in my subject 'Drama and the Stage' with people I found easy, and a good way to get along with people I barely knew. They were able to be open enough just to have a conversation with me. As I was teamed up with practically all of them, they made it easier for me working on scenes. The comfort I felt made me feel I was on cloud nine. I felt so at ease with all of them; the environment of the stage made me stronger inside because I managed to be able to have new friends. I got along with a man who made me feel included with anything. I felt more accepted in the practical sessions like media and drama, than I did in the tutorials and lectures. In the hands-on experience, it was easier than in the lecture topics. The students included me in these classes.

#### 4.4. Teaching Methods That Support Students during Their Time at University

The reason this topic is important is because it would be helpful if teachers found a way to understand what things make it hard for students with disability to work out what the teachers are asking them to learn. Teachers using visual aids make it easier for the students to be more involved in the topic.

Most of the time I felt welcomed by all the tutors in their classes, but I sometimes found it hard to follow what was being said. Some of the tutors spoke quite fast, and when they moved around in the class, while talking, I could not hear them, especially when they walked behind me. I also found it harder to follow the lesson if the tutors did not use a power-point presentation: this is where I got confused and could not concentrate. Sometimes they said things I really did not understand; this is because the academic language is too hard. I tended to blank out at times, not understanding the content of the subject.

Some of these points are also highlighted by some other students and teachers. For example, Kubiak (2017) comments that when it comes to communication for people with disability, this can be hard if they were not getting the opportunity to be involved in the class. This would make them feel as though they cannot contribute to be part of that community. To use their own voice and to be heard by other people would be essential.

Other students with intellectual disability told Kubiak (2017) how they can be supported in the class. It was easier for students to learn at their own pace, with non-judgmental teachers. He suggests that for some students, it was helpful if they already had the information before the class so that they were prepared for the lesson. The use of brainstorming on the blackboard in addition to color-coding mind maps was helpful. Additionally, if students kept a daily record of what happened in the class, they could recollect what they had done. Students in both the Kubiak (2017) and Plotner and May (2019) studies found the use of power-point presentations very useful, where students could see the words as well as read them. Including a printout of the power-point slides to remember the lesson was also helpful.

What helped me was having mentors, recordings of the lectures and tutorials, having information before the lecture, and power-point presentations. It helps if the tutors speak slower and stand in front of me because I need to see their faces and what they are saying. Read aloud software on the computer is extremely helpful to learn what the lesson will be about ahead of time, and for the readings. I have a recording device where I record the sessions being given, and I can then listen to them later when I get home. Sharing this information with other people at home makes it easier to understand the essays or trying to get my head around what I was supposed to do for the assignments. In these conversations at home, I can take my time to learn more about what I have to do.

It would be good if the university accepted that students with intellectual disability can manage the study with the right support and teaching modifications. For example, aids for visual learners and extra time to complete studies. It has taken me a longer time than other students to bring together all the information I need to understand the assignment. It took me nine years to complete my studies because I only did one topic a semester, sometimes two if it was a workshop.

## 5. Conclusions

I feel I have gained so much from being at university. Gaining this much knowledge is worth it because this is what I want to be. This experience has changed me as a person in ways that have made me more confident in myself. I think I have broken new ground, because the results that have come from the work that I have done have been very positive.

I have learnt to reach up to the point where I could possibly make a career out of some of the new thoughts and skills in my life. I believe I have gained some skills whilst being at university, and the ability to see where I am going in life. I have also learned about how there are different ways to learn about a subject I am interested in. There are so many things I have learnt, and I can talk about, and this has made me feel more part of society.

This can be so educational—for example, cultural theatre. In the future, I will always look back remembering what it was like obtaining that experience.

While there have been many wonderful parts, it has not been an easy journey. The thought of going to university is exciting, but I was not always sure where it was going to lead in the future. There are many things which are confronting when you are the only person with intellectual disability in your lecture or tutorial group. How does a person with disability cope when stepping into the class seeing people who saw them as being different? How do people with disability cope with the loneliness when other students do not talk to them? This was something I had to face every day.

Knowing you are not alone makes a big difference. I remember how it felt when I was with mentors: I had someone to talk to and become friends with. To me, it felt as though someone actually listened and guided me all the way through my university experience. Once they have a mentor with them, people with intellectual disability know they are not alone. The reason is because they feel there is a safety net, but the major reason is that people with disability have someone to turn to.

I was born with Down Syndrome, and it is part of who I am—I do not know anything different. One way I know about myself is the way other people treat me. Sometimes this makes me feel good about myself, when I am made welcome and like I am wanted in class. Other times, I have been ignored or treated badly. This makes me feel there is something wrong with me. There is nothing wrong with me. I know I can learn, I can feel, and I can see the world the way I choose to see it. People with intellectual disability have all the feelings everyone has, and we want to belong. We have a right to have an education.

What makes people with intellectual disability different is the way they are treated by other people. It would be good for students with intellectual disability to be accepted and treated with respect like other students are. People may have a different way of learning, and it would be good if this was recognised.

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## Article

# How Being a Researcher Impacted My Life

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**Abstract:** Doing research can help people to learn about a lot of different topics. For example, researchers can learn how to work in a group, collect and analyze data, how to make accessible materials, and get to know their own strengths. In this paper, a researcher shares what she learned while working on two research projects about young adults with intellectual/developmental disabilities and co-occurring mental health conditions. The first project was peer mentoring. In this project, we focused on individual needs for someone who may be struggling with mental health. The second project was about workplace disclosure. In this project, we tried to find out if young adults disclose their mental health conditions at work and in job interviews. We explain how we did the projects, how the researcher learned to do research, and what made it easy to learn. We also share about the impact of doing research on the researcher's personal life. Finally, we share why doing inclusive research is important and how to help researchers with disabilities feel like they are valued members of the research team.

**Keywords:** inclusive research; participatory research; intellectual disability; developmental disability; mental health

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## 1. Introduction

This paper is about the experience of a co-researcher with a disability doing research. She worked on research with Ariel since 2018. Alix shares her experience on two different projects and why doing research is important to her. We wrote the paper together. Ariel wrote questions for Alix to answer on her own. Then, they met together to talk about what Alix wrote, make edits, and add more details. Usually when they met, Ariel typed everything that Alix said. Then, Ariel looked at everything Alix wrote, organized it, and got Alix's feedback to make sure she did not change the meaning.

We decided that it was not important to write about how to do inclusive research or why inclusive research helps make research better from the perspective of Ariel. Many researchers have already written about this (e.g., Frankena et al. 2019; Schwartz et al. 2020a; Stack and McDonald 2014; Walmsley et al. 2018), especially from the perspective of academics (Strnadová and Walmsley 2018). Alix felt it was very important to write this paper because often papers are written by people without disabilities. This paper is special because it is written by someone with real-life experience explaining how she did the research, which has been done by few other people. While some teams have written together (for a review on this topic, see Strnadová and Walmsley 2018), we only identified one article where an individual co-researcher took the lead in the full manuscript (White and Morgan 2012). Other times, teams of co-researchers wrote about their research process and their experiences (e.g., Abell et al. 2007; Cook et al. 2021; Williams et al. 2005). However, these examples are limited, due to the many challenges of publishing inclusively in academic journals (Riches et al. 2020). In this paper, Alix shares her experiences, what helped her to conduct research, how research impacted her life, why *she* thinks it was important that she was involved, and how she felt as an important member of the research team.

## 2. Study 1: Peer Mentoring

### 2.1. *What the Study Was about and What I Did*

The peer mentoring study was about a program for individuals with intellectual/developmental disabilities and mental health challenges. In peer mentoring, mentees met with mentors who taught coping strategies and the skills they can utilize in their day-to-day life. We individualized each mentee's plans and activities, so they all reached their own goals.

First, we had to make peer mentoring (Schwartz et al. 2020b). Second, we were peer mentors. Third, we looked at data to find out if the mentoring helped our mentees (Schwartz and Levin 2021).

#### 2.1.1. Making the Peer Mentoring Program

Before mentoring happened, we had to learn how to mentor someone like us. We met at Boston University once a week. I worked with three other researchers with disabilities. They all went to the same transition program that I went to. That was cool, because we all knew each other, and I did not have to learn about new people. It was also cool that we were able to work with Boston University graduate students who were around my same age.

Ariel made the activities and the mentoring script. I helped to give feedback on what to keep and what not to keep. We worked together by looking at PowerPoints. We said what pictures and words should or should not be in the peer mentoring materials. We tried the activities before we mentored and gave feedback. I joined afterward, but I know we also did focus groups with young adults all around Massachusetts to see if they liked the peer mentoring activities. Before peer mentoring started, we also made videos about mental health to show the mentees. That was really fun!

When we were making mentoring, it was helpful to have interactive activities, like the PowerPoints. I am a very visual person, so the pictures were helpful. It was also helpful that the other researchers broke down the information into small parts. There were a few confusing moments, but the people at Boston University explained everything well, and I figured it out. The graduate students were really helpful. They helped with activities and hung out and talked with us. They also helped me enter my work hours.

#### 2.1.2. Being a Peer Mentor

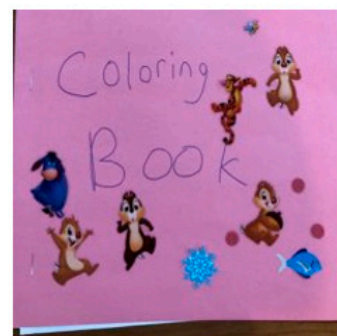
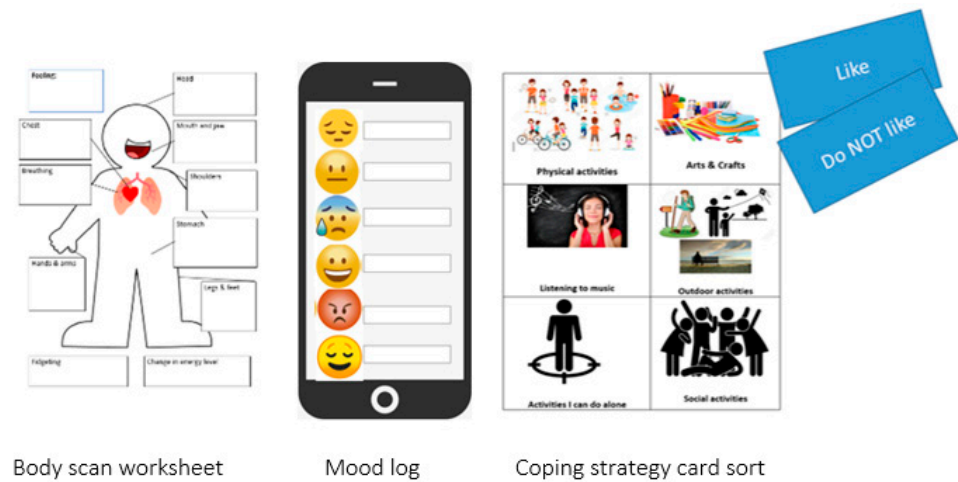
I had two mentees who I met once a week at their house or school. Other mentors met with their mentees at other places in the community, like libraries or coffee shops. When we first met our mentees, we went over how mentoring would happen. We explained what we would do if something went wrong. We worked on a contract together that we all agreed on. We did lots of activities. During our sessions, I taught them lessons about mental health by doing a worksheet, an activity, or showing a video we made. Some of these activities were a body scan, barriers and support worksheet, and mood logs (Figure 1).

Our goal was to pick two coping strategies with the mentee. We determined what coping strategies our mentee would work on by doing a card sort. The card sort also helped us to find out what their interests were. Examples of coping strategies from my mentees included making origami, a coloring book, or going to the park. After they picked their strategies, we helped them to work on their coping strategy and discussed any worries or concerns they were having. Each week, I also checked in with my mentee by a phone call, text or email about how they were doing.

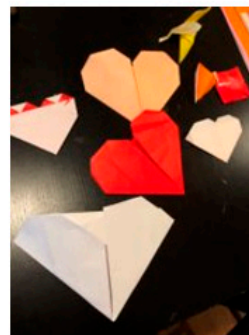
To help me to be a better mentor, I had a supporter who I talked to weekly about the week's mentoring session. We talked about the script and the activities I would do. Sometimes if the mentoring script was confusing, we would edit it to make it better.

During the peer mentoring group, before we even started meeting with mentees, we talked about what to do in an emergency situation. We had a texting system. We would text a stop sign to our supporter if there was an emergency. We would text a yield sign if there was something I needed to tell my supporter later. I never had to use the stop sign,

but it was there just in case. I thought the texting system was good, and it was helpful that Ariel worked near one of my mentees. Once, when I had a problem, she came running over to help.



Example coping strategy 1



Example coping strategy 2

**Figure 1.** Example of peer mentoring activities.

### 2.1.3. Looking at Data to Find Out If Mentoring Helped Our Mentees

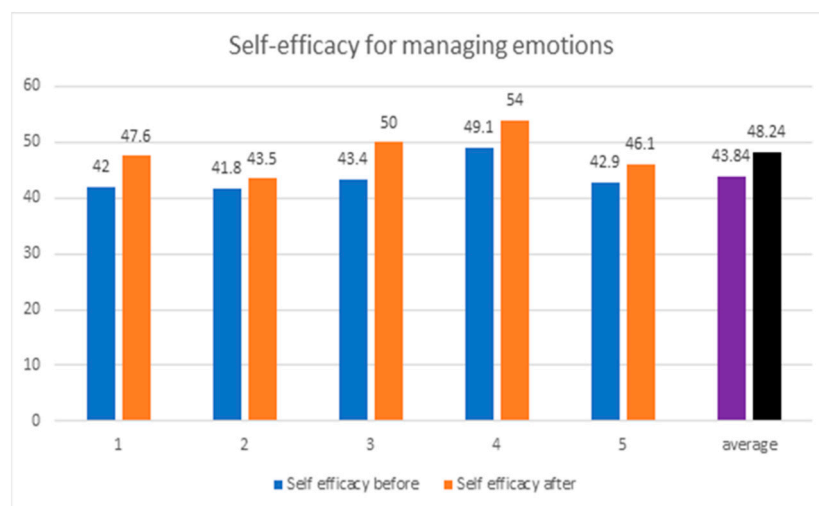
After mentoring, we looked at the data. The data included interviews with the mentees and their parents and surveys about mental health symptoms that the mentees and their family had said. To analyze the data, we made charts on what the mentees and their family had said. For example, when the research team met at Boston University, we did an activity where we got a bag of quotes showing what people liked and did not like. We worked together with a partner and got help from Ariel and the graduate students to sort quotes from the mentees into categories and glued the quotes on paper (Figure 2). One group worked on positive things about mentoring and another group worked on negative things about mentoring. We presented the charts to each other. Then, we talked about what they liked and did not like as the research team so we could know what to change. When I was looking at the data, I kept thinking back to my actual mentoring sessions. I could remember what my mentee did and how some of the data matched my experiences. I would ask questions if other people had similar experiences during mentoring. This helped me understand the information more.

Positive Things			
About mentor		Activities	
Qualities			
Quote	Main idea	Quote	Main idea
"My mentor was calm and relaxed and wasn't worried and stuff...we had stuff in common."	Calm and stuff in common	"The drawing book was my favorite."	Drawing book best part
"I liked that my mentor didn't do things that hurt me...my mentor is nice."	Mentor nice and didn't hurt	"I like going outside."	Going outside best part
"My mentor is funny...it was a lot of fun with my mentor."	Mentor was fun and funny	"I liked going to Dunkin' Donuts."	Dunkin' Donuts best part
"My mentor didn't push too hard."	Mentor was easy going		
Mentor understanding			
Quote	Main idea		
"I think my mentor being autistic made him more qualified to understand."	Easier to understand when some disability		
"My mentor was understanding."	Mentor was understanding		

Negative Things and Changes			
Negative		Changes	
Quote	Main idea	Quote	Main idea
"It was awkward."	Awkward	"It's something I was already working on."	Not new information
"It was boring because I didn't want to do it."	Boring	"I am kind of weird when I am put on the spot for writing. I tend to get writer's block."	More prep time
		"These are alone activities for me."	Strategies alone if want

**Figure 2.** Example of the qualitative analysis of feedback about peer mentoring.

We also looked at graphs of the survey data that Ariel made to see if there were changes in their mental health symptoms after mentoring (Figure 3). If I had seen the graphs before I mentored, I would not have understood them as well, because I like to understand things by doing them. When Ariel showed us the graphs, she reminded us of the training we did that related to the different topics in the graphs and how we worked on mental health symptoms in mentoring.



**Figure 3.** Example of an analysis graph.

We talked about making changes to peer mentoring based on the data and what we remembered did and did not work while we were mentors. For example, a couple people said they were getting bored with the barriers and supports worksheet and that it took too long (Table 1). So, we made it into a card sort to make it more fun. We are planning on doing peer mentoring again. Because of the COVID-19 pandemic, we will be doing it virtually and we can have mentors and mentees from outside of Massachusetts.

**Table 1.** Selected quotes about peer mentoring.

What Mentees Liked about Mentoring	What Mentees Wanted to Change about Mentoring
<ul style="list-style-type: none"> <li>• “[My favorite part was] spending time with Alix and making good conversations . . . she was very calm and relaxed, and she wasn’t worried and stuff . . . we had stuff in common . . . she was a very good person. [She made me feel comfortable because] she wasn’t yelling, ‘cause I don’t like yelling . . . she was very understanding”.</li> <li>• “[Alix] is funny!”</li> <li>• “My favorite one is going to coffee . . . it was a lot of fun”.</li> <li>• “The drawing book is a lot of fun to make”.</li> <li>• “I like that [my mentor] is not an ablest person. Because some mental health providers they think that helping people and hurting people are the same thing . . . And that’s an awful thing to have experience with and they can just be terrible and [my mentor] was not like that . . . And I think him also being autistic make him more qualified to understand”.</li> </ul>	<ul style="list-style-type: none"> <li>• “Maybe talking more about myself . . . stuff that’s on my mind”</li> <li>• “Practicing the coping strategies . . . I think it might be good if we did it more often.”</li> <li>• “Spend more time”</li> <li>• “Maybe, a little bit more obscure knowledge . . . instead of trying to teach you about mental health, which you no doubt already know if you are at my age, you already know about it because you grew up around it . . . teaching you how to, take responsibility for yourself, like learn about your rights, as someone who has problems with mental health, things like that”.</li> </ul>

## 2.2. What I Learned from Peer Mentoring

In the mentoring project, I learned how to work on a research team. I learned that giving an idea is good. I also learned time management, because if you have a meeting with a mentee you have to be on time. I set alarms on my phone and I made sure I had a ride. Peer mentoring helped me a lot with communication with other people. I opened up to talk with other professionals, like my mentee’s school counselor, people at a conference, and someone from another university who asked us to make a podcast (Boston University Mentoring and Research Team 2020).

Mentoring helped me have conversations with people in my personal life. I struggle making friends, because sometimes I do not know how to start a conversation, and this program really helped me with suggesting ideas about how to talk to people. It also helped me to learn cues, like if someone does not want to talk to you, because we talked a lot about how to communicate with the mentees.

*I also learned about other people. For example, boundaries are important. If someone is having a hard time, you want to give them space, and then ask again. Mentoring also helped me learn how to give other people a chance to talk. Sometimes, I get really excited about sharing my ideas. I learned to hold back and give someone else a chance.*

## 2.3. Why It Was Important That I Was Involved

People with disabilities have so many more strengths than they have challenges. Giving someone the opportunity to mentor someone just like them is a good idea because they understand where they are coming from. That person comes from experience not by going to school and getting a degree, but because of their own life experience. I personally feel we need more mentors like me because I have an understanding that cannot be taught in a classroom. I feel I have a connection with my mentees and we probably have had the same struggles. In some ways, we speak the same language. I feel I can truly understand what the mentees are talking about and understand their experiences.

It is important that young people with disabilities helped make the peer mentoring program, instead of just adult researchers without disabilities, because as a person with a disability, I understand their daily struggles. When I was growing up, I needed a lot

of support, academically and emotionally. I really looked up to people who helped me, and I thought it was super important. I really wanted to give back to someone who was struggling just like I was.

### 3. Disclosure Project

#### 3.1. What the Study Was about and What I Did

Our research was to learn more about the experiences that young adults with intellectual/developmental disabilities and co-occurring mental health conditions have at work. We wanted to know if they are receiving accommodations they need in the workplace. We also wanted to see what they were having challenges with at work. A big part of this study was learning about disclosure. Disclosure is when you tell someone about your disability. We wanted to know if people disclose their mental health conditions at work, and if they do, how they did it (Interview with Boston University Research Team 2021; Schwartz et al. 2022). In this project we interviewed 12 young adults with intellectual/developmental disabilities and mental health conditions to find out how they disclosed at work and to hear their stories.

To conduct the research, we worked as a team. I was really lucky to work with an amazing team of researchers who helped me every step of the way. They gave advice about what to say during the interviews. We collaborated and shared our ideas as a group. There were three researchers on this team that had an intellectual/developmental disability and mental health conditions. Ariel, who was working at Boston University, was also part of the team. We met every couple of weeks on Zoom. We created the questions that we were going to ask to the participants and also made a survey about accommodations and how mental health impacted young adults at work. We came up with the questions for the survey and response options. We had some ideas for the survey that Ariel said she never would have thought of without us. One of those ideas was to have really specific response options on the survey that would give us more information about accommodations (Figure 4).

**Working the same time each week, even if other people at my job have to work on different times each week**

- ☐ I got this accommodation
- ☐ I kind of got this accommodation
- ☐ I did not get this accommodation, but I think it might have helped me
- ☐ I did not get this accommodation and I do not think that I need it

Working the same time each week, even if other people at my job have to work on different times each week.

Please tell us about how you kind of got this accommodation

Working the same time each week, even if other people at my job have to work on different times each week.

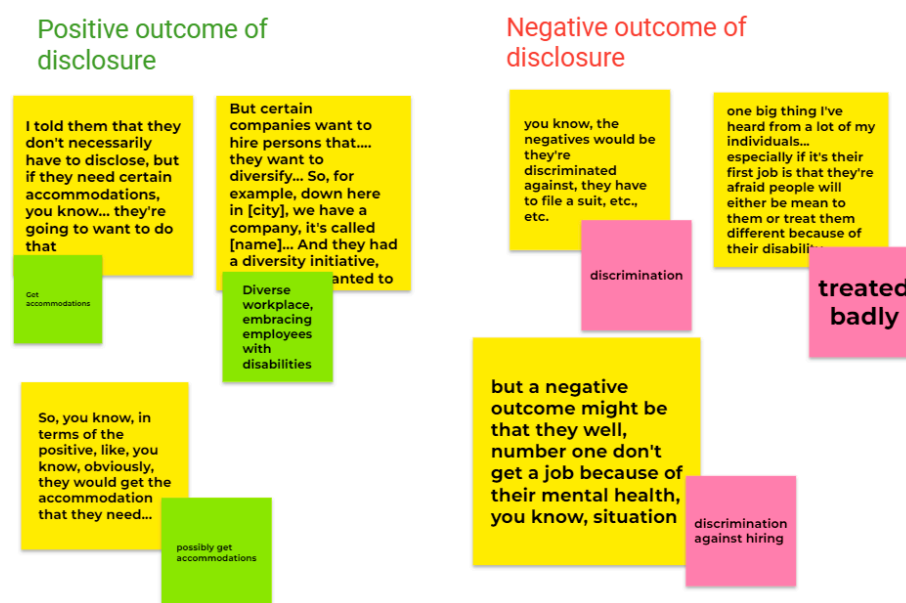
Why did you not get this accommodation?

- ☐ I think I needed this accommodation, but I did not ask for it
- ☐ I asked for this accommodation, but I did not get it
- ☐ Someone offered me this accommodation, but I decided not to take it

**Figure 4.** Response options developed by the team.

For the interviews, we put all the questions on a Google Slideshow that we shared. When we were interviewing a young adult, there was one researcher and Ariel in the interview. We took turns asking questions and listening to their stories. Ariel would change the color of the question once we were done getting the information we needed. If we needed more information, Ariel privately chatted suggestions for another question to ask, or reminded us about “who”, “why”, or “how” questions. We had different topics on each slide to make sure that we were asking the correct question. I thought it was really helpful that each slide had a few questions. The Google Slides were on a screen that only me and Ariel could see. We audio recorded all of the interviews and graduate students at Boston University transcribed everything the participants said so we would have all the data. Ariel had also talked to job coaches and transition specialists in focus groups and recorded what they said. We also analyzed that data. We spent a long time gathering the data!

After we interviewed all of the young adults, we analyzed the data by looking at Jamboard to help us to understand it completely. Ariel read the hundreds of pages from the focus groups and interviews and found quotes about different topics. Some examples of the topics are: accommodations, how people disclose, and what happened when people disclosed. She put the quotes on post-it notes in Jamboard. We moved the post-it notes into categories based on the main idea in the quote. Then, we either made more categories or changed the name of the category to help us to understand the data (Figure 5).



**Figure 5.** Example of the qualitative analysis using Jamboard. Quotes are in yellow; co-researcher’s “main idea” labels are in green and pink.

I really liked this project because I enjoy listening to other people’s stories and trying to help them as much as I can. It was interesting to me, because I could relate to some young adults and what they shared.

### 3.2. What I Learned from the Disclosure Project

In the disclosure project, I learned a lot about the different jobs young adults had. I learned how they disclosed at work. After doing data analysis I really understood what some people were going through at work and what support they were getting and not getting. I personally think that, if you struggle with something, someone should know about it, so you do not go to a job and have to struggle. This does not mean you have to disclose a disability, but you can ask for help.



### 3.3. *Why It Was Important I Was Part of This Project*

We are coming from the experience of having a disability. The things that we were researching and talking about are our real-life experiences. I felt like I could relate to some of the concerns the participants were having. During some interviews, after a young adult told us a story about what happened at work, I could say, “that happened to me”. That might have made them feel like they are not the only one. As a researcher with a disability, I have been through so many job trainings and have spoken to so many professionals about work that it came naturally to me. This also helped me to come up with interview and survey questions. I felt like I could bring a lot of good ideas that might help other young adults with disabilities. I would be curious if a team of researchers without disabilities found the same things.

### 4. **How Research Impacted My Life**

Research positively impacted my life. I really liked being a researcher because I have always wanted to help people, and this gave me an opportunity to do that. I really enjoyed listening to the stories the young adults had in the interviews for the disclosure project. It makes me feel happy when other young adults share stories with me because, sometimes, I can relate to them. I also was able to learn about my own strengths and be more confident.

I learned things that helped me in my own life. For example, in peer mentoring, I learned more about communication, and in the disclosure project, I learned about accommodations I could have asked for. I also learned about how to teach other people about coping strategies and mental health. Both studies helped me to learn how to organize information when we made charts or put information in a PowerPoint.

Doing research helped me realize how many strengths I have. For example, I realized that I have strengths in communication, being professional, and listening to what someone is saying. I am very creative. I got to use my creativity by sharing ideas. For example, I gave ideas of what we should put in the video we made about peer mentoring. I also gave ideas about how to improve peer mentoring activities. One idea was making the body scan on the computer instead of on paper.

I also was able to use my communication skills. When I am talking to someone, I always want them to feel that they are heard and that I am acknowledging what they say. For example, when someone tells me a personal story, I say, “thank you so much for sharing that. I know that can be really hard”. This was really helpful in research because some of the topics that we were talking about could be sensitive and hard to talk about.

Doing research helped me think of new options for myself. I learned more about helping people instead of being the person who got help. It is very different. Research helped me see that I am a good advocate for young adults with disabilities and that advocating is something I really like to do. When I learned new skills, I felt like I could be a leader. Ariel taught us the skills to lead a mentoring session. To prepare to lead, we looked at PowerPoints and did hands-on activities, such as role plays. These activities helped me understand it right away. I felt like I was the leader when I was mentoring because I was the person teaching.

This job helped me get other jobs. I used to work in food service. Then, I started the mentoring project, and I realized that I was really passionate about working with people with disabilities and mental health conditions. I looked for a job working with people. It took a long time, and that led to some mental health struggles, because I had jobs I did not like. The mentoring program opened a lot of doors for my career. Mentoring gave me the experience I needed. I also asked Ariel to tell my job coach and other people that I could work with kids and teens really well. Now, I am a preschool teacher.

### 5. **How Researchers without Disabilities Can Help Researchers with Disabilities Feel Welcome**

Researchers without a disability can make researchers with a disability feel welcome by listening to their ideas, supporting their ideas, and including them in group decisions.

Ariel and the other people helped me to feel like I belonged when they listened to my ideas and supported me if I did not understand something. They also used visuals, which helped me a lot. Another way that helped me understand the data was working in small groups. Ariel really broke the data down and explained it to us in a way that we understood. That structure helped me understand it better.

Now that we have worked together for three years, I feel even more comfortable sharing my ideas. I also felt as if I belonged, because other people on the team had disabilities. I could relate to what we were talking about, and I knew how it felt from my own personal experience. I had real life experiences, so I had a lot to say. People can read books about people with disabilities, or watch videos, and do so much research, but the experts are the people that experience disability in their own personal life.

## 6. Conclusions

As a researcher, working on these projects, I felt it was really unique, because I was able to promote and develop the research, and usually people with disabilities do not do things like that. Being a researcher was a very important experience for me. I always knew I wanted to help people, but I did not know what type of people I wanted to help. These experiences helped me learn I wanted to help people with disabilities, just like people helped me when I was younger. Doing research helped me open up about what I think is important and I learned many skills, just like the other co-researchers also learned many skills in their research (e.g., McDonald and Stack 2016; Strnadova et al. 2014; White and Morgan 2012).

As I was working on the research team, I contributed all of my strengths to the group and was an advocate for the things that I felt were important for people like me. Because Ariel designed the research to play to my strengths and understood how important my life experience was, it made it easy to contribute. In this group I felt comfortable sharing my ideas, because Ariel always gave my ideas a try (Milner and Frawley 2018; Schwartz et al. 2020a). After many years of working on the research, I have gained a lot of skills and strengths and learned new information about how to help somebody like me. The longer I do research, the better I become at it and the more I see how I have made a difference in the projects (Kidd et al. 2018). I am very excited to keep working on the projects and making a difference in somebody else's life. It is one of my passions.

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## Commentary

# Exploring My Life Path by Asking 600 People What They Love about Theirs

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**Abstract:** A young man with Down syndrome and an early adopter of self-managed supports wanted to have a great life, but he needed to be sure what a great life was for him. He decided to ask successful people, “What do you love about your life?”, which he felt was a question that gets right to the heart of the matter. In this paper the young man and his father will outline their journey as co-researchers in collecting/filming 600 stories across ten countries, with some interviews prearranged but many occurring spontaneously at music, film, and arts festivals. The initial findings of “what people loved about their lives” fall into the following categories: Family, Work, Home, Travel, Health, Pets, and Life Itself. Positive side effects for the young man covered: self-confidence, ability to connect with people, opportunities, working relationships, and ongoing friendship. The implications of taking a social journalism approach to collecting stories will be discussed in line with the question “What makes for good inclusive research”? The journey of the co-researchers speaks to the outcome that it is worthwhile to research your life path, accessing elders’ wisdom. The tools of inclusive research are powerful when applied to a citizen’s life questions. Each person values their life in unique ways, yet there are many commonalities.

**Keywords:** down syndrome; qualitative research; quality of life; self-advocacy; happiness

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## Introduction

Fionn is a young man with Down syndrome who rents an apartment in Galway. Jonathan, his father, supports him to live independently. Together they follow Fionn’s dreams: they travel to experience unique landscapes and natural phenomena; and they meet communities and individuals, by offering workshops and talks, and by performing music. They weave all these together into amazing adventures.

Fionn is one of the first in Ireland to adopt self-managed supports. He wants to have a great life, but he needs to be sure what a great life is for him. Gathering information about what is a great life for others was a way to gain clarity on his question: to determine his life path. And through the process of meeting, greeting and interviewing many people, a great life is happening along the way.

There has been much written about the value of inclusive research in line with its principles of ensuring that the research questions are relevant to the life of the person involved in collecting information (Johnson and Walmsley 2003). Their reflection will demonstrate how such data collection has been life-giving for Fionn, leading him to widen his circle of contacts as well as provide him with “an adaptable way to a sustainable and meaningful career” (Angus 2022, p. 1).

## How They Went about This Reflection

As a team of two co-researchers they discussed what they would like to share about their inclusive research journey and how it had impacted Fionn’s life journey. They had several discussion sessions following which Jonathan would draft the ideas into a script that Fionn would listen to and then agree or suggest additions and/or modifications. The

reflection is a joint effort using Jonathan's strength as a writer and Fionn's strength of contributing to discussion and interpreting ideas from his own perspective of being an inclusive researcher. The reflection is written in the third person which allowed for some details being personalised to either Jonathan or Fionn versus the plural use of "we". For the purpose of the reflection there are a number of what the authors have described as Spin Offs for Fionn arising from doing inclusive research.

### **The Happiness Project**

In this commentary the authors have chosen to reflect on what they have learned from their Happiness Project which they have developed and which is an ongoing citizen research project containing more than 600 open-ended interviews filmed in ten countries over seven years. Initially they met only with people with Down syndrome. This project began in the summer of 2013, when Fionn was a teenager. It arose from the desire to share insight into the lives of a small group of people with Down syndrome from the west of Ireland. It was decided to make a video to be shown on the first night of 600 km charitable cycling tour for the benefit of people with Down syndrome. Jonathan asked Fionn to decide on a single interview question they could ask all of the participants in the film, and Fionn suggested: What do you love about your life?

For Jonathan, the question initially sounded a bit awkward, a bit too naked or naïve. The more he ruminated with it, the more the simple brilliance shone, a profound question that could be asked a dozen times of the same person and could elicit a dozen responses, one that could lead toward greater appreciation of one another's lives. It illustrated well the core principle of inclusive research that research question/s need to be owned by the person with the lived experience of disability (Johnson and Walmsley 2003).

For the Happiness project it was important to film a variety of people with Down syndrome, including those who, through communication challenges, could not be expected to speak on camera. The method settled upon for this latter group was to query a loved one, usually a family member, and film the person doing the activity they love. This way the project was far less language dependent. All interviewees both verbal and non-verbal were videoed doing things they love: ocean swimming, surfing, racing greyhounds, baking cakes, dancing, playing with pets, and driving a car.

An edit of the video was made (with Fionn playing fiddle for the soundtrack) and it was warmly received when screened at the end of the first day of the race for the tired cycle riders. A subsequent article in the local paper caught the eye of a national TV chat show, and they were invited to show clips and talk about it as guests on the show.

For the purpose of the commentary there are a number of what the authors have described as Lessons Learned for Fionn arising from working on inclusive research projects. These are now explored below.

#### **Lesson Learned: Doing the Pilot Happiness Inclusive Research Project Enabled Fionn to Speak to the Media as an Agent of Attitude Change for People with Disability**

The end of the cycle race could have been the end of Fionn's search to understand what people loved about their lives however Jonathan was still grappling with how to help him settle on something fulfilling, where his gifts could be shared. They both agreed that it would be foolish to rush into a career decision and determined to continue the Happiness Project, extending their focus to include people with a range of different interests and accomplishments. By broadening the group and learning what was most important to a larger group of individuals, Fionn believed that he might gain insight into areas of life that he had not thought about in relation to his own life. At the same time both agreed that the project was a way of developing their father /son relationship as one built on shared experience of doing research together.

### Recruiting People to Answer Fionn's Question

Fionn's network of contacts reflected how, with Jonathan's support, he had built a start-up career that included his interests in music, art, and education. His wide network came from his busking on the Galway traditional music scene playing the fiddle, from exhibiting his artwork both in Ireland and beyond and doing inclusive research as a member of the Inclusive Research Network of Ireland ([http://www.fedvol.ie/Inclusive\\_Research\\_Network\\_IRN/Default.241.html](http://www.fedvol.ie/Inclusive_Research_Network_IRN/Default.241.html), Available Online: 26 November 2022) and Citizen Network (<https://citizen-network.org/map/fionnathan-productions>, Available Online: 26 November 2022). The fluidity of Fionn's world led him to decide on approaching people for interviews on meeting them at the range of events he and Jonathan attended together. This covered concerts to gallery exhibitions, from lectures to movie premiers. Such an approach was not unlike street interviews done by journalists (Gubrium and Holstein 2001). This decision coincided with Fionn and Jonathan gaining free access to these types of events as journalists.

#### **Lesson Learned: Doing Inclusive Research Led to Fionn to Be Recognised in Other Valued Roles Both as Interviewer and Event Journalist**

As part of the flexible approach to recruitment potential participants were asked for their verbal consent to film them answering the single question put to them by Fionn., What do you love about your life? It was explained by Fionn supported by Jonathan how these videos were recorded to learn about the person's life, so Fionn could gain insight into how other people lived and how this might help him to decide what he wanted to do with his life. They shared with each interviewee how they would post the interview online, providing them with the link and contact details if they wished to have the video deleted. As their interviewing continued their video making skills also grew. They became adept in using professional film making equipment, including digital cameras, tripods, microphones, and lights. They found that a smartphone often worked best, as people were more at ease and appeared to speak more freely. They agreed with Wolfensberger (2013) that their new roles of interviewer and journalist added value to their lives.

#### **Lesson Learned: Doing Inclusive Research for Fionn Gave Him Experience in Learning New Skills on the Job**

- *Doing the Interviews*

The interviews were posted on Fionn's YouTube channel, titled Fionnathan Presents The Happiness Project: What Do You Love? (<https://www.youtube.com/channel/UCEUi8gOAbuMUXdZRE5Yw0PQ>, Available Online: 26 November 2022). Here the date of the interview, location, a description of the events surrounding events, a biographical sketch and links to the interviewee's online profile are available. They were then cross promoted on social media such as Facebook and Twitter. Some of the videos were linked through to Fionn's website, [www.fionnathan.com](http://www.fionnathan.com), Available Online: 26 November 2022. Interviews about the project were done with traditional media (TV, radio, and newspapers) as well as podcasts and blogs.

The methods used by Fionn, with Jonathan's support, to hear and record what people loved about their life, supports the issue raised by (Milner and Frawley 2019) who have called for action in inclusive research to provide space for researchers with the lived experience of disability to select how they collect data without being reined in by traditional research methods. For data collection to work for Fionn and Jonathan as two co-researchers, one with an intellectual disability and the other as a supporter, the data collection needed to fit with the spontaneity of the event where they meet potential interviewees. Also, they did it together challenging the traditional belief of a potential conflict of interest between them as father and son. Their view in response to such potential criticism was that doing research together reflected their respective roles as partners in a company that they had set up called, Fionnathan Productions as a social enterprise that aims:

1. to help Fionn have a great life
2. to share the journey in hopes of helping others to have great lives
3. to change the world by removing obstacles that prevent people from having great lives (Angus 2022, p. 19).

Making media productions, doing research, and promoting inclusion provided them with an opportunity that moved beyond vested interests to developing sustainable interests that became life enhancing for Fionn.

Looking back to the beginning of the pilot, there was a moment when the Happiness Project might have never started. “On the first day”, Jonathan reminisced, “as we travelled out to collect stories, Fionn spoke from the passenger seat, saying, ‘I think maybe you should ask the question, and I’ll hold the camera,’ to which I responded, ‘How about you try it out. And more than a few, so you know what it’s like past the start’”. Fionn agreed, leading to Jonathan’s viewpoint that he has grown to exude self-confidence. He is surprisingly capable, and his good cheer is disarming, cutting through social barriers and calling up honest reflection. People feel safe opening up to Fionn, it seems, intuitively recognising a lack of guile. Perhaps surprisingly, as meeting people with Down syndrome is a relatively rare occurrence for many in society, those we interview seem to find Fionn immediately relatable. Simply put, he’s a highly skilled interviewer.

**Lesson Learned: Doing Inclusive Research for Fionn in a Space That Is Not Bounded by Traditional Methods Allowed Him to Collect Information in a Doable Way That Built His Confidence as an Interviewer**

- *What Was Learned about What People Loved about Their Lives?*

The interview collection now numbers over 600 stories. More than 100 participants are famous enough to have Wikipedia pages about them. Interviewees’ ages cross the adult lifespan, from teenagers to people in their 10th decade. Many of the people they have collaborated with have intellectual or physical disabilities with important things to say.

The technique that was used in the pilot project to interview subjects with all levels of speaking ability served to support them in engaging with a very diverse body of participants. They shared thoughts with a deaf interviewee through a translator who spoke and signed. With non-English speakers, they used a combination of gestures, smiles, and smartphone apps.

This fluidity of approach allowed the interview style to change to fit the circumstance. Interviews with the touring troupe from Shakespeare’s Globe Theatre presupposed their love of acting. Fionn instead asked a rhyming couplet: “Which line, from this play, is your favourite to say?”

Many people find being asked by Fionn, “What do you love about your life?” quite a moving experience. Dozens say, “that’s a wonderful question,” or sometimes “what a beautiful question,” or even “you probably have asked me the most important question you could ask anybody.” Sometimes people say “um . . . umm . . .,” or “that’s a really difficult question,” and two even said “that’s an awful question.” Generally, though, even such respondents warm to the theme.

Once, a touring musician from America settling in for the interview asked about the origin of Fionn’s name. Briefly the Irish myth of the third-born son, a simple man who gained all wisdom from the Salmon of Knowledge unintentionally, while serving others was shared. In the ensuing interview, the participant referred to this story to describe her creative process, saying, “You can’t be like a king. One has to be like a servant, one needs to be ‘broken enough’”.

Each person interviewed valued their life in unique ways, yet there are many commonalities covering the following eight areas: Family & Friends; Work; Travel; Home; Nature; Health and Well Being; Hobbies and Education.

Here are some direct quotes selected by Fionn that relate to these categories as ones that he found that were meaningful to him. He pointed out that all the quotes come from a place where people were living lives doing things that made them happy. What both Fionn

and Jonathan found amazing was that there were no negative answers. They wondered if their own excitement to ask this question led people to only think positively. The power of positive thinking was at work.

### **Family & Friends**

"The influence of my mother."

"My family, my friends, my grandchildren."

"I love my family. Because of them I able to keep grounded, and I remember that what I do, I'm doing for them"

### **Work**

"I try to love almost everything, approaching our lives and our work like we're making art and music."

"I love making films. I get to do a job that I would pay to do—please don't tell Disney that."

"I am enjoying a number of opportunities to grow in my profession. I have been assisted by conservation colleagues not only in Zambia but in the Southern region."

### **Travel**

"I enjoy traveling to strange and new places."

"I love traveling. I think that has really changed my life."

"I love being here in Dublin for my first time."

### **Home**

"Home." ("And what do you love about home?") "Breakfast."

"I love going place, which only makes coming back home all the sweeter."

"I love living here on campus and having fun with all my frineds."

### **Nature**

"I love nature."

"I really enjoy getting close to really wild animals, and big wild animals, at times. And then I like getting a chance to watch them for a long time."

### **Health and Well Being**

"Gathering primary sources, and helping people use them."

"Interdependence, and being there for each other, is way more valuable than independence."

"I love that my live is surprising in the best and deepest ways."

### **Hobbies**

"I love the fact that I discovered, by sheer chance, that I could play music."

"What I love about my life is I'm a teenager, and I listen to music."

"I love gardening."

### **Education**

"Opportunities to never stop learning."

"Men like you, asking questions like that."

"My son taught me that pretty much everything the world values is of no value. That money isolates you from other people."



Responding to the question “What do you love about your life?” often leads to emotional responses where tears and laughter are shared, and Fionn has received many spontaneous hugs. Here is a favourite moment, when Fionn’s interviewed a retired secondary school history teacher in a small village.

“That’s a profound question, and it would take me a long time to do it justice. But I would say . . . I will just tell you that I have been blessed, in my studies, in my job, in my entire life, with good health, a good wife, a happy family, and what can I say? a great, great life, in every possible situation.

And I am thoroughly happy. I have so many blessings, and so many things to be grateful to.

And thank you for asking me a question that’s so profound, so deep, and profound, and would take, actually, a long time to answer adequately. But it is a hugely important question.

Now, could I ask you a question?”

“Sure.”

“The same question to you: What is most important to your life?”

“I suppose, this moment, interviewing you”

(Nearly overcome with emotion) “Bless you”.

**Lesson Learned: Doing Inclusive Research Led to Fionn Being in Receipt of Positive Statements about His Role as Interviewer, Leading to him Feeling That He Was Appreciated**

- *What Was Learned by Fionn about His Life?*

Fionn and Jonathan agreed that the most enjoyable part of the research cycle was sharing what they had learned with others who are interested in the topic and receiving their responses. They have been asked to deliver talks to social science students on courses in thirty colleges and at multiple conferences, in cities such as Honolulu, Copenhagen, Amsterdam, Glasgow, Bristol, Sydney, Brisbane, Vancouver, Montreal, Detroit, Philadelphia, and Austin. On the surface their presentations may appear as purely educational, but they serve a deeper purpose for Fionn being recognised as a valued presenter arising from doing research in a manner that best suits his abilities and interests. This outcome was life enhancing for Fionn as it paved his life pathway with speaking opportunities that would often snowball into other invitations. For example, families would often refer Fionn to other family groups after gaining insight into his life as inspiration for their own family member with a disability. A further example of one presentation leading to another happened three years ago, when Fionn had an opportunity to interview Tim Shriver, Chairman of Special Olympics. He was profoundly impressed by the question, and during a dinner celebrating the launch of a UNESCO Chair, asked Fionn if he would partner to deliver the post dinner address. Fionn described his project to the gathering, and Tim invited all to reflect on what it was they loved about their lives, providing a minute of silence. Then, volunteers shared their responses to the question with Jonathan recording it all—six more interviews, in the bag.

What was also learned by Fionn was that celebrities, leaders, and other people of influence was open to being interviewed if the question is appealing and the approach flexible, and ideally instant. In getting to ask this one major question about what people love about their lives the outcome for Fionn has not been a chosen pathway emulating anyone person that he has interviewed but rather he has become more himself becoming not only an expert on what people love about their lives but also being open to becoming an Ambassador for a Global for Citizen Network (<https://citizen-network.org/about/citizen-network-research>, Available Online: 26 November 2022), as well as founding officer of the National Down Syndrome Policy Group (NDSPG) UK (<https://ndspg.org/who-we-are>, Available Online: 26 November 2022). Recently, he lobbied 107 MPs (probably a world

record for an Irishman) contributing to the recent passage of the Down Syndrome Act (2022). As a Research Officer for the NDSPG, he with support from Jonathan established an Advisory Group of people with Down syndrome from all around England. You can probably guess what the first focus group question was.

Perhaps the biggest honour of all: Fionn is Chair of the new Special Interest Inclusive Research Group for the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) (<https://iassidd.org/sirgs/inclusive-research/>, Available Online: 26 November 2022) and the first Council Member with intellectual disability in the organisation's 58-year history.

**Lesson Learned: Asking People What They Love about Their Lives Has Enabled Fionn to Recognise That He Has Leadership Potential Becoming a Member of Both Inclusive Research and Advocacy Groups Which All Play a Part in Building Him a Sustainable Future**

## Conclusions

Fionn and Jonathan have approached this reflective commentary as two co-researchers describing a body of work that has warmed hearts of 3 million others (latest YouTube count <https://www.youtube.com/channel/UCEUi8gOAbuMUXdZRE5Yw0PQ/about>, Available Online: 26 November 2022). They hope that this journey, attempting to discover a young man's life path, might stimulate interest in both professional academics and aficionados of knowledge to break (or at least bend) some of the rules and conventions of who can do research, and for what purposes.

Finally, it will come as no surprise that when Fionn was last asked about what he loved about this life his answer was "I love meeting people from all corners of society, and I love to hear their stories and share my stories with them. I want to make the world a place where everyone belongs, and I think that can happen when we listen to each other."

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## Article

# On the Road Together: Issues Observed in the Process of a Research Duo Working Together in a Long-Term and Intense Collaboration in an Inclusive Research Project

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**Abstract:** Inclusive research practices can lead to progress towards an inclusive society. With this study, we aimed to gain insight into dilemmas and catalysing processes within the long-term collaboration of an inclusive research duo: one non-academic researcher who lives with the label of intellectual disabilities and visual impairment, and one academic researcher. Both researchers kept personal diaries about their collaboration process. Inductive thematic analysis, individually and as a group of authors, was employed. Our findings reveal six necessary conditions for diversity-sensitive work in inclusive research: (a) experiencing belonging within the research group, (b) empowering people in a team through growing self-awareness and competence-building, (c) having room for reflection and searching for various ways of communication, (d) sharing power and ownership of research processes, (e) having enough time to foster the above conditions, and (f) joining in a mutual engagement in accommodating vulnerability in dialogue and collaborative work. Awareness of stigma-related issues and the risk of tokenism is also required.

**Keywords:** collaboration; inclusive research; intellectual disabilities

## 1. Introduction

The way society views people with intellectual and developmental disabilities (IDD) is shifting—values such as inclusion and empowerment have become more important (Zaagsma et al. 2020). In research, co-creation and collaboration with people with IDD are sought in response to this change, and to provide the evidence and tools required to foster societal inclusion. Working together with the people the research concerns is framed as “inclusive research” (Sergeant 2021). Advocacy of inclusive research practices is found prominently in the field of intellectual disability research (Nind 2014), but co-researchers are often unsure of how to proceed, and frequently encounter problems with communication, ownership and control, and equitable partnership (Bigby and Frawley 2010). Inclusive research contributes to the quality of both the process and outcomes of research when it helps to recognise, foster, and communicate the contributions of people with intellectual disabilities, and when it endows better lives for the wider population of people with intellectual disabilities (Walmsley et al. 2018), “to redress wrongs, both past and present” (Nind 2014, p. 15). However, research conditions should be considered to

ensure quality, prevent tokenism, and protect the well-being of all people included in the research team (Bigby et al. 2014; Chapman 2014; Strnadová et al. 2014).

The authors use the definition of inclusive research of Walmsley and Johnson—“research in which people with learning disabilities are active participants, not only as subjects but also as initiators, doers, writers and disseminators of research” (Walmsley and Johnson 2003, p. 9)—as a basis for their research projects. Walmsley and Johnson (2003) state that inclusive research (1) must address issues that really matter to people with intellectual and developmental disabilities, (2) must engage in research that ultimately leads to improved quality of life for them and their families, (3) must access and represent their perspectives and ambitions, and (4) must take place in a research community that treats people with IDD with respect. This fourth principle implies that inclusive research must be built on respectful collaboration between people who have scientific knowledge and people who have more practical, experience-based knowledge. This is not always simple: we agree with Chalahanová and colleagues that “time is needed to relax into relationships that are allowed to build slowly and organically” (Chalahanová et al. 2020, p. 155).

Prompted by the United Nations Convention on the Rights of Persons with Disabilities, inclusive research has gained increased attention (Embregts et al. 2018). However, good intentions are not enough to conduct inclusive research in practice. With this article, we have engaged with Nind’s call for critical self-reflection and shared reflection within the field of inclusive research (Nind 2014). We aim to provide a clear account of what happens within our long-term collaboration, and why and how we engage in collaborative production of knowledge between an academic and a person who was traditionally thought of as a participant or object of study (Duggan 2020; Frankena et al. 2018). Acknowledging that developing an equal relationship throughout the research process is a crucial departure point for true collaboration (Duggan 2020; Embregts et al. 2018; Frankena et al. 2018; Nind 2014), this article presents in-depth research into the process of building an equal relationship.

The central research question of this study is:

What themes, problems, and processes are observed in the process of a research duo (one non-academic researcher who lives with the label of intellectual disabilities and visual impairment and one academic researcher) working together in a long-term and intense collaboration on an inclusive research project in which they developed, organised, and delivered training to inclusive research projects in The Netherlands? This has been concretised in the following sub-questions:

- How have the researchers experienced their intense collaboration?
- What were the advantages and added value of inclusive practice?
- Which struggles and oppositions did they encounter within their own collaboration, and in the wider context?
- How did they deal with these challenges, and what is the value of their solutions for future inclusive research?

The research duo developed a training and coaching package for inclusive research teams within the context of a larger four-year inclusive research project, “Working Together, Learning Together” (WTLT). The research duo collected questions and needs for training from ten inclusive research projects in The Netherlands. Based on literature research and the information collected, researchers sought to learn how to develop and provide training and coaching to inclusive teams. The training development process was designed in an action-oriented and iterative spiral of learning, building and creating modules, evaluating and reflecting, adjusting the training modules, etc. The development of this training has been described in Sergeant et al. 2020. We learned from international research (Nind 2014; Nind and Vinha 2014; Strnadová et al. 2014) about the importance of training, team building, talking things over, and collaborative reflection. The training was developed because training and coaching for inclusive research teams were not available in The Netherlands (Sergeant 2021), despite increased calls for inclusive research, including from Dutch and international funding agencies.

The data on which this article is based were collected while the inclusive research duo created the training together (Sergeant et al. 2020). In this iterative process, the research duo shared all tasks, explored what this collaboration needed, and reflected on the themes and problems they encountered on the road to jointly developing and organising the training. Providing insight into the critical reflection process of a research duo enables a deeper understanding of themes, dilemmas, problems, and catalysing processes involved in working closely together. By documenting this work, we aim to inspire and support future inclusive research projects.

## 2. Methods

From 2016 to 2020, the seven authors conducted a nationwide inclusive research project in The Netherlands. For this project, we were asked by The Netherlands Organisation for Health Research and Development (ZonMW) to bring together questions and needs regarding inclusive research from 10 Dutch research projects (Sergeant 2021). Based on the questions and needs gathered, we started creating a training programme for inclusive researchers through an iterative and inclusive research process. Therefore, WTLT employed action-oriented qualitative research methods. In action-oriented research, “emphasis is placed on producing knowledge that can be used by community partners to contribute to positive social change and the well-being of individuals, families and communities” (Small and Uttal 2005, p. 938.) Our research work involved a reflective practice of developing training for other inclusive research teams, continually building on findings. We used action-oriented research, because we aimed to catalyse—on the road—positive change through creating time and space for training (Kidd et al. 2017), and by supporting trainers and participants to become more reflective in their work and collaboration.

The study spanned four years, as the research duo worked closely together and collected data in various forms. The Medical Ethics Review Committee of VU University Medical Centre (FWA00017598) confirmed that the Medical Research Involving Human Subjects Act (WMO) did not apply to this study and approved this study. This article focuses on this long-term collaboration between the first author as the academic researcher (Researcher 1) and the second author as the researcher who lives with the label of intellectual disabilities and visual impairment (Researcher 2). We refer to this pair of researchers as “the research duo” in this article. Researchers 1 and 2 did not know each other prior to the study. The researchers were paired on this project because Researcher 1 has experience working alongside people with disabilities and because Researcher 2 has experience in contributing to inclusive research projects. In Figure 1, the inclusive research duo is presented. The photo is a still – printed with consent of both researchers—from the film the duo made to introduce their collaboration and research project on developing training for inclusive research teams. The film can be downloaded from <https://youtu.be/pOT2iRiEps4> (accessed on 14 January 2022).



**Figure 1.** Inclusive research duo.

### 3. Study Design

The research duo worked together to develop and give a package of training and coaching sessions. During this process, the research duo collected data through participant observation. In participant observation, researchers are involved in the setting under study as both observer and participant (Maso and Smaling 1998; Reason and Bradbury 2001). Participant observation helps to identify and guide relationships, to learn about interaction, to examine how things are organised and prioritised in a setting, and to learn what is important to people (Kawulich 2005).

Based on these participant observations, the research duo wrote reflections in the form of extensive fieldnotes in individual research diaries at least two times per week, for four years. The research question and sub-questions served as starting points for our writings in the research diaries. As Bolger and colleagues state, “In diary studies, people provide frequent reports on the events and experiences of their daily lives. These reports capture the particulars of experience in a way that is not possible using traditional designs” (Bolger et al. 2003, p. 579). For this diary study, the research duo embedded an event-based design. A diary report was entered directly after every interview, training, or meeting connected with the research project. This event-based design was appropriate because the process of working together included triggering events—events that the research duo experienced as very positive or very negative—and attention to these could unfold dynamic phenomena (Bolger et al. 2003, pp. 590–91).

The research duo also decided to share several stories from these diaries in 35 published blogs and vlogs, which also form part of our research data. The blogs and vlogs were created based upon the diary notes. One additional blog was written by a journalist after he interviewed the research duo on why the research duo worked together, on what the duo encountered in their joint work, and on how they dealt with hindrances and challenges (Lingbeek 2017).

This process of creating diary notes provided a way to document our research journey and an early opportunity to critically reflect on experiences not long after they had occurred. The rationale for deciding to create blogs and vlogs based on the diary notes was to

support our action research goals, to make our research work and results more visible and accessible to a broader public, and to be more transparent about the methods and process of our study (Hookway 2008; Mortensen and Walker 2002; Reason and Bradbury 2001). The blogs and vlogs included texts, images, and films to reach populations otherwise geographically or socially removed from the researchers (Hookway 2008). All blogs and vlogs were published (in Dutch) on the site of Kennisplein Gehandicaptensector (<https://www.kennispleingehandicaptensector.nl> (accessed on 14 January 2022)), the Dutch online knowledge exchange platform on disability, inclusion, quality of life, care, and support. The diary notes, blogs, and vlogs were created during the four phases of the research project: (A) literature research and introductory meetings, (B) exploration of needs and gradually building up the training program, (C) expanding the team and involving more research projects, and (D) adjusting and reorganising the training (Sergeant et al. 2020). Every quote used for this manuscript is assigned to Researcher 1 or Researcher 2 and to a research phase A, B, C, or D in the Findings section.

In summary, the participant observations resulted in diary notes created—separately—by both researchers. Some of these diary notes were processed by the research duo and published as blogs and vlogs. The process of formatting and publishing the blogs and vlogs was facilitated and supported by Kennisplein Gehandicaptensector. For this article, all the quotes from the diaries and blogs are translated by first author, supported by a native English speaker.

The present study was conducted through teamwork, which was valuable in helping us to assess the study from a more critical perspective and to recognise and address its limitations. To deal with the threats to validity (Robson 2002)—referring to the integrity and application of the methods undertaken and the precision with which the findings reflect the data (Noble and Smith 2015)—we applied the following strategies. Firstly, as already stipulated, the large team of researchers (all authors) provided valuable feedback and suggestions for improvement. Secondly, the research work was conducted over four years: this prolonged involvement yielded a large amount of data, retrieved in various settings and situations, over four research phases (Sergeant et al. 2020). The third strategy is triangulation: we used different instruments of data collection, as explained above.

#### 4. Analysis

Qualitative data consisted of diary entries (field notes from participant observants), and the online blogs and vlogs, which included film and photos as well as text. A thematic analysis was conducted. Thematic analysis is the process of identifying patterns or themes within qualitative data (Braun and Clarke 2006). Four steps were taken during this process.

First, all research data materials were printed, listed, and numbered. Every researcher in the team of seven authors received a package of data. Materials were divided and shared in a way that ensured analysis of every piece of raw data by a minimum of two people, to integrate different perspectives and interpretations.

Second, the researchers familiarised themselves with the data by repeated reading or viewing, searching actively for meanings and patterns (Braun and Clarke 2006). Once the researchers had familiarised themselves with the data, they engaged in coding the data, identifying important sections of text, and attaching labels to index them (Braun and Clarke 2006). In this second step, the data were open-coded, with data fragmented and titles assigned using short terms and phrases. Through this inductive thematic content analysis phase, individual researchers were asked to document theoretical ideas and reflections developed through immersion in the data, including values, interests, and growing insights (Lincoln and Guba 1985). The aim of this step was to stay as close to the content as possible and to guarantee authenticity. Researcher 2, who already had extensive experience in coding in other research projects in the past, used accommodations during the analysis phase based on her needs, including a computer screen magnifier and large print copies of text.



Third, the research group gathered in the same room with their code lists and notes. The aim of the meeting was to code axially, whereby the open codes that belonged together were sorted under a theme (Braun and Clarke 2006). The group used Post-it notes on a wall to shape an overview of the identified themes and to support the search process. In the joint meeting, the findings of Researcher 2 were shared first and guided the whole group, providing structure throughout the meeting. It is important to note that this research group has worked together on a long-term basis. Therefore, the atmosphere was collegial, while still being intense and critical. This process of joint analysis was filmed.

In the last step, coding was selective, determining the relevance and coherence between themes (Braun and Clarke 2006). The first author used the film of the joint analysis meeting, the photos of the Post-it wall, all the different code lists, and notes of the researchers. The first author sent the results of this selective coding process to all authors and received feedback. We tried to ensure that the academic's point of view did not silence the perspective of the non-academic researcher by using the original coding documents of all researchers involved, and by re-watching the group analysis process together with Researcher 2. The comments given by Researcher 2—without the others being present—were also included in the analysis process. This process took months to come to a structure that was satisfying to all involved in the analysis process. The result of this inductive analysis process is the backbone of this article.

## 5. Findings

In this section, we present the results of the analytical process. Through the collaborative analysis process, we inductively derived a manageable structure of six significant themes:

1. Belonging
2. Self-awareness and competence-building
3. Communication
4. Sharing power
5. Time
6. Vulnerability

Although we reached consensus that data cohered together meaningfully within these themes, and we agreed that there was a clear distinction between themes (Braun and Clarke 2006), we also noticed links between themes. These links are elaborated in the Discussion section.

In the Findings section, we embed extracts of raw data from field notes/diaries, blogs, and vlogs to illustrate the complex story captured in the data, to do more justice to the richness of the data rather than to provide only a flat description (Braun and Clarke 2006).

### 5.1. Theme 1: Belonging

In their personal research diaries, the research duo frequently wrote on the theme of belonging and how this is impeded because of prejudices and (self-)stigma. As Researcher 2 told a journalist:

*“At a certain point, you know that society is like that. I know no better than people looking at me or staring at me. That happens, I can't see that because of my visual disability. But my researcher colleague sees that and gets angry about it”.* (Lingbeek 2017)

The theme of prejudice and (self-)stigma was often elaborated upon as an important barrier for belonging in research and in society, something that stands in the way of equal cooperation. On this theme, Researcher 1 (R1) and Researcher 2 (R2) wrote in their diaries:

*“People speak to my colleague with a high [childish] voice. Sometimes people speak to me and ignore her. My colleague says she is used to this . . . She wonders about me getting upset by this”.* (R1—phase B)

*“This research is very confusing to me. My whole life people say to me that I do not know. And now my research colleagues tell me that I do know. That I should take more*

*initiative. That they don't have the answers too. When I think about this, I experience it as a compliment. But it is confusing anyway". (R2—phase A)*

While meeting other inclusive research teams, the research duo witnessed hierarchy-based dynamics. They saw people struggle to not be seen as the most disabled one in the room. The research duo observed people debating about who was the best expert by experience, which is illustrated by this quote from the diary of Researcher 1:

*"We witnessed discussion and quarrels today between experts by experience on who is the best researcher? They concur about who is the most attributed and able to contribute to the research. This battle reveals—I think—their hard work to belong to the research project, doing their ultimate best to succeed". (R1—phase C)*

The research duo talked about this experience. They learned how important it can be to organise reflection and dialogue on (changing) responsibilities in their own collaboration, leaving the research project, quitting, and taking up less or more work. They decided this should not occur in a way where one person feels disrespected or that their work is not valued, but both should feel that they can share ambitions or place limits and can decide for themselves whether to (temporarily) quit or continue.

We connected these results with the concept of belonging, referring to the definition of inclusion that means not only "taking part", but also having rights and responsibilities as a legitimate member of a group (Van de Putte et al. 2018). A group can exist at different levels, from the macro level (society as a whole) to at the micro level (in this case a research group): people may (not) feel part of "regular" society and/or might (not) experience belonging within the research group.

## 5.2. Theme 2: Self-Awareness and Competence-Building

Self-awareness and competence-building were catalysed for the research duo. Researcher 1 wrote in her diary about her encounter with her colleague, Researcher 2. In this encounter, Researcher 2 explained that while working in the research context, she realised that she is more than "a disabled person" and that she did not want to narrow her work down to just the disability experience:

*"My colleague told me today she doesn't like the idea of working for a self-advocacy movement run by people with ID anymore. She started feeling uncomfortable because—in her job—each time she must introduce herself as a person with ID". (R1—phase D)*

Acknowledging and valuing differences in perspectives, experience, and knowledge come forward as vital elements in inclusive research. At the same time, lack of education was reported by Researcher 2 as a burden and cause for frustration. The following quote from Researcher 2's diary discusses being excluded from regular education because of her disabilities, while being involved in inclusive research has allowed her to develop talents and skills:

*"I am not happy with the education I had. I wished I had gone to an inclusive school. I never had the opportunity to do the studies I aspired to. Now I am happy with the opportunity to learn on the job and to contribute to research". (R2—phase D)*

The intense and long-term collaboration inspired Researcher 1 to think about her own disability experience:

*"Growing up with a grandmother with major psychological problems and having a daughter with a metabolic disease, I begin to realise that these life experiences have contributed to a deeply rooted awareness of inherent complexity and entanglement of life experiences and knowledge". (R1—phase D)*

## 5.3. Theme 3: Communication

For both partners to join the research work, sometimes other methods of communication were needed considering the visual impairment of Researcher 2, as depicted in a diary quote by Researcher 2:

*“From the introductory meetings we have included our notes in an (online) Prezi presentation (prezi.com) . . . Because I have a visual impairment, this helps me a lot . . . We have an overview of the meeting . . . And at the same time, I can make one section of the presentation much bigger”. (R2—phase A)*

Collaboration with visual artists, photographers, and filmmakers was found to be an indispensable condition for the research duo, as illustrated in a blog written by Researcher 2 about a film the research duo created together with filmmakers in phase A to introduce their research work to a diverse public (see also Picture 1, a still from this film):

*“In this film two tough women are driving a Cabrio. The film has the appearance that they get the job done together and are on the road together for this. Under all circumstances! And we do that too... My colleague and me. Before we made the film, we looked for what binds us: we love good music, travel, the feeling of freedom . . . and in the Cabrio that all comes together”.*

We could show this film to students, to professionals, to researchers, to experts by experience, and their families. They all could grasp the essence of our message: we try to collaborate, and that is interesting, sometimes difficult, and always far away from the “pity discourse”.

Learning from these experiences, the research duo created a film (<https://www.youtube.com/watch?v=wStYLc1a7-Y> (accessed on 14 January 2022)) revealing what they have learned from their research work instead of choosing for an “easy read” article. We believe that this makes the research results more widely accessible: no reading skills or large investments in time, energy, and focus are needed.

Thus, from our data, we learn that sometimes, other communication modes are needed because of the researchers’ impairments, or because of participants’ needs, but also to make the research results more widely accessible to a broader public.

#### 5.4. Theme 4: Sharing Power

The theme of power in the research work focuses on how decisions are made, who is in control, and who has influence in the research process. The research duo learned that in every phase of the research work, they had to keep searching for their (changing) roles and responsibilities. The quote below goes back to the start of the WTLT research project. Researcher 2 asked Researcher 1 for “the next step”. Researcher 1 wrote in her diary:

*“It was as if Researcher 2 asked me to give her the answers. And I do not have them. It is as if she asked me to give homework. This is not how I want to work together”. (R1—phase A)*

This incident was crucial for shaping the research duo’s collaboration. Long talks and many hours of collaborative reflection were needed to work this out for both researchers. Both researchers felt like they kept on profiting from this incident. The academic researcher said, “I don’t know”, which brought confusion, but also space for Researcher 2 to take more power and control.

Every research project starts with decisions about the focus of the research question and the design of the research. In our research project, Researcher 2 had a decisive role in this phase. She contributed to setting the research agenda, designing the research process, and deciding where the money goes. In her diary, Researcher 1 wrote the following on fostering shared power and ownership in inclusive research:

*“If we want researchers to design and write projects in co-creation with experts by experience, grant-giving organisations will need to provide the necessary time to co-create and co-write. The grant-giving organisations will also have to acknowledge that predictions on the used methods and the timeline are more difficult to make if you collaborate with experts by experience. Some extra space for adjusting time and method to the needs of the team will be appropriate”. (R1—phase C)*

Ownership of the research and the research question was of major importance in the research duo's collaboration. Both researchers were eager to realise the goals of the research. This helped to motivate them during their four years of intense collaboration.

#### 5.5. Theme 5: Time

This theme is strongly intertwined with all the other themes but proved to be an important condition in itself. Researcher 1 wrote, after she met Researcher 2 for the first time:

*"Our first date took place in my house. After a long day talking and getting to know each other, my new colleague says to me: 'I know what you need. You need structure. And I am able to give you this.' I smiled. Ouch. She already recognises something that is very true. Structure is what I need; and I need somebody else to help me create it".*  
(R1—phase A)

Having enough time to get to know each other surfaced as a major issue during our research. The duration of the research project can catalyse ownership of the project and ambitions to evoke positive change through research. The research duo shared thoughts on the cruciality of creating enough time: to get to know each other, to discover what the other needs, and to take up roles in the project that fit the temperament, competences, and ambitions of the researchers.

#### 5.6. Theme 6: Vulnerability

When the research duo started delivering training to inclusive teams, they reported feeling insecure. They had many questions about how to enter these teams and how to position themselves. As Researcher 1 wrote:

*"We felt being watched. We had to be good; we felt like we were not allowed to make mistakes".* (R1—phase A)

However, this changed over time:

*"Now we feel more relaxed in the cooperation: the cramp disappeared. Vulnerability is an important issue: can we be vulnerable; can we make mistakes and learn from that?"* she later wrote. (R1—phase C)

The research duo struggled in the beginning of their collaboration with mutual engagement in dialogue. Researcher 1 admitted in her field notes that she was used to taking care of people with disabilities, instead of working with them as colleagues, giving feedback and sharing thoughts. This is illustrated in the next quote from her diary:

*"How must I share my thoughts with my colleague? How can I bring in my questions, insecurities, and delicate thoughts on our collaboration? I am afraid to hurt her feelings".*  
(R1—phase A)

The research duo learned that admitting to themselves and others that they were constantly struggling and searching was very helpful in their collaboration. This process brought relief and tranquillity to their relationship and their research work.

### 6. Discussion

In our research, it became clear that if people with disabilities and their colleagues become aware of their knowledge, their power, and the danger posed to their collaboration by (self-)stigma (Scior et al. 2015), something changes in their lives and in their collaborations. The research duo started their work together with a binary vision, juxtaposing the academic researcher and the non-academic researcher living with disabilities. On the road, they discovered how entangled their lives are, how Researcher 2 became a researcher with academic skills herself, and how Researcher 1 came to reflect more on her own life story and experience.

For all research members to be able to flourish and to develop talents, a diversity-sensitive context (MacDonnell and Macdonald 2011; Peels and Sergeant 2018) must be

created, with training and coaching provided as needed. On the one hand, this context must provide support and protection for all members of inclusive research teams, and on the other hand, it must presume and support competences of all team members: both have been identified as very important pre-conditions for inclusive research (Embregts et al. 2018; Strnadová et al. 2014).

An overarching theme in our findings is related to stigma. Scior et al. (2015, p. 15) define stigma as “the co-occurrence of these stigma components: labelling, stereotyping (that is negative evaluation of a label), prejudice (that is endorsement of negative stereotypes), which lead to status loss and discrimination for the stigmatised individual or group.” During an intense collaboration in which the researchers almost did everything together, the research duo became aware of the impact of prejudice, (self-)stigma, and (their own) binary thinking, which influence not only the position of people with disabilities in our society, but also their role in research. The label of intellectual disability can cause low self-esteem (self-stigma), lower expectations in society, and being positioned lower on the research participation ladder (Arnstein 1969; Kliewer et al. 2015; Tritter and McCallum 2006).

Our research data reveal that more participation is not always better. What counts is meaningful participation, in which all participants are convinced of the importance of the contribution of all involved, and of the worth of each other’s knowledge to the team. Rather than being asked to participate for instrumental or tokenistic reasons, people with IDD should be seen as bringing more diversity, quality, and richness to the research process and (dissemination of) products. This means time for reflection on inclusive collaboration is crucial (Bigby et al. 2014; Johnson and Johnson 2009; Strnadová et al. 2014): open and sincere dialogue and reflection help greatly and can form a solid basis for daily work. Our data show the importance of collaborative reflection on the meaning of disability, on what people need within a research collaboration, and on the experience and impact of prejudice and (self-)stigma during inclusive work processes. It is only possible to discuss this if there is time for slow research, if there is shared history and reciprocal trust. Attention must be also paid to matching talents, roles, and tasks in the research process (Embregts et al. 2018; Frankena et al. 2018; Nind 2014).

## 7. Future Research

The authors recommend further investigation into how inclusive research in a disability-focused context and the conditions associated with its success can be a catalyst beyond research that is inclusive of disabled people, leading towards a less hierarchical academic world and a more supportive, democratic, and safe space for researchers. This is especially important in IDD research, because the long history of excluding and disempowering people with an IDD label from research processes has likely impeded progress and may at times have contributed to abusive practices.

People with intellectual disabilities and people with mental health problems are often seen as the lowest in the disability hierarchy (Deal 2003; Scior and Werner 2016). This hierarchy perpetuates the notion that some disabilities are more acceptable than others in our culture. This hierarchy can be internalised and deployed by people with disabilities, as well as by those without. From the data, we observe that the disability hierarchy appears to be a barrier to inclusive research. Future research is needed to gain deeper insight into this process.

Currently, many organisations provide funding on the condition that leading researchers work closely together with experts by experience. However, tokenism can still lurk within such constructions, along with the risk of “data robbery”: stealing the stories shared by experts by experience without acknowledging their ownership (Embregts et al. 2018; Nierse and Abma 2011; Nind 2014). The authors recommend further research to gain insight into what conditions must be met to ensure that research participation and co-creation deliver on their promise. Based on our findings, we would like to encourage future researchers to engage in critical reflection on their own collaboration process, frankly writing on both the richness and the struggle that comes with inclusive research.

Changes made to the Dutch research funding environment following The Netherlands' ratification of the UN CRPD have fostered more inclusive research, but in The Netherlands, as elsewhere, funding mechanisms continue to disadvantage disabled researchers, and especially those with IDD who may need additional funded support to fully participate. For example, non-disabled researchers are more likely to earn a salary for their research, while disabled co-researchers may be relegated by funding or disability benefits rules to no or very low remuneration. This impacts the potential of inclusive research, including ours, to be truly "equal". Research environments continue to valorise production over contribution and effort, which can also disadvantage researchers with IDD who expend considerably more effort to contribute. In our research process, we worked hard to manage financial equality as well as intellectual property. Both researchers were paid and were involved in every phase of the research process, being valued in their expertise. We realise some inclusive research teams work in different conditions, and are struggling with payment and time pressure. So, based on our results, our final advice for further research is to rearrange the way of funding.

### 8. Limitations

We recognise the limitations of analysis based upon the experience of one research duo in The Netherlands. As mentioned earlier in the Methods section, prior to this study, Researcher 1 already had experience working alongside people with disabilities and Researcher 2 already had experience in contributing to inclusive research projects. Nevertheless, because the research took place during a process that involved close contact with multiple inclusive teams, we believe we have identified some critical contextual factors which are crucial for inclusive research and for collaboration within teams.

An important factor in the research duo's communication was that, with support and specialist equipment, Researcher 2 was able to keep a reflective diary and contribute to blogs and vlogs. Some research participants with IDD would need more support to reflect on their experiences and act as self-advocates within a research setting; research participants who are non-literate or non-verbal would need different forms of support to contribute and to document their contribution.

### 9. Conclusions

In this research, we documented and explored the issues, observed in the process of a research duo working together in a long-term and intense collaboration on an inclusive research project (WTLT) in which they have developed, organised, and delivered training to inclusive research projects in The Netherlands.

Our findings reveal six necessary conditions for diversity-sensitive work in inclusive research: (a) experiencing belonging within the research group, (b) empowering people in a team through growing self-awareness and competence-building, (c) having room for reflection and searching for various ways of communication, (d) sharing power and ownership of research process, (e) having enough time to foster the above conditions, and (f) joining in a mutual engagement in accommodating vulnerability in dialogue and collaborative work.

Within our research results, one could identify a "true contradiction" (Rieger and Young 2019): (a) Inclusive research needs a well-prepared diversity-sensitive research environment, but at the same time, (b) "fear of doing it badly should not prevent us from attempting it" (Sin and Fong 2010, p. 21). Struggle is central in inclusive research, and therefore, we believe we are all responsible for welcoming this experience of negotiation and transformation, and discovering what Melanie Nind (2014, p. 84) means by "the full potential of inclusive research".

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## Article

# A Closer Look at the Quest for an Inclusive Research Project: 'I Had No Experience with Scientific Research, and then the Ball of Cooperation Started Rolling'

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**Abstract:** The original adage of the movement of people with disabilities 'Nothing about us without us' is fortunately more and more adopted in the research world. There is, for example, increasing recognition of the importance and value of actively involving people with intellectual disabilities in research projects on topics that are relevant to them. In a current doctoral research project, a co-researcher with an intellectual disability was recruited to work together with the doctoral researcher. Now that this project is nearing completion, it is time to look at some aspects of their collaboration and see what we can learn from this process. In several (joint) meetings, the researchers reflected on their personal experiences with working and researching together. Our reflections are presented using three overarching themes: preparations for the collaboration, collaborating as a complex process, and conducting research together. The discussion focuses on what can be inferred from these personal experiences with regard to the following three topics: how inclusive research can be organised best, the possible benefits of the collaboration for the researchers involved, and the possible impact of the collaboration on the quality of the research.

**Keywords:** inclusive research; participatory research; intellectual disabilities; collaboration

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## 1. Introduction

The position of people with intellectual disabilities in scientific research has changed significantly in recent decades. Whereas for a long time they were not involved in research (others spoke for them), since the end of the 1990s, we have witnessed efforts to take a different approach. Their involvement in this regard has morphed from being exclusively research participants to gradually becoming more actively involved in the various stages of the research process. Bigby et al. (2014a) differentiate between three different approaches to how people with intellectual disabilities are actively involved in research: (1) an advisory approach (people with intellectual disabilities provide advice to academic research teams), (2) a leading and guiding approach (people with intellectual disabilities initiate, lead, and execute their own research about issues important to them), or (3) a collaborative group approach (people with intellectual disabilities work in an equal partnership with academic researchers). Each of these approaches creates opportunities, in different ways and to different degrees, for people with intellectual disabilities to influence research and help take decisions relating to aspects such as research topics, design, and used methods.

The literature on this topic cites various good reasons why it can be both important and valuable to have people with intellectual disabilities take an active role in research projects. For example, the UN Convention on the Rights of Persons with Disabilities (United Nations 2006) emphasises the right of people with disabilities to be involved in issues affecting them. In addition, being actively involved in scientific research can have a beneficial effect on the individuals directly involved (e.g., learning new skills, gaining insight into the experiences of (other) people with intellectual disabilities) and by extension on other people with intellectual disabilities and by extension on people without disabilities working with the latter (Frankena et al. 2015; Stack and McDonald 2018). It is also experienced that involving people with intellectual disabilities can contribute to the quality and relevance of research. For example, researchers with an intellectual disability can have a ‘technical’ contribution by developing materials that are appropriate for the research and its participants (Nind 2014; Frankena et al. 2015; Puyalto et al. 2016). Individuals with intellectual disabilities are also recognized as advocates who can help to concretize more abstract terms such as autonomy, empowerment, participation, and inclusion, bring good practices to the fore, and who take the lead in uncovering barriers (regarding, for example, accessibility, supportive relationships, or transition to adulthood) (Chalachanová et al. 2021).

When people with intellectual disabilities take on an active role, the term often referred to is inclusive research. In an article from 2018, Walmsley et al. attempted to define a ‘second generation’ of inclusive research, taking into account the evolutions that have occurred since the beginning of the 21st century. According to these authors, inclusive research can be described as follows (p. 758):

- Research that aims to contribute to social change, that helps to create a society, in which excluded groups belong, and which aims to improve the quality of their lives.
- Research based on issues important to a group and which draws on their experience to inform the research process and outcomes.
- Research which aims to recognize, foster, and communicate the contributions people with intellectual disabilities can make.
- Research which provides information which can be used by people with intellectual disabilities to campaign for change on behalf of others.
- Research in which those involved in it are ‘standing with’ those whose issues are being explored or investigated.

Practices of inclusive research are increasingly being realized in different places around the world and with different ‘target groups’. In this regard, we are inspired by research centres and groups with years of experience. The fact that they have realized many projects, built a large network, presented and published a lot but also (and above all) that they have been able to exert a lot of influence on local practices and policies offers opportunities to learn from them. We would like to briefly describe two inspiring examples below. To begin with, in Ireland, we can learn from the intense cooperation between the National Federation of Voluntary Service Providers, Trinity College Dublin, and University College Cork. García Iriarte et al. (2014) and Salmon et al. (2018) report on the pathways this network developed to conduct research about topics that are important for persons with disabilities. They worked with training workshops, organized a continuous dialogue about their projects, used creative tools (such as role plays) to develop skills of researchers and co-researchers, worked hard to make sense with the teams of the data, and presented their work in local, national, and international meetings. At the same time, these researchers are able to keep a very critical stance towards their own work not wanting to become the very type of research it aims to challenge (Salmon et al. 2018). A second example is located in the USA, where Nicolaidis et al. (2019) report on the practices of AASPIRE-USA regarding trying to develop guidelines for the promotion of the inclusion of autistic adults as co-researchers. They put a strong focus on being transparent about partnership goals, clearly defining roles and choosing partners, creating processes for effective communication and power sharing, building and maintaining trust, disseminating findings, encouraging community inclusion, and fairly compensating partners. It is important to learn that for persons with autism (the

group that is often strongly entwined in a clinical model), the time has come to participate in research. The lessons learned in research projects with people with autism can help us to make the framework for research projects and the communication about the projects clearer for colleagues-researchers with intellectual disabilities as well.

As a result of the growing attention to inclusive research and the increase in research initiatives with an inclusive approach, the knowledge shared (through publications) on this topic is growing. The publications can be roughly divided into two groups. There are articles that primarily focus on personal experiences of inclusive research and reflections on collaborative research (e.g., Strnadová et al. 2014; Dorozenko et al. 2016; Riches et al. 2017). In addition, other publications attempt to arrive at assertions that can be generalised across inclusive research initiatives, such as attributes that should be taken into consideration when conducting inclusive research (Frankena et al. 2018), competencies that are considered important for researchers with and without intellectual disabilities in inclusive research initiatives (Embregts et al. 2018), and contextual and team-level factors and processes that foster and maintain inclusive research (Schwartz et al. 2020).

Through this article, we want to align ourselves with the tradition of incorporating personal experiences. For the first two authors (both researchers, of which one has an intellectual disability), this article represents the culmination of an extended period of collaboration within a research project (see Section 2.2). The first author positions herself in a tradition of doctoral students opting for a more inclusive approach in their research work. Already in 2008, Björnsdóttir reported on the tensions that inclusive research during a PhD trajectory evokes within a competitive academic environment and the danger of academic researchers falling into the same trap of the exclusion that they criticize society for (Björnsdóttir and Svensdóttir 2008). By focusing on the tension between inclusive research and traditional ethical guidelines at research institutes and universities, Morgan wanted to make future PhD researchers aware of possible incompatibilities linked to, e.g., disclosure, the tension between empowerment and protection, and the application of shared partnership, equality, and transparency within an academic context (Morgan et al. 2014). Moreover, Dorozenko's recent call for PhD students working with inclusive research to have sufficient reflexivity and critical reflection (e.g., regarding the risks of repeating oppressive power relations) was very inspiring for the collaboration described here (Dorozenko et al. 2016).

The aim of this article is to reflect on our own research collaboration by exploring our personal experiences of how our collaboration in research works best, as well as the benefits that our collaboration has brought to us personally as well as to the quality of the research. We hope that our experiences can provide support to other researchers who wish to set up and conduct inclusive research. This article was realised thanks to the substantial contributions of several people who are all co-authors. Mark and Miriam form the research duo that worked together on a research project for several years (see Section 2), and for this article, they reflected on their collaboration. Geert, Karin, and Alice were involved in this research project as supervisors and advisors. Not only did they advise the research duo on 'technical' research issues but also on conducting research inclusively. Christine was asked to help the research duo compile and situate experiences (see Section 3). With regard to the writing of this article, Geert, Miriam, and Mark took the lead, and the other three co-authors reviewed previous versions of this article.

## 2. Context

### 2.1. The Research Duo

Mark and Miriam both work as researchers at the Philadelphia Care Foundation (PCF) in the Netherlands. The PCF is a care organisation for people with an intellectual disability, which offers a wide range of support services throughout the Netherlands. Over a period of almost four years (December 2017–October 2021), Mark and Miriam worked together on a research project into the experiences with an online support service of people with intellectual disabilities living independently (more on this in the next section). In addition,

Mark works several hours a week as an assistant on other projects within the PCF. Mark and Miriam introduce themselves below. Mark: *'I am 45 years old. I was born prematurely and for a long time I believed I had a developmental disorder. I went to a special education school. For a long time, I felt like I had a hard time making friends, but I did have contacts with other people. Once I finished school, I had various jobs in administration. I often felt like I wasn't taken seriously at work. I also had the feeling that I was only half-participating in society. I had the feeling that something was wrong, but I did not know what it was. In 2005 I was diagnosed with PDD-NOS, a form of autism. That's how I ended up coming into contact with Philadelphia [the service organisation]. Then things started to change. There were opportunities at work to focus on my talents in a partially sheltered way, I was able to develop myself. This was enhanced when I joined various client councils within the organisation. I felt I was being taken more seriously. I mattered. Through people at the client council, I came into contact with Miriam in 2017. She was looking for a colleague to conduct research together. At the time, I had no experience with research, let alone scientific research. Back then, I couldn't have told you what research involved. And then the ball of cooperation started rolling'*. Miriam: *'I'm 40 years old. I went to a mainstream school and completed studies at university, where I was able to gain a lot of knowledge and skills in the area of scientific research. After my studies, I did various jobs conducting research. Sometimes these were projects in which we tried to involve the 'target group', such as young people in mainstream education. However, these were not truly inclusive projects. As such, when I joined Philadelphia in 2016 I had no experience with inclusive research'*.

## 2.2. The Research Project

The project that Mark and Miriam worked on involved research into the online support service DigiContact. This service is offered by the PCF as part of a broader package of support services for people with intellectual disabilities living independently (in their own homes) (Vijfhuizen and Volkers 2016). DigiContact offers 24/7 remote support, where people with a support need can contact a team of specially trained support workers via either an app or link on their mobile phone, tablet, or computer or via a standard telephone. The aim of the project was to compile knowledge on the experiences of both support users and professionals of DigiContact regarding the potential value of its support for people with intellectual disabilities living independently. During the course of the project, five sub-studies were performed of which each focused on a different question. A scientific article was (or will be) drafted in English on each sub-study (Zaagsma et al. 2019, 2020a, 2020b, 2021).

The research project started in 2015 with a different researcher duo. After one year, both members of this duo left the project because neither of them wanted to continue working as researchers. After this, Miriam started working on the project in February 2016. During the first year, she worked with another co-researcher for several months. Mark was recruited as a co-researcher in 2017. For Miriam, the research project formed the basis for her PhD at the Amsterdam UMC (Vrije Universiteit). Throughout the project, she was able to devote 32 h per week to the research project. When Mark was recruited, he was offered a contract to work on the research project for an average of 8 h per week. He also worked a varying number of hours on other projects within the PCF. Besides Miriam and Mark, three senior researchers (fourth, fifth, and sixth author) were involved in the different sub-studies into DigiContact. They provided advice for the research and supported Miriam in her PhD.

## 3. Materials and Methods

In this article, we reflect on the personal experiences of Miriam and Mark with conducting research together during the research project on the potential value of 24/7 online support. By doing so, we align ourselves with the tradition of an auto-ethnographic approach, in which personal experiences are described and analysed in order to understand broader cultural experiences (Ellis et al. 2010).

During the course of the research project, data on the collaboration were logged in various ways. To begin with, both Mark and Miriam independently kept a logbook in which

they wrote down their personal experiences, thoughts, questions, doubts, and difficulties on a weekly basis. During the first weeks of the project, Mark was supported by Miriam on how to keep a logbook (e.g., by discussing together what to note, when to do this, with how much detail, etc.); after this, he continued to do this by himself. In addition, Mark and Miriam had regular conversations together about the research and their collaboration in particular. These conversations were not always planned in advance and did not have any fixed structure. Notes of these conversations were recorded in the logbooks.

In preparation for this article, five meetings were organised and held (in the spring and summer of 2020), in which Miriam and Mark reflected on their collaboration under the guidance of a moderator (3rd author). This moderator was able to reflect on their experiences and ask questions from an outsider's perspective. At the start of these meetings, the moderator, Miriam, and Mark discussed topics that would be interesting to explore. Examples of topics were: expectations of conducting research together, how different research activities (e.g., analysing data) were carried out, and perceived facilitators and barriers in the process of collaborating. Before each meeting, the moderator prepared a list of questions she could use to fuel the conversation when needed (e.g., 'What were difficult moments during the project (and why)? What are you proud of (and why)?'). The notes in the logbooks were used as input for the meetings, with Mark and Miriam going through them in advance to refresh their memories. To prepare for this, a plan of action was drawn up by the researchers together. This plan included a guideline regarding what to do (e.g., what to pay attention to, how to make notes of topics that seemed important) and a plan on when to do this (the work was spread out over multiple shorter sittings because the collection of notes was quite comprehensive). Following up on this plan, the researchers worked independently from each other to review their own notes without needing further support. The five meetings took place remotely via videoconference, on account of the COVID-19 measures in place at the time. Three of the five meetings were conducted jointly. In the other two meetings, the moderator talked with each researcher individually, focusing in particular on elements that were related to Mark and Miriam's unique and highly personal perspective. Each meeting was recorded and subsequently transcribed by an external agency.

The transcripts of these five meetings and the logbook notes formed the research material. To decide on which reflections and experiences to present, Miriam and Mark went through the material while keeping the three topics of reflection in mind (i.e., how inclusive research can be organised, the possible benefits of the collaboration for the researchers involved, and the possible impact of the collaboration on the quality of the research). They started this process separately from each other. Both of them read all the transcripts and notes. To assist with ease of comprehension, Mark also listened to the audio recordings of the meetings, as this helped him retain his attention and grasp the meaning of what was being said. They both used marker pens to highlight parts of text on a given topic, always writing the gist of the text in the margin. They each made a list of the experiences they personally found important. These lists were shared with each other by e-mail. As a next step, Miriam and Mark compared and discussed the experiences on their lists in order to come up with a joint overview in which their experiences were integrated. This process took place (mostly) via videoconference calls due to COVID-19 restrictions being still in place. This overview was shared with the other authors in order to decide together with them on which experiences needed to be highlighted in this article. The starting point in this was to present experiences that we were convinced would interest other individuals involved in inclusive research.

#### 4. Results

The experiences are discussed and explained on the basis of excerpts from the meetings. These excerpts were translated into English by a certified translator. The experiences are presented using three overarching methodological themes: preparing for the research collaboration, collaborating as a complex process, and conducting research together.

#### 4.1. Preparing for the Research Collaboration

The first methodological theme describes the period leading up to the collaboration and emphasises the importance of good preparation.

##### 4.1.1. Philadelphia Opts for Inclusive Research

The decision to adopt an inclusive approach in the research project did not appear to be a priority for either researcher in the first instance. The decision to set up and conduct inclusive research was not made by the researchers themselves. It was the steering committee of the research project (with representatives from the PCF and the senior researchers from the university) that put forward and decided on the idea of inclusive research at the outset of the project. Both Miriam and Mark were candid and stated that at the time of their application, they were primarily interested in the topic of the project and the accompanying work activities. The inclusive nature of the research project was for them an attractive and interesting extra. Miriam: *'The position first attracted me because of the subject of the research project: the digitisation of care for people with intellectual disabilities, and studying client experiences. The possibility of obtaining a PhD on the subject was also interesting ... I didn't have any experience with inclusive research, although I did have ideas and expectations about it. I saw it as a nice challenge to take on, and an enriching experience. I expected to learn from my colleague what it is like to live and work with an intellectual disability. And that it would provide openings to make the research more accessible and allow people to participate in it'*. Mark was interested in DigiContact and wondered whether this form of support would suit him if he lived independently. Above all, Mark was looking for *'... a job that would give me more influence. The job was also all the more interesting because it was a paid job. [Mark was already doing certain tasks for the PCF, but these had been voluntary up until that point]. Plus, I am the kind of person who is always eager to learn, and I am interested in other people. The research project gave me the opportunity to meet other people. Working together intensively with someone on a new area of work also gave me a safe feeling'*.

##### 4.1.2. The Search for a Good Research Duo

Making the decision to set up and conduct inclusive research is one thing. We learned in this research project that everything stands or falls with the quality and sustained commitment of the research team. The research project we report here was suspended on two occasions after people quit the project. The first research duo (the predecessors of Miriam and Mark) quit at the same time because neither of them wanted to continue working as researchers. After Miriam started on the project, she worked briefly with another co-researcher before starting work together with Mark (and finishing it together). This collaboration ended after several months because the role of co-researcher did not match well with their talents and ambitions, and the level of support that was needed to enable their participation in research activities was beyond what the organisation and Miriam could provide. During this collaboration, there was no job coach involved, as was the case in the collaboration between Mark and Miriam (see also Sections 4.2.1 and 4.2.4).

This difficult start meant that in the search for replacements, other strategies were tried out in order to put together a research duo that could collaborate effectively together. For example, the initial approach for recruiting the co-researcher was to disseminate flyers with accessible information about the research project and the role of the co-researcher. The candidates who applied were interviewed and hired by staff from the PCF but not by the other researcher (Miriam). When the search for a co-researcher started again, a more focused approach was taken, and Miriam was involved in the interviews with candidates. The support person for the client councils at the PCF (someone with a good idea of the ambitions and talents of clients) had focused interviews with persons whom he thought would not only be suitable but would also be interested in the research project. With regard to suitability, specific attention was paid to verbal and social skills (with a view to conducting interviews) and the ability to travel independently (e.g., by public transport). Mark was seen as a highly suitable and motivated candidate. Following both a telephone

conversation and face-to-face contact between Mark and Miriam, they concluded that their expectations matched well. Moreover, both had a good feeling about these first contacts and could see themselves working together intensively for a longer period of time. *'It was immediately obvious to me that it was a good match'*, says Mark on the subject.

The first time they clicked turned out to be an important basis for the subsequent collaboration. According to Miriam: *'When we needed to search for something, or when things weren't going so well, we could always fall back on the experience of that first connection. For example, issues were discussed openly and we were able to look for solutions together in an open and pleasant way'*.

#### 4.2. Collaborating as a Complex Process

An organisation may decide to organise and facilitate inclusive research, and researchers may decide to participate in it, but this is no guarantee that the research will run smoothly. The second methodological theme addresses the difficulties we experienced in working together as a research duo.

##### 4.2.1. Time (and a Lot of Organising) as an Important Factor

As happens with many employees, Mark had to make arrangements with his former employer before he could join the research team. The fact that Mark, as a person with a disability, could not simply decide to change jobs is notable in this regard. He explains: *'After the job interview for the position of co-researcher, and the happy moment when I heard that I had been hired, I immediately started to find out whether it was administratively possible to take on the job . . . As someone with a disability, I have to deal with the UWV<sup>1</sup>. This is a good institution because it ensures that I can participate in the labour market. But at that point it was also holding me back from self-development. Even though I felt I no longer fitted in at my previous job, the UWV felt that my permanent job was more important because it offered me income security. Fortunately, Philadelphia identified this problem and enlisted the help of a job coach. Despite the mediation of the job coach, we could not get in contact with my then employer. In the end, Philadelphia started looking for additional projects for me within the organisation alongside the role of co-researcher; that way the job coach had a credible story and convinced the UWV that this new workplace was suitable for me. This all took four months. I remember these months as a period with a lot of uncertainty, disappointment and hope. In the meantime, Miriam and I were in touch every now and then. We also went out to dinner once. When we met up, we discussed everything that had to be arranged, but Miriam also talked about the state of play of the research. As such, we were both up-to-date with the situation'*. All this shows that finding people with disabilities to perform the role of co-researcher can be difficult, even if it is a paid job. The system gives priority to security of income rather than self-development and learning new skills. It was a tense period for Miriam as well, as conducting inclusive research with the co-researcher not being able to actively participate yet was not easy. Fortunately, her manager at the PCF took care of all the 'organising work' so that she could focus on the research work.

As we can see, this research project had a challenging start. Miriam was obliged to keep waiting for her co-researcher and had to manage the first sub-study and the data collection for the second sub-study on her own. Mark was on the sidelines and witnessed a few developments (including a series of interviews) that he would have preferred to have been involved in. Despite the fact that Mark was given a lot of time to familiarise himself with the subject of the research at the start, it is clear that analysing research data that one has not collected themselves is not the best and most pleasant way to join a project. Nevertheless, Mark says that he has good memories of his first weeks in the research project. He felt he could make a contribution for other people with disabilities and that the research was meaningful and not just for himself. Mark felt highly appreciated and was impressed by the fact that so many people were interested in the research (he participated in a working group and attended a conference): a new world appeared to be opening up.



#### 4.2.2. Getting to Know Each Other Really Well

The first weeks in which Miriam and Mark worked together were crucial in laying the groundwork for a good collaboration. They took the time to get to know each other well. Mark was introduced to the rest of the department. Moreover, his first day at work was rather special. Mark explains: *‘As we had had regular contact in the preliminary stage, the first working day was a very pleasant start to the whole experience. Moreover, the first day—a Saturday—was a conference day. This took place at a hotel in Amsterdam. Miriam had to give a presentation about DigiContact. I only had to go along and listen. But once there I was introduced to everyone as the co-researcher, and in a room full of researchers! Important contacts were made that day for the research project, and I was given a lot of information, but in bite-sized chunks. It was a special start for me with all the contacts and information. That week I was also given an article in English that Miriam wrote, to read’.*

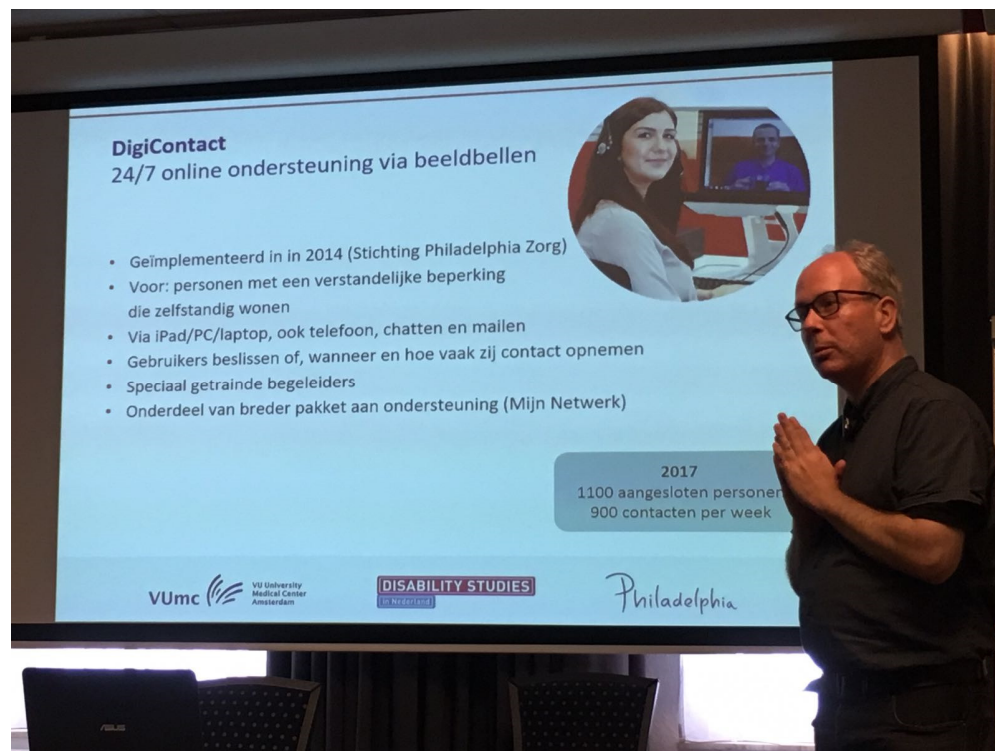
Besides this very intensive start (for Mark), Miriam and Mark learned that there is more to working together successfully. Miriam: *‘It was essential to take our time, have regular lunches in addition to the necessary functional talks, or catch up on things going on in our lives outside of work. These conversations were crucial for building a good working relationship. We got to know more about each other, we learned how we could work together, and each other’s habits, for example the fact that I like to have a quiet start to work in the morning, became clearer. That way, you can get on the same wavelength, and it is important to maintain a good working atmosphere’.* (Figure 1) Finding enough time to connect with each other outside of working on research activities together was sometimes challenging, for example, due to Miriam wanting to make pace in order to meet certain deadlines (related to her PhD planning) and Mark experiencing the pressure of working on several projects (besides this research project) at the same time.



**Figure 1.** Going for pizza (10 July 2018).

Conducting research for and within a large organisation such as Philadelphia also means that getting to know that organisation and being introduced to it and its broader research network are important. Mark explains: *‘Fortunately, I already knew a number of people in Philadelphia through my work in the client council. I attended a lot of meetings on the research project, and got to know many people from Miriam’s research network. After a few months,*

*I was also able to make a contribution in presentations about the research project. In the beginning, I mostly talked about my role as co-researcher; but after a while I could also give more and more information about the research itself' (Figure 2).*



**Figure 2.** Mark presenting (21 June 2018).

#### 4.2.3. The Need to Keep Reflecting

As Mark recounted: ‘We did a lot of research together in the first few weeks. That seems normal, because I had no experience with scientific research. But the fact was, I only worked on the research project for 8 h a week, while Miriam worked for 32 h a week. So we took the time to find out where I could be most useful. It was important in this regard to look not only at what needed to be done, but also at what our interests and talents were. That’s why it is so important to get to know each other. We decided not only to touch base each week regarding the practical aspects of the research project, but also to set aside time two or three times a year to discuss our collaboration in more detail. Conducting the research together was an important part of the project; so this was taken seriously. We also kept a logbook, this was also important for the research’.

In this research project, working together to a clear structure proved valuable. For example, Mark and Miriam worked together on a fixed day of the week as much as possible, and this day started with a meeting where there was an opportunity to catch up in general and to discuss the work. They always made clear agreements about who would take on which tasks. These agreements were put into an overview that was accessible to both researchers.

The flexibility that is sometimes required when conducting research was an additional challenge for Mark, as he was also working on other PCF projects. For example, the interviews could not always be planned on the fixed working day, and there were not always tasks for the full eight hours, or, conversely, there were too many tasks. Mark took up this challenge together with a job coach: this coach taught him how to make overviews of the activities he needed and wanted to do, plans were revised, and in his digital agenda, he learned to work with time blocks in different colours (each project a different colour).

#### 4.2.4. Roles, Allocation of Tasks, and Decision Making

Looking back on the collaboration, a number of things stand out with regard to roles, allocation of tasks, and decision making. For example, before starting the collaboration with Mark, Miriam had had a difficult experience working with a previous co-researcher, which stayed at the back of her mind and made her feel unsure about working with a co-researcher. It is clear that the PCF played a highly valuable role in this regard: the foundation created the conditions that facilitated both parties in their collaboration. For example, by hiring a job coach for Mark, Miriam could be a colleague for him and did not (also) need to take on the role of a support worker. By finding several projects for Mark, he could get started without being thrown in at the deep end.

Mark and Miriam allocated tasks in mutual consultation. As Mark had substantially less time available for the project than Miriam (8 versus 32 h per week), it was not possible for him to be involved in all activities in the same way. In this respect, a distinction was made between activities that they performed either together or independently from each other and activities in which Mark adopted the role of advisor. The starting point for this distinction was their personal skills and interests, as well as the expectations regarding in which activities Mark's participation and input would add the most value to the project. Miriam explains: *'Mark discovered he really liked to work on data analysis, and we both felt that his involvement led to broader and richer insights. This made us decide that Mark would spend a relatively large part of his time on analysing, and less on, for example, writing texts. Making such decisions was sometimes difficult, as in some situations Mark wanted to be involved in something, I remember specifically one time when we had to prepare for a presentation, but we decided that he would not be involved because there wasn't enough time.'* When several sub-studies were performed at the same time, it was easier for Mark to first finish his work on one sub-study before moving on to the next.

During the research project, Mark never took 'the lead' over a sub-study. Questions such as whether this would have produced more results, or given more scope for experimenting with different research methods, therefore remain unanswered.

#### 4.2.5. Collaboration during the COVID-19 Pandemic

This research project was hit full-on by the COVID-19 pandemic. Mark and Miriam were about to start with a new round of data analysis, and they had to find a way to continue this activity remotely. They describe below how working remotely disrupted their working rhythm, appointments, and rituals. Mark: *'During the final phase of our research, the Netherlands was struck by corona. This meant that we had to work from home; I felt very limited in the options available. We drifted apart a little bit because we had less contact with each other, and we weren't able to motivate each other as much. We did call every week and we were in contact via WhatsApp, but we sometimes lost the focus of our research'*. Miriam: *'In the first chaotic phase of corona, we lost sight of each other for a while. We learned to find a new digital rhythm. We were lucky that many of the interviews were already completed and we already had the research material. We called each other once a week to clarify and divide up the work. It was also an opportunity to catch up. The analyses had to be carried out remotely. Fortunately, the lockdown didn't stay very strict for too long, and we were eventually able to sit together again in person. But after a few months, we had to switch back to digital as the measures were tightened again. We went back to videoconferences, and trying to find each other with regular phone times. And in the meantime, we had to continue working on our own tasks'*. Having to work together remotely guided the researchers towards analysing data more independently from each other. Before COVID-19, data analysis was largely performed together, in the same room, using post-it papers or other materials to record codes and cluster them (see also Section 4.3.2). Now the researchers had to change tactics. They read and coded the transcripts separately and independently (and without further support) from each other. Mark and Miriam were both comfortable with this, as they felt they had built up sufficient experience with coding in previous studies. They printed transcripts, highlighted pieces of texts, and wrote their codes in the margins. The clustering of codes in sub-themes and themes proved to be more

difficult to do together remotely, as they missed the (visual) grouping processes they had used before. Fortunately, this process could be picked up again after a few months when it became possible to (occasionally) work together in the same room.

#### 4.3. Conducting Research Together

Conducting research involves certain activities. This third methodological theme addresses our experiences of conducting research tasks together. Two specific tasks that took an important position in several phases of the research project were chosen: interviewing and analysing.

##### 4.3.1. Interviewing

For the research project, two rounds of interviews were completed during the collaboration between Miriam and Mark. In Mark's own words: *'I was going to do qualitative research, this is a term I didn't really grasp - especially at the beginning. Here, conducting research together meant first preparing questions together. These questions had to fit the research topics we wanted to know a lot about. We learned to first draw up a research question together and then turn it into research, so that we got answers to these questions. I always tried to prepare our meetings for this. I wrote down ideas to ask questions about between our meetings, so I was prepared for the next work meeting with Miriam. That way, my share in the topic list became increasingly clear. Besides consultation sessions, we also shared files within Philadelphia; we shared and emailed with each other regularly and came up with the best possible list of questions. We also drew up a letter of invitations together; I also called the potential participants to arrange appointments. At the start, I had no personal experience with interviewing, so we went to do a trial interview with someone I knew well. This data was not used for the research project. We interviewed both supervisors and clients who used DigiContact. We usually had several interviews with these clients. In between the interviews, we were able to sit together and discuss. This allowed me to grow in my role as interviewer. In the beginning, Miriam asked most of the questions and I supplemented her from time to time, but by the end the roles were reversed.'*

##### 4.3.2. Analysing

As regards the analysis of the interview data, Miriam and Mark worked closely together to find the most convenient way to make everyone's share as rich as possible. Mark became a highly active researcher during the analysis (Figures 3 and 4). As he says himself: *'The analysing often started during the interview itself. We noted our observations individually during the interview, and used them as the first step in the analysis. There was an external person who would type up all the interviews for us verbatim. If these typed texts came back, they had to be anonymised; that was quite a job, a task we could divide up. Bullet-point summaries of the interviews were also made, Miriam usually did this. The people we interviewed were subsequently approached to check whether we had correctly understood them; this is referred to as a member check. Miriam went back to the professionals and I handled the clients. In-depth analysis is something that takes a lot of time. I learned that the different perspectives sometimes contrasted with each other, and I knew that I could make a difference with my perspective as an expert by experience compared to the insights of the professional researcher. We also focused a lot on the different research questions, which required going through the research material again several times. Sometimes I preferred listening to audio recordings of the interviews rather than reading the transcripts. So that's what I did. We used different methods to perform the analysis. Sometimes we wrote our findings on post-its. We also sometimes highlighted sections of interviews when we were taking excerpts from them. Whenever I learned new things in other projects, I would present them to Miriam and we would see if they could be used in our collaborative research. For example, visual analysis methods were also used: things were then grouped and pasted together like a collage. At other times, we would perform the analysis with several people on the research team and look at the data from the broader research team.'*





**Figure 3.** An analysis session with the entire research team (8 March 2018).



**Figure 4.** An analysis session of Mark and Miriam (3 June 2019).

## 5. Discussion

At the start of this article, we explained that we would reflect on three topics, based on our personal experiences: (1) how best to organise inclusive research, (2) the possible benefits of the collaboration for the researchers involved (Mark and Miriam), and (3) the possible impact of the collaboration on the quality of the research. In this discussion, we first look at what we can infer about these topics from the research material presented. We then briefly compare our results with the recent research literature on inclusive research.

Regarding our experiences on how to organise inclusive research, it is clear that this was difficult during the start of this research project. For example, the first research duo quit after a year, the co-researcher of the second duo quit after a few months, and after that, it took a long time before Mark and Miriam could really start working together. Our experiences led to several insights. First, we experienced that not everyone is motivated, ready, and able to become a member of a team doing inclusive research. It is therefore important to recruit researchers and co-researchers who are suitable partners in inclusive research. It also underlines the importance for organisations and research institutes that want to engage in inclusive research to provide education and training on inclusive research methodologies (García Iriarte et al. 2021) for researchers (both academic researchers and co-researchers). Second, we learned that hiring people with disabilities as paid researchers can come up against various administrative hurdles. A research job is often temporary and not always stable over longer periods of time. Many people with disabilities are caught in the ‘golden safety net’ of social security: they have a good monthly income; however, this can be at the expense of further self-development and taking on new challenges. Third, we learned that the party who commissions the research (in this project, a large service organisation) can play an essential role in inclusive research, a role that does not have to result in interference with the body of the research. In this project, the PCF really ‘stuck its neck out’ for the final duo. For example, Mark was offered more than one project to provide him with a stable income. In addition, the unavoidably slow pace of inclusive research was well understood: more time was allocated to the research project. In this project, introducing a job coach proved to be a golden asset. This job coach could work in a supportive manner in the function of what Morgan et al. (2014) named transparency. The job coach could also, especially during the first phases of the research, help to inform and clarify certain aspects. This intervention allowed both researchers to really work as colleagues, and thus this aspect of power imbalance could be mitigated.

As regards the benefits to both researchers of conducting research together, the research data show benefits to the co-researcher: Mark got a job that allowed him to have a more direct influence on the quality of life of people with disabilities. A (research) world opened up to him in which he gained respect, and he states that this had a great influence on his self-confidence and his ability to acquire new skills. He learned to listen carefully to people, ask the right questions, and see that the perspective of the experienced expert could really contribute something to the research. The academic researcher also personally benefitted from the opportunities that were created for Mark to have a voice, to exert control, and to make decisions, as this made sure that this project was not ‘just another’ PhD that only reflected the perspective of non-disabled experts or researchers (Björnsdóttir and Svendsdóttir 2008; Dorozenko et al. 2016). The academic researcher also learned from their long-term collaboration about ways in which they could best work together and conduct research together. In this regard, it was especially difficult situations from which she could learn, such as a previous collaboration with a different researcher with intellectual disabilities in which the roles of being a supporter and being a colleague became too intertwined.

Finally, as regards the quality of the research, we would like to emphasise in particular the fact that Mark, as a co-researcher, seized opportunities through his involvement in various projects to take methods from one research project to the next. For example, methods for visually grouping data were contributed in a very creative way and provided additional depth. In this regard, we go further than Björnsdóttir and Svendsdóttir (2008) who

state that well-executed inclusive research is of the same value as non-inclusive research. In our research project, the inclusive approach led to a higher value—something that can be deduced, for example, from the very high number of articles that were eventually published within this PhD. In addition, the slow pace at which the research advanced also ensured that all research steps were prepared and experienced more intensively by both researchers (see, for example, the way Mark describes how research questions and interview questions were meticulously coordinated (Section 4.3.1)).

In this final section, we compare our research findings with some other sources on inclusive research. Several authors, including Nind (2011), Dorozenko et al. (2016), and Tilley et al. (2021), call for continued attention to and a critical reflection on power processes in inclusive research. In our project, Miriam was determined (after a previous rather unsuccessful collaboration with another co-researcher) not to take on a ‘carer role’ vis-à-vis her new colleague. Mark had to be a genuine colleague. Hiring a job coach for Mark clearly made a difference in this regard, as already discussed in the second paragraph of this discussion. At the same time, the findings also show that when a co-researcher has significantly less time available for the research project than the academic researcher, this has the potential to contribute to an imbalance in power. Besides this search for collegial roles, it is also noteworthy that Mark was able to learn a great deal during the various sub-studies regarding conducting interviews and analysing data. This contributed to feeling more self-confident about his research skills. Whereas in some projects, co-researchers are only or primarily involved in data collection, in this research project, the co-researcher was involved in all phases of research, as well as data analysis. Mark joined the project at a point when the data of a sub-study needed to be analysed. From the outset, he clearly contributed an experience-based perspective, but this came into a sharper focus when he was able to try out a number of methods (e.g., highlighting parts of the texts he was given). Still further, he was able to collaborate with several people from the research team for analysis (at these moments, the 1-on-1 with Miriam was opened up) and contributed his own analysis methods (a visual grouping method). It is clear that advancing insight, time, and growing research competencies all contributed to an increasingly equal power balance between the researchers. This brings us to the three approaches to inclusive research as outlined by Bigby et al. (2014a) and presented in our introduction. We believe we can say that, despite all the barriers, this research can for the most part be situated in the collaborative group approach (i.e., people with intellectual disabilities work in an equal partnership with academic researchers) (Bigby et al. 2014b). Mark was given the space to realise his dream of having a job that would allow him to influence the quality of life of people with a disability. He took full advantage of the opportunity to bring the perspective of the experienced expert into the research project and to influence the progress of the research. In our opinion, there were significant attempts in this research project to take seriously the (power) balance between researchers with and without disabilities.

As a final topic of the discussion of our findings, we return to Walmsley et al.’s (2018) view of inclusive research. In studying the ‘second generation’ of inclusive research projects, they advocated for a special consideration for the difference that can be made by co-researchers with disabilities and for the possible impact they (also) have on the quality of life of people with disabilities. In our research project, Mark joined the team with the clear intention of making a difference for people with disabilities. We believe that, partly due to the way in which he took responsibility within the project, the DigiContact support service (being the object of the research project) was put in the picture both from the perspective of experience experts and as a realistic support option. Regarding the latter, it was shown that although DigiContact is not a miracle cure that can replace all onsite support and works equally well for everyone, it does offer people an additional support alternative that can contribute to their possibilities to participate healthily in society.

When looking back at our reflection process, we feel it would have been valuable to include more people who were also involved in or had an impact on our collaboration. For us, it was an important insight that ‘others’ played an important role in our collaboration.

This was especially the case for the job coach who supported the co-researcher regarding various work-related issues and the organisation that commissioned the research project and created the conditions under which our collaboration was shaped. For this reason, it would have been interesting to involve these parties and also include their experiences and points of view. For future reflections on inclusive research processes and experiences, it is advisable to think (in advance) about which actors play a role in (or have an impact on) the collaboration and to include their voice in reflection processes as well.

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**Data Availability Statement:** The data presented in this study (transcripts) are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

**Conflicts of Interest:** The authors declare no conflict of interest. The authors also declare that the funder had no role in study design, the collection, analysis and interpretation of data, the writing of the report or the decision to submit the paper for publication.

## Note

- <sup>1</sup> The 'Employee Insurance Agency' (Uitvoeringsinstituut Werknemers Verzekeringen) is a Dutch government body responsible for implementing employee benefit schemes.

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# Reflections on the Implementation of an Ongoing Inclusive Research Project

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**Abstract:** This reflective piece is co-authored by four members of an inclusive research team, who have been working on a project that aims to create an online resource with a video curriculum vitae of individuals with intellectual disability to showcase their achievements and skills. Taking the view that conducting research inclusively is a dynamic and ongoing process, we discuss our experiences in implementing the project and the steps we took to ensure that the process was as inclusive as possible. We first present an overview of the aims of the project and what we have achieved so far. We then provide our individual perspectives on the experience of being involved in the project so far and how inclusive it has been. Together, we then reflect on the main outcomes of the project so far, on the factors that affected how we implemented it, and on how we plan to work towards the last phase of the project.

**Keywords:** inclusive research; employment; COVID-19; intellectual disability

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## 1. About Our Project

We are a team of individuals with and without intellectual disability. We are working on a project called *ĊaVetta għall-Futur: Creating video curriculum vitae with persons with intellectual disability*. The first part of the title means “key to the future” in Maltese. The idea for this project was developed from another inclusive research project on overprotection that was carried out by Isabel and Anne-Marie (Callus et al. 2019). From this research, we could see that, although there are many people with intellectual disability in Malta who are overprotected, there are also many individuals who have the support they need to develop and use their abilities. Therefore, the aim of this project is to show what many people with intellectual disability are capable of achieving when the people around them believe in them and support them.

The focus of the project is on employment. The main reason for this, as explained by Anne-Marie, was to help us obtain funding for the project. However, focusing on employment meant that we could not present the lives of people with intellectual disability who do not work and are not looking for work. On the other hand, employment is an important aspect of adult life and, therefore, very important for people with intellectual disability too (Autism Society 2018; Garrels and Sigstad 2021).

By creating these video CVs, we could show how people with intellectual disability succeed thanks to the support of parents and other family members and those who work with various service-providers, employers and colleagues. People with intellectual disability also succeed thanks to their own efforts and abilities, as shown in the videos. Creating CVs through a video also means that we used a medium that is accessible for people with intellectual disability and which can be viewed many times (Goodwin et al. 2015). The videos are available for free viewing on YouTube.

Following ethical approval from the University of Malta, we issued a call for applications and held interviews with those who applied. After lengthy discussions, we chose the ten individuals who we agreed would represent the widest variety of experiences of people with intellectual disability in the employment sector.

So far, we have produced ten video CVs of people with intellectual disability who work or are looking for work. Those who work do so in different places, including a local council, a hotel, a factory, in residential aged care and in a disability organisation. These video CVs also show other abilities of the ten individuals with intellectual disability, especially in sport, handicrafts and the performing arts. We have included some stills from four of the videos.

In the second part of the project, we created a video that provides disability equality training (DET) (Carr et al. 2012) for employers regarding people with intellectual disabilities. As persons with intellectual disability, Isabel and Cristina also provided their reflections as experts by experience (Care Quality Commission 2021). We also created instructions on how to create a video CV. In the final part, we plan to produce more video CVs to show a wider range of abilities and achievements of people with intellectual disability in Malta. After the end of the project, we plan to analyse the content of the video CVs in an in-depth manner and discuss this content together, along with the possible impacts of the project.

These videos show the capabilities and achievements of people with intellectual disability and how much they can succeed in an environment in which they are provided with the support that they need. The implementation of the project itself is also a testimony to this dynamic and ongoing process, since the four members of the team contributed with different skills and areas of expertise. We also supported each other where needed. We made sure that all members of the research team were actively involved in each phase of the project and that any written material was produced in an easy-to-read format. We pooled our ideas about how to develop the project idea, obtain funding and implement the project, and, as García Iriarte et al. (2021) describe, we provided each other with different “forms of material, social and emotional support” (p. 16).

In the next sections, each of us reflects on our experience in implementing this project.

## 2. Isabel

I work as an office support worker at the Commission for the Rights of Persons with Disabilities (CRPD).

I think that this project is very important because, by making these video CVs, we showed that people with intellectual disabilities can work with different people: those with a disability and those without. This project also means a lot to me because the people with intellectual disability who took part do many different things. Many of them do not mention work only, they also mention drama, music, pottery, dance, sport, handicrafts and going out with their friends. With these videos, we met a lot of people with intellectual disability who were not overprotected and had a job. But when we carried out research on overprotection, as mentioned above, we met people who were overprotected and did not work. I think that this shows that when a person is not overprotected, they can do a lot of things.

When Anne-Marie and I wanted to do this project, we had to find funding. We tried to get funding from private companies but it was difficult. Then, with COVID-19, it became even more difficult to do so. I suggested to Anne-Marie to apply for funds from a programme called PEKTUR, which is run by the CRPD where I work. This was a very good idea because we got funds for ten video CVs in 2020 and then, in 2021, we had some more funds to do the DET video. I am happy that I made this suggestion because it meant that we could work on our project.

The fact that we worked in a team of four researchers was very helpful. We had different ideas that we could use and there were more people to do the work. I had already worked with Anne-Marie on the overprotection project and we both felt that, since this new project involved much more work, it would be better to have a bigger team. We therefore

invited Cristina to join us so that there were two co-researchers on the team. This way we could share our experiences together. Once we obtained funding from CRPD, Sandra also joined us and we had someone who specialises in media on the team as well.

There were some parts of the project that I enjoyed and others that I didn't. After we received the applications from those who were interested in taking part, we held interviews with them. I really enjoyed holding these interviews with the applicants. There were the four of us doing these interviews. We did many of them online because of the pandemic, but I still enjoyed them and also our meetings. We held some of our meetings in person—for example to choose the ten participants—and other meetings online, for example, to discuss with the ten chosen participants about what to include in their video CVs.

What I didn't like was the fact that Cristina and I could not go to most of the filming sessions. This was because of the COVID-19 restrictions, especially because most of the filming had to be done at the place of work of the participants. The employers could only accept a few people to attend; those doing the filming and Sandra or Anne-Marie to supervise. There was an opportunity for Cristina and I to attend a long filming session in which different persons were being recorded speaking. I really enjoyed this. If we could have done this more often, the project would have been more inclusive.

It was very interesting to take part in the DET video. During the filming, I met new people. I was filmed at the office where I work. It was great to have support; for example, the script I had written was printed in a large format so that I could read it during filming. It was also a great experience for me and Cristina to speak in this video because, in this way, we were able to help the people who watch the video learn from our experiences and we were able to share our thoughts about the importance of employment for people with intellectual disability. I hope that we manage to do more interesting video CVs and maybe even make one for myself.

### 3. Sandra

As the Communications Manager for the Commission for the Rights of Persons with Disability (CRPD), my role on the *Čavetta għall-Futur* team was to share my technical skills on how to produce videos, as well as to represent the Commission, which part-funded the project. On a personal level, I am also the mother of a young child with Down Syndrome, so the project was doubly meaningful to me because any strides made in the world of intellectual disability, employment and representation have direct and personal implications for my daughter's future.

The project set out to be as inclusive as possible by sending out an open call to all people with intellectual disability on the Commission's database, inviting them to apply. We received 20 applications and interviewed all the applicants. At this point, the pandemic was already presenting challenges, as people living in institutions were not allowed to leave their communities; interviews with these applicants were therefore carried out online.

The four members of the team discussed the applications and we selected ten which seemed to be the most representative across as broad a range as possible, factoring in age, gender, residence, disability, ethnicity, employment status, and skill level.

Already at this point, it became clear to me that the project, in its conception, was nothing short of extraordinary. We had embarked to create video CVs for persons whom society would have no trouble writing off in a few moments, especially in an employment context, where value is generally determined by a narrow definition of productivity. We therefore re-interviewed the ten selected applicants with the aim of uncovering layers of skills and aptitudes of each one. In this way, we came up with a script for each person that included all the brushstrokes; not just traditional employment skills, but also soft skills such as being a team player, creativity, dedication, punctuality, kind-heartedness, discipline and perseverance in reaching a goal.

The final result is, I think, moving and extremely eye-opening at once. Not only do most of the people in these videos have jobs they love and are good at, but they are also loved and valued by their colleagues for who they are and what they bring.

In retrospect, the main challenges to the process were brought about by the pandemic. For instance, filming had to be restricted to the presence of one team member. Team meetings also had to be moved online, with the corresponding loss in physical participation and teamwork.

There were other challenges intrinsic to the nature of the project too. The project includes participants who are non-verbal, so we had to be creative with their scripts, making sure that their skills and qualities were still articulated by their colleagues and tutors. Rather than having a centred narrative articulated by a protagonist, their stories were related mainly by the voices of those around them, which turned out to be equally moving and effective.

Taken together, however, the videos are a set of voices of people with intellectual disability and those who support them, which not only show the richness of the qualities and skill sets these persons bring but are also profoundly human. They are a reminder that, even at the workplace, where dealings are often done solely in terms of productivity, given the right setting and support, people with an intellectual disability truly have a lot to offer, not just in the work they do but also in the qualities they bring, which can change the dynamic of a workplace to one that is ultimately far more inclusive for all concerned.

#### 4. Anne-Marie

I am a lecturer in disability studies and my main research interest is the empowerment of people with intellectual disability, including through inclusive research. This project is different from other research projects that I have been involved in so far. In these projects, my focus and that of various co-researchers has mostly been on the difficulties encountered by people with intellectual disability. With this project, we could focus only on the positive stories of different people with intellectual disability. It is important to show positive aspects of the lives of persons with intellectual disability. Another positive experience came from working in a team of four, with each of us having different types of expertise and different perspectives.

Getting funding was not easy. We originally wanted to have a series of short videos of the life stories of different persons with intellectual disability in Malta. However, it was difficult to find funding for this idea. We were advised that a focus on employment would be easier to fund. The idea of producing video CVs made the project more attractive to funders, even if we did not manage to get all the money we hoped to get all at once. We could only choose participants who were in employment or were looking for work. This meant not being able to choose people who were very young, as well as older people with intellectual disability, and those who—for different reasons—were not involved in employment. We did not leave them out because they do not have valuable lives. We are aware that focusing only on individuals with intellectual disability who have noteworthy achievements can feed into the ableist narrative that disabled people's lives are only worth living when they have achieved success (Campbell 2008). However, the project did become an excellent opportunity to show the employment experiences of the individuals whose video CVs were created. Many of them also have other skills, which we included in the videos because they are important as well.

Working inclusively was not easy because of the COVID-19 pandemic. One challenge was to do interviews and meetings online as much as possible. Online meetings between us four were not a problem because we all have access to the internet and learnt how to use online meeting platforms. However, some of the persons with intellectual disability who applied to take part did not have internet access or they did not have anyone who could help them use the internet. Therefore, we held some interviews in person.

Another challenge came with the filming of the video CVs. There was a lockdown in Malta and work on this part of the project was put on hold. Once people were getting vaccinated, we could start again. However, there were a lot of restrictions and we could not all attend the filming sessions, especially when we went to the participants' workplaces.

Fortunately, we had one long filming session at the University of Malta where all the research team could attend.

The delay in starting the filming also meant that we had a very short time in which to finish the first phase of the project. If we had delayed any further, we would have lost the funding. As Embregts et al. (2018) state, doing research inclusively needs a lot of time and we had to take some shortcuts. Most of the editing was done by Sandra and myself. However, we all watched the final version together to make sure that everyone was happy with the video CVs. For the DET video and the information on how to make a video CV, we had more time to work inclusively. In line with the principles of inclusive research set out by Johnson and Walmsley (2003), we developed the content of the DET video and the information on how to make a video CV together. With regard to the former, we agreed together on the speakers to be included in the video. Additionally, Isabel and Cristina participated in the video itself. As for the latter, we built the information together and made sure that it was easy-to-read.

We now have funds for the last part of the project and we need to make sure that we work more inclusively. I think it will also be useful to keep a diary in which the four of us reflect on how we are feeling about the way we are working on the project. That way, we will be able to reflect further on the inclusive research process once the project is ready, and use these reflections in the article that we plan to write together, once the project is ready.

## 5. Cristina

I work in the Head's office in a school. I help the secretaries of the primary and the secondary schools. Before COVID-19, I worked in the reception, sorted out books in the library and did office work like shredding, photocopying and laminating. Now I work in the office only and am doing new work as well, such as sorting students' records in alphabetical order and also doing work on the computer.

When Anne-Marie and Isabel asked me to join them to work on this project, I did not have any experience in research. I learnt a lot from the project. I learnt that doing research is a lot of work but it is worth it. I learnt a lot about the lives of other people with intellectual disability and I learnt how to interact with different types of people. I also learnt how, by doing research, we can increase awareness of the rights of individuals with intellectual disability.

After we chose the participants, filming had to be done. We could not all go to the filming because of COVID-19 restrictions. However, Isabel and I attended a filming session where different participants came to talk about their life and the people who knew them talked about them. We really enjoyed watching the filming being done.

Isabel and I did not apply to have a video CV for ourselves because we are part of the research team and coordinating the project. We wanted to give other persons with intellectual disability the chance to have their video CV made. However, when we saw the filming being done, we really wanted to have our own video CV. It was very interesting and I would like to have my video CV made. I would like to show other people what I am good at and to show them how capable persons with disabilities are. That way, we can educate other people.

When the videos were ready, we met to see them. We really enjoyed watching the video CVs. We could see that people with intellectual disability are capable of doing different types of work. There are those who work in factories or in offices, those who do cleaning work, kitchen helpers and also other types of work. There are also many people with intellectual disability who have other skills. There are people who are actors, dancers, play a musical instrument or handicraft. These activities help them to continue developing their abilities. I spoke about these things in a video we did to provide training for employers, so that they know that they can employ people with intellectual disability.

There is now more funding to do more video CVs and I will be able to apply to have my own CV made. I hope I get chosen. It will be very exciting! I hope that with the new video CVs, we will be able to show even more abilities of individuals with intellectual disabilities, because we are all capable of doing different things. For example, I paint

pictures and had an exhibition in my hometown with my paintings. There are other things I used to do before COVID-19. The same thing happened to other people with intellectual disability: they had to stop some activities because of COVID-19. I hope that with the new video CVs we can still show the different types of work and activities that we are capable of doing.

## 6. Conclusions

These videos can be used by scholars and students conducting research about individuals with intellectual disability. They can also be used for teaching and training purposes for employers and colleagues of people with intellectual disability, as well as professionals who work with the latter. The videos can also be a useful tool to make parents and other caregivers aware of what many individuals with intellectual disability can achieve when they are given the right opportunities, and support and can also be a source of empowerment for people with intellectual disability.

Reflecting on the way we carried out the first two parts of the project has been very helpful for us to identify the strengths of our team and the aspects of our work on the project that need improving. These reflections can also be helpful for other inclusive research teams and the main conclusions are presented below.

The importance of having the right opportunities and support was something that we experienced directly as an inclusive research team. Through working together, we could see how valuable it is to appreciate the experiences and perspectives of different people. We also saw how providing each other with support made our team stronger. The fact that we get on well with each other and enjoy working with each other was also a very positive factor.

The changes that we had to make show how conducting inclusive research has to adapt to the realities of the world we live in. The most significant changes were the decision to focus on employment related activities so as to obtain funding, and the adaptations to how we carried out the project due to the COVID-19 pandemic. Being flexible in carrying out inclusive research is important, but it is vital not to make too many compromises, otherwise it is easy to lose sight of the original intentions of the project, or to end up not working inclusively at all.

We are really looking forward to the next part of our research. We plan to keep a record of our work and what we think about how we are doing the work. That way, we can find ways of being more inclusive. Moreover, once the project is finished, we can reflect more in-depth on the inclusive research process. We also want to work on making sure that these video CVs are watched by as many people as possible, so that the project achieves its aims.

See CàVetta għall-Futur (2020) for the link to the videos from this project.

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## Case Report

# Being an Inclusive Researcher in a National Consultation Exercise—A Case Study

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**Abstract:** This paper presents a case study of the Inclusive Research Network (IRN), an inclusive research group founded by the Centre for Disability Studies, contributing to a National Disability Research Agenda (NDRA) setting project. IRN members with ID carried out their own consultations with disability stakeholders. This paper sets out the experiences of the IRN members in facilitating focus groups as part of phase 2 of the NDRA project. As this project took place during the COVID-19 pandemic and state lockdowns, this paper also provides a reflection on new ways of carrying out research and provides an insight into the process for other groups seeking to engage in inclusive research of this nature in a challenging and changing environment. IRN members showed great interest in being involved in the project, and their motivations aligned with the project's objectives. Facilitating the focus groups on Zoom took some preparation and posed accessibility challenges but enabled a more diverse group of people to attend. IRN members with ID improved their online facilitation skills and confidence but concluded that they preferred working face to face. IRN members overcame the challenges presented by online focus groups, and their involvement added value to the NDRA project. Researchers are encouraged to continue practicing inclusive research in times of remote working and virtual interaction and to share their experiences for mutual learning.

**Keywords:** inclusive research; intellectual disability; disability studies; qualitative research; COVID-19; lived experience

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**Accessible abstract:** Doing research about people with intellectual disability together with people with intellectual disability is called inclusive research. It is important to do inclusive research, but sometimes, it is difficult to do. It is important that researchers who do inclusive research write about how they did it and explain how they solved problems so other people can learn from them. In this paper, we describe how a group of researchers with intellectual disability reflected on interviews that they did with a group of people as part of a research project. They did this reflection by thinking and talking about the interviews to find out what went well and what did not during the research process. The researchers found that COVID-19 made it harder to do research. The focus groups had to be done online, and this made it harder. Even though there were difficulties, the researchers were good at learning new ways of doing research. Reflecting on this process gave us some new information about how to do inclusive research.

## 1. Introduction

Inclusive research has become increasingly recognised as a fundamental part of best practice in conducting research with people with intellectual disability and is a core part of intellectual disability research. Inclusive research was developed out of the emancipatory and participatory paradigms of disability research. These emphasise the rights that people with disability have to be involved in and drive the research about the issues that affect them. They also seek to empower and protect people from marginalised communities

(St John et al. 2018; Stone and Priestley 1996; Walmsley and Johnson 2003). While there is an increasing body of literature around the conceptual underpinnings of inclusive research (Bigby et al. 2014a), there is often little practical information on how to conduct this kind of research in collaboration with co-researchers.

Inclusive research with people with disability has been a part of the disability studies discourse for almost three decades. Walmsley (2001) coined the term ‘inclusive research’ to denote research involving people with intellectual disability as ‘more than just subjects or respondents’, and it is recognised as best practice to ensure that people with disability are included in research (Bigby et al. 2014a; García Iriarte et al. 2014, 2021; O’Brien et al. 2014; Walmsley 2001; Walmsley et al. 2018). Inclusive research focusing on the lived experience of people with disability can be used to empower and recognise the contributions of people with intellectual disability (Bigby et al. 2014b; Walmsley et al. 2018). It can also be used as a powerful tool for advocacy and to enact social change (Johnson et al. 2014).

The Inclusive Research Network (IRN) is a research group run by the Centre for Disability Studies (CDS), an affiliate research centre of the University of Sydney, Australia. It includes people with and without intellectual disability who develop and work on their own research and participate in other research projects. The group has been active since 2009 and has been involved in a number of research projects over the last 12 years. The members of the group have extensive experience as researchers, and the group has presented the results of their research at national and international conferences and published multiple peer-reviewed articles (Adrian et al. 2013; Riches et al. 2017, 2020). The IRN takes the form of a collaborative working group as described by Bigby et al. (2014b). The group has shared purpose between the academics and co-researchers, and control of the group is dispersed among group members (Bigby et al. 2014b). The group aims to develop new knowledge to improve advocacy and generate social change.

The National Disability Research Agenda (NDRA) was a project funded by the Commonwealth Government of Australia through the National Disability Research Partnership and co-led by the University of Sydney Centre for Disability, Research and Policy and CDS. The aim of the project was to create an agenda that would provide a clear vision to disability research and is based on the knowledge of lived experience. There were three phases to the project: Phase one involved a research mapping exercise to identify existing disability research, research gaps and priorities. Phase two comprised a national survey and consultations with stakeholders carried out by disabled people’s organisations, advocacy organisations and project consortium members. Phase two aimed to determine these stakeholders’ priorities for disability research. Phase three constituted the synthesis of the findings from previous phases, the refinement of prioritisation and the proposal of areas of research to inform a research agenda (Smith-Merry et al. 2022). Inclusive research is an embedded principle in the Australian disability research agenda, and as such, consultations led by and involving people with disabilities, including people with intellectual disability, were supported.

This paper sets out the experiences of the IRN members in participating in and facilitating focus groups as part of phase 2 of the National Disability Research Agenda project. As this project took place during the COVID-19 pandemic and state lockdowns, this paper also provides a reflection on new ways of carrying out research and provides an insight into the process for other groups seeking to engage in inclusive research of this nature in a challenging and changing environment.

## 2. Materials and Methods

The IRN group supported the NDRA in two different ways. Firstly, in April 2021, five IRN members participated in a consultation, facilitated by a CDS research team staff member, to share their own views on disability research priorities. Secondly, in July and August 2021, the IRN carried out their own consultations with disability stakeholders in the form of three focus groups. Prior to that, the IRN met to discuss who IRN members with intellectual disability thought should be invited to the focus groups. Responses included

other people with disability, family members, professionals and politicians. Another meeting was arranged to revise the focus group questions that had been prepared by the NDRA project team in consultation with disability organisations (Smith-Merry et al. 2022). Questions were revised to ensure that they were worded in an accessible way based on the perspective and expertise of the IRN members. Before each focus group session, a short meeting took place to agree who would ask each question.

Focus group participants were recruited via the CDS mailing list and received the National Disability Research Agenda participant information sheet and consent form. Ethical approval for the consultations was received by the University of Sydney.

### *2.1. NDRA Consultations*

In total, 18 people, including people with disability, family members, carers and service providers participated in the focus groups which were held via Zoom. Each session was facilitated by 4–5 IRN members with intellectual disability and the IRN facilitators (the first and second author of this paper) without intellectual disability. Facilitators without intellectual disability welcomed participants and facilitated introduction rounds of the sessions. Then, IRN members with intellectual disability and IRN facilitators without intellectual disability took turns in asking participants questions from the focus group guide. The ‘share screen’ function on Zoom was used during the sessions to share the focus group guide. This way, each IRN member could read aloud the questions they had chosen to ask participants.

### *2.2. Reflection Process*

The findings that are presented in this paper are the result of a reflection process about the NDRA consultations undergone by IRN members with intellectual disability and IRN facilitators without intellectual disability. The reflection process took place during the group’s monthly meetings between September and November 2021. The reflection was integrated into the usual meeting agenda and took approximately 30 min in each meeting. At each meeting, approximately 3–5 members were present. The first reflection step was to ensure that the IRN members would be interested in discussing and writing about their experiences. Once that was confirmed, the group agreed questions that each person would reflect on and answer as a way to share the learning from the project experience. This was done by explaining the concept of reflection to the group and then asking members to come up with questions the group could ask themselves to structurally think about and tell other people about the consultation process. The group decided to reflect on their motivations for joining the project as participants and as facilitators, how the focus groups were held and strengths and areas of improvement of the process. Next, the IRN came together again to go through these questions, reflect on the focus group sessions and answer the questions while the IRN facilitators took notes. Afterwards, the IRN facilitators without intellectual disability met to reflect on these questions and on the topics IRN members with intellectual disability had highlighted.

### *2.3. Process of Writing This Paper*

It was the aim of this paper to include IRN members with intellectual disability in the writing process to ensure involvement in the research process across all stages. However, the aforementioned lockdowns in New South Wales prevented the group from meeting face to face and changed the way we work. Previously, IRN members worked on papers using practical and visual approaches, for example, bus stops (participants rotate between several stations and reflect on questions or provide content to a certain topic while using comments from the previous groups as prompts), working with flip charts and coloured markers to highlight and interlink concepts. Many of these methods did not translate to Zoom or required the use of several additional platforms that would have made participation more challenging and potentially excluded some members. Furthermore, keeping the group focused and engaged was hampered by the online environment. As a response, we decided

to decrease the meeting duration and hold some short, additional meetings as needed. Therefore, fully co-authoring this paper was not possible under the given circumstances. Nevertheless, IRN members with intellectual disability provided reflection which was written up together as a group and represents one part of the paper. IRN members also reviewed and provided feedback on the final draft. The following gives a brief overview of our inclusive writing process: Once the reflections were recorded as notes, the group turned these notes into reflective paragraphs from the perspective of the IRN members with intellectual disability, which are highlighted throughout the text. This was again done on Zoom through a simple shared screen that showed the reflection notes. With an IRN facilitator without intellectual disability as the scribe, these notes were turned into full sentences. The IRN facilitators without intellectual disability further added their own reflections to the paper and discussed the findings. This process resulted in the present paper, with sections of the results written by the IRN members with intellectual disability and all other sections written by the authors without intellectual disability. The finished text was taken back to the IRN members and was revised in summary together. This means that the IRN facilitators without intellectual disability summarised the key points of each section and presented them to the group to ensure that everyone agreed with the final product. This was done as it could not be expected that every member read the paper individually, and reading out the full paper during a meeting while ensuring engagement was deemed as unrealistic.

### 3. Results

The following section presents IRN members' and facilitators' reflections about the focus group experience including some learnings made. Reflections cover IRN members' participation in the focus groups, their motivations for being involved in the project as a researcher, the process of facilitating their own focus groups, things that went well and areas of improvement.

#### 3.1. Why Were We Interested in Joining the Focus Group as Participants?

##### *Perspective of co-researchers with Intellectual Disability*

We wanted to join the focus group because we wanted to find out more information about disability research. We were interested to hear about other people's views, and we wanted to make sure that people hear what we think is important. We also joined to feel included in making decisions.

##### *Perspective of researchers without Intellectual Disability*

When we asked the IRN members whether they wanted to be involved in the project, they were very motivated. Most of them had been involved in the IRN for years and were familiar with focus group participation, inclusive research and advocacy work. Hearing the IRN members' responses to this question was very encouraging, as their narrative about inclusion in decision making and having a voice reflected the purpose of the NDRA project we were working on. As researchers who feel strongly about the inclusion of people with intellectual disability, it was motivating to hear that the IRN members saw the focus group as an opportunity for exactly that.

#### 3.2. Why Were We Interested in Being the Researchers?

##### *Perspective of co-researchers with Intellectual Disability*

We were interested in being the researchers because we wanted to get useful information from other people, especially with lived experience of disability. We were hoping to find out about their stories. We noticed that it was difficult for some people to answer the questions because they did not have a lived experience of disability.

*Perspective of researchers without Intellectual Disability*

When preparing for the project and asking the IRN members whether they were interested in co-facilitating, they were never hesitant to commit to being the researchers; in fact, they were very excited about it and suggested who should be invited to the focus groups. They were comfortable asking questions with appropriate support, and it was clear that they have had previous experience in interview and focus group co-facilitation.

Apart from the overall project objectives of inclusion in decision making, IRN members placed emphasis on hearing about other people's experiences. This was also highlighted whenever we reflected on the focus groups experiences in a group meeting, as IRN members recalled participants' stories and said how interesting they had found hearing them. At the same time, as researchers, they placed substantially more weight on stories of lived experience of disability. Taking place during a long COVID-19 lockdown in New South Wales, the organised focus groups also created opportunities for social interaction and storytelling, which was otherwise limited. The social aspect of the groups also became apparent when some focus group participants and IRN members mutually agreed that they would like to stay connected after the project.

## 3.3. How Did We Do the Focus Groups?

*Perspective of co-researchers with Intellectual Disability*

We did the focus groups on Zoom. We split up into smaller groups of about 4–5 participants. This made it easier to speak up, and we felt positive about asking questions. We felt that it got easier to ask the questions the more often we had done it. We liked it better to ask questions than being the one answering them. One thing that happened was that participants without intellectual disability sometimes turned the questions on to us. We didn't feel like that was very respectful of our role as researchers.

*Perspective of researchers without Intellectual Disability*

We started our preparation a few weeks before the first focus group. At a meeting, we revised the NDRA focus group questions. Prior to that, one of us had already put the questions into an Easy Read format that included photo symbols. At the meeting, the IRN members decided to reduce the amount of questions we should ask. Questions that asked about two concepts, for example, "What are the most important things people can research about disability and the lives of people with disability?" were broken down into two separate questions, as the IRN members said this would be easier to understand. We also included a short definition of research, in Easy English, as an IRN member pointed out that some focus group participants might not know what research is. It was great to see how the IRN members took charge of the questions and were confident enough to point out questions they found—or thought that others could find—hard to understand. Facilitating focus groups during a phase of lockdown in New South Wales meant that we had to conduct them virtually via Zoom. One IRN facilitator without intellectual disability recruited participants via email, coordinated and scheduled the groups. Co-facilitating focus groups with researchers with intellectual disability on Zoom was a completely new experience for the facilitators without intellectual disability. Through previous IRN meetings on Zoom, members were familiar with the medium, but even though they are experienced in focus group facilitation, they had not done this on Zoom before. This meant that the entire group learned together from experience. The IRN members reflected this shared learning when they described how asking questions got easier over time.

The IRN members indicated that they preferred being the researcher to the researched. However, in some cases, they were called on by group participants to answer questions in the focus groups. Most participants indicated that the lived experience of people with disability should be privileged over that of service providers and carers. This meant that sometimes, the IRN members were called on to give their perspectives rather than simply facilitate the group as was intended. It was clear that people were intending to be inclusive, but in some cases, it did not feel as though the IRN members' roles as researchers was being respected. This was a very unexpected observation, as both IRN facilitators have previously held focus groups and never had a similar experience.

### 3.4. What Went Well?

#### *Perspective of co-researchers with Intellectual Disability*

We had a mix of people with and without disabilities and people coming from different organisations. It was good to hear different views about what the National Disability Insurance Scheme can do better for people with disabilities.

#### *Perspective of researchers without Intellectual Disability*

Conducting the focus groups via Zoom meant that a wider range of participants were able to attend. It was a useful opportunity to obtain a variety of perspectives on key areas of disability research.

We found that using Zoom made it easier for people to attend from different regions. This way, we were not restricted by distance. People also did not need to make travel or accessibility arrangements as they were attending from their own homes.

### 3.5. What Did Not Go Well and What Can We Do Better Next Time?

#### *Perspective of co-researchers with Intellectual Disability*

It would have been good to meet the participants face to face. This would have made participation easier for some of them. Some things were difficult on Zoom. Next time we do a focus group, we want it to be face to face. We have done other focus groups in the past where we visited people in person. We liked that much better.

#### *Perspective of researchers without Intellectual Disability*

There were a number of issues that arose conducting these focus groups. Some of these were logistical. We encountered a number of difficulties using Zoom. We found that conversation was sometimes stilted via Zoom and it was difficult for conversation to flow, particularly when the researchers needed to read the shared screen.

We also found that there were some accessibility issues with Zoom. We had an ASL interpreter attending one of the groups, but it was difficult to have the screens reflecting focus group participants while still ensuring that the interpreter was appropriately visible. It was also an issue for the facilitators who needed to read the questions from our shared screens. We finally solved this issue by posting the questions in the chat box.

We found that in some cases, the heterogeneous mix of service providers and people with disability meant that the discussions were inaccessible to the IRN members. Some of the service providers used jargon and did not adjust their language appropriately. This may have made it more difficult for the IRN members to facilitate the groups, and may have contributed to a feeling of "speaking over" the IRN members.

As mentioned previously, the IRN members have conducted face to face focus groups. When we reflected on the process of conducting these focus groups, they were clear that they much preferred face to face interactions, and that they were looking forward to going back to that mode of interaction. While they adapted to the online environment and were happy to have learnt new skills, we all agreed that it was overall a more difficult process via Zoom.

## 4. Discussion

The purpose of this paper was to describe and critically reflect on our experience, as an Inclusive Research Network of people with and without intellectual disability, of conducting inclusive research for a national research project during the COVID-19 pandemic. We believe that it is crucial to regularly reflect on our practice to ensure that we can improve and grow. Even more so, we find it is key to share our own experiences, critical reflections and resulting learnings with others who want to practice inclusive research. During our own journey of working with the IRN, we have been actively seeking other inclusive researchers' accounts to learn from their successes and mistakes. We found that often, the importance of conducting research inclusively and the resulting benefits are highlighted, and this is crucial to motivate others to work inclusively. However, we found that even though many academics report difficulties, the research process and the challenges connected

with it were only described by a few researchers in detail (Miller and van Heumen 2021; Tuffrey-Wijne et al. 2020). Our hopes are that by being transparent about the challenges that can arise when conducting research inclusively, but describing how we overcame them, showing that our project was still successful, we can take away some of the unknown some researchers might feel who are at the beginning of an inclusive research project.

Reflecting on our work on the NDRA, we found that the IRN members showed a great interest in being involved in the project, and their motivations for doing so aligned with the project's objective of hearing the voices of people with lived experience. The IRN members reported that they enjoyed being the researchers and asking questions and that they preferred this over being the researched. Facilitating the focus groups on Zoom took some preparation and offered some accessibility challenges. On the other hand, it enabled a more diverse group of people to attend, as they were not restricted by distance. Overall, IRN members with intellectual disability enjoyed working on the project and developed their Zoom facilitation skills but concluded that they preferred working face to face.

Throughout the project and during reflection, the IRN members demonstrated how they had internalised the project objectives and recognised it as an opportunity to have their voices heard and influence decision making. It is part of the IRN's vision that people with disability can and should be involved at every stage of research, and it appears that members recognised this project as an opportunity to do so. Even though the project was not initiated by the IRN, they showed interest in the project, took ownership of the research and its objectives and exercised some control over the process. They worked as collaborators with us researchers without intellectual disability. Riches et al. (2017) previously reported how these characteristics of the IRN's work showed consistency with the principles of inclusive research that Walmsley and Johnson (2003) published almost 20 years ago. This paper is an opportunity for the IRN members with intellectual disability to demonstrate the importance of lived experience in inclusive research as well as the research skills they have developed over time.

An observation that made a lasting impression on IRN members and facilitators alike was how participants called on the IRN members with intellectual disability to answer some of the questions. This was only done by focus group participants without intellectual disability and was very unexpected to us, since as researchers without intellectual disability, we had never experienced this before. Given the groups were mixed and there was a tendency for providers to ask questions of the researchers with intellectual disability, in future, it may be better to ensure all participants in a particular group are service providers, or carers, or people with disability rather than mixing the groups. It may also be necessary in the future to reiterate that the IRN members are facilitating in their capacity as researchers. This may highlight an education need among non-researchers/service providers as to the role and potential of people with intellectual disability as researchers. To date, academic accounts focus on inclusive research training for people with disability (Morgan et al. 2015; Nind et al. 2016; Tuffrey-Wijne et al. 2020). Training that teaches researchers and service providers how to work with inclusive researchers is not widely available. One example of such training developed in the Netherlands was reported by Sergeant et al. (2020). Implementing such training more widely could also potentially shift the roles for people with intellectual disability from being the one who is trained to being the expert and trainer.

IRN members advised who should be invited to focus groups and were involved in question revision, focus group facilitation and reporting. Their feedback during question revision facilitated important insights on the level of difficulty and allowed for the modification of the questions to ensure all participants were supported to participate in focus groups. Recognising that the questions needed adjustment and ensuring that they were easy to understand was a 'distinctive contribution which only co-researchers with intellectual disability [could] make' (Walmsley et al. 2018). Walmsley and colleagues identified this 'distinctive contribution' as an important characteristic of inclusive research that adds value to a project. Other characteristics include that the co-researchers' contributions are highlighted and that the work positively impacts on the lives of people with intellectual



disability (Walmsley et al. 2018). In the project described, IRN members with intellectual disabilities' contributions were highlighted throughout the process and in the present paper. Improving the lives of people with disability through creating disability research priorities is the ultimate aim of the NDRA. Thus, it can be inferred that the involvement of the IRN in the NDRA added value to the project.

Drawing on previous focus group experience, IRN members with intellectual disability successfully co-facilitated the focus groups. It must be noted here that IRN members' previous experience with focus groups was in face-to-face environments using tools such as flipcharts and coloured markers to record discussed themes. Working remotely for an extended period of time made it impossible to use these methods and presented a challenge for IRN members with intellectual disability to transfer their experiences. Nevertheless, the group adapted well to the online environment and developed more confidence in Zoom facilitation.

A possible limitation to this project is the potential influence of acquiescence and repetition on responses in individuals with and without intellectual disabilities (Perry and Felce 2004). In the weeks leading up to the focus group, we held several short information sessions about the project and purpose. The repetition of the project agenda could have potentially influenced members' responses and led them to give desirable answers, for example, that they are interested in the project even though they may not be. We made efforts to minimise this risk by regularly asking the IRN members whether they were still interested in the project, explaining to them that there were no right or wrong answers to this question and that answering no would be totally acceptable. We believe it is important to be aware of this potential bias when researching inclusively. Regularly checking in with project team members to ensure that they support the project and its aims is crucial.

## 5. Conclusions

In the future, we think it is essential that more researchers report in detail about their inclusive research processes to ensure critical reflection and learning and to encourage other researchers to make their own projects more inclusive. Working inclusively under COVID-19 restrictions can seem daunting and impossible, but we would like to encourage researchers to do it. Despite the challenges, inclusive research can successfully be completed online. Nevertheless, we do not believe that virtual meetings should replace face-to-face interaction past the point of COVID-19 restrictions, as our reflections have shown that the IRN members with intellectual disability value face-to-face meetings. When working with people with intellectual disability as co-facilitators of interviews or focus groups, particularly when the interviewees do not have a lived experience of disability, it might be necessary to clearly define and reiterate the roles of the persons participating in the interview to prevent questions being turned back on co-researchers. Another way of addressing the issue could be that inclusive research groups develop training for researchers and service providers, to teach them about how to work with inclusive researchers.

Together, we learned that even though conducting inclusive focus groups online presented multiple challenges, we still managed to facilitate fruitful discussions that generated valuable insights for the NDRA project. Likewise, even though facilitating focus groups on Zoom was not necessarily something most IRN members liked, they persisted, gained experience, and improved their confidence in the Zoom environment. When working with co-facilitators with intellectual disability, the roles of everyone involved in the focus group need to be clearly defined and might have to be reiterated for focus group participants.

We encourage researchers who practice inclusive research to share details of their research processes, challenges faced and strategies used to overcome them to promote critical reflection and learning and to encourage other researchers to work inclusively.

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## Article

# Reflections on Working Together in an Inclusive Research Team

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**Abstract:** The funding of a research project working with local governments and people with intellectual disabilities led to the establishment of an inclusive research team within a university faculty. The core team consisted of four people, including a design researcher, an architect, a disability advocate and a community researcher/self-advocate. Though there are ample attention and resources devoted to the front-facing parts of a university being visibly inclusive—mostly from a physical access perspective or focussed on the student experience—less attention has been directed to what it means to develop and support inclusive research and aligned work opportunities for people with intellectual disabilities within a university campus. For this reason, the paper explores what it was like for our team that included non-traditional academics and people with intellectual disabilities to work at a university in a design school (not a disability-related research centre). We employ a process of collaborative autoethnography to reflect on how different team members took the lead across different parts of the study. We conclude with a set of tips for the development of more inclusive research teams within university settings.

**Keywords:** inclusive research; intellectual disability; university; inclusive employment; collaborative autoethnography; autoethnography; ethnography; disability; inclusion

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## 1. Introduction

Although there has been increasing attention and resources devoted to university life being inclusive of people with intellectual disabilities, this has primarily focused on the student experience and educational program design and delivery (Bumble et al. 2019; Plotner and Marshall 2015). However, universities are places of employment as much as they are places of education. When it comes to the employment of people with intellectual disabilities, universities tend to be acknowledged not as potential employers themselves, but as playing a role in providing pathways to employment of people with intellectual disabilities through education (Wehman et al. 2018; Wilson and Campain 2020). Opportunities for universities to be inclusive workplaces, employing people with intellectual disabilities as staff members, has been explored far less.

Many universities promote themselves as environments for equality and diversity inclusive of gender, ethnicity, social class, sexual orientation, physical ability, identity and cultural background (Buitendijk et al. 2019). Despite this, universities have an ableist track record, particularly as employers of people with disabilities (Mellifont 2021). Brown and Leigh (2018) consider ableism to be endemic in academia. Pointing to the continuing stigma of disabilities for university staff, Brown and Leigh (2018) discuss a discrepancy in rates of disclosure of lived experience of disability between student and staff populations. Brown and Leigh discuss the relatively high disclosure of lived experience of disability in students (11.5% in the UK) but ask the question—"Where are all the academics with disabilities, chronic illness or neurodiversity?" (p. 968).

This paper reports on reflections of an inclusive team that includes people with intellectual disabilities as university employees. Though we do not have a clear indication

of the number of people employed with an intellectual disability, there is evidence that people with intellectual disabilities are underemployed in Australia and the UK (Australian Bureau of Statistics 2012; NHS Digital 2021). We can learn about the experiences of people with intellectual disabilities who have held professional roles in research from qualitative and ethnographic research articles published internationally. These are important in documenting the rich and varied experiences of people with intellectual disabilities as researchers (Bonham et al. 2004; Schwartz and Durkin 2020; Walmsley et al. 2018).

The practice of inclusive research with people with intellectual disabilities is an established field of research (Nind 2014; Nind and Vinha 2012, 2014). Literature reviews have reviewed the scope of literature informing the conceptualisation of inclusive research (Bigby et al. 2014), the value of inclusive research (Walmsley et al. 2018), the voice of co-researchers with intellectual disabilities (Strnadová and Walmsley 2018) and more recently, citizenship of people with intellectual disabilities (Chalachánová et al. 2021). There is also an established body of research dedicated to community-based participatory research with people with intellectual disabilities (McDonald and Stack 2016; Nicolaidis et al. 2015; Stack and McDonald 2018). Though not directly focused on people with intellectual disabilities, Nicolaidis et al. (2019) developed a comprehensive set of practice-based guidelines to promote the inclusion of autistic adults as both co-researchers and research participants.

In sharing our experience of working together in an inclusive research team, we hope to contribute to knowledge about how diverse teams work together and complete research within a university setting. We have found, as did Schwartz et al. (2020), that the characteristics of the team members, including our values, have informed the way we have all worked together, who took the lead and when, how we approached any structural barriers and the outputs arising from the research. It is this documenting of what we learnt together, and what we would do differently, that we aim to share in this paper.

Like Schwartz and Durkin (2020), we too note that our project may not be considered ‘best-practice’ inclusive research, because one of the principles of inclusive research is that it must be driven by the interests of co-researchers with disabilities and owned by them (Johnson and Walmsley 2003). In our case, the research grant and project topic were developed and applied for by the lead researcher prior to the team being assembled. Noting this limitation, we provide our reflection on the structural barriers to inclusive research—notably, that a grant must be awarded, and funds allocated, before a research team can be offered contracts. In our case, there would have been no funds to employ a person with an intellectual disability to work with to prepare the grant application.

In this paper, we employ a method of collaborative autoethnography to describe how a team of four people with both academic and non-academic backgrounds worked together to conduct a qualitative research study. The project was designed around building resources to support the inclusion of people with intellectual disabilities by local governments. Our team also included a core member with an intellectual disability. We reflect not only on what it meant to be a part of this team and project, but how the team experienced the university environment and system.

### *1.1. About the Team and the Research Project*

In 2018, a researcher in the Faculty of Design, Architecture and Building at an Australian university was awarded a grant to undertake an inclusive research project. The project set out to explore ways to support local governments to be more inclusive of people with intellectual disabilities (Carnemolla et al. 2021a, 2021b; Robinson et al. 2022). Any outputs arising from the project were intended to increase the participation of people with intellectual disabilities in their own communities and within the civic structures of their local councils.

Once the funds were secured, we recruited and employed our core project team. Our team comprised four people who have varied experience in disability self-advocacy (lived experience of intellectual disability), disability advocacy, research and design. Our objective was to find ways to inform the local government about what it means to be inclusive of

people with intellectual disabilities. The project was funded by the National Disability Insurance Agency (NDIA), and the team were contracted for a period of 18 months.

Important to note, because of its influence on how and when team members were engaged and contributed to the project, is that only one team member, the research lead, had a long-term academic contract with the university. The lead researcher was also responsible for managing the team and was the team member who developed and applied for the grant that funded the project. All other team members were employed on a casual contract and were engaged after the grant was awarded.

The team was assembled after the grant was awarded. Prior to this, the lead researcher had no previous experience employing or managing a diverse team, including people with intellectual disabilities, in a university setting. There was no known precedent of inclusive research within the university's school or wider faculty; there was consequently no policy or protocols to be guided by and no colleagues to advise the team.

Throughout this paper, we use the initials of team members and co-authors to indicate how contributions were shared across the team. The research lead (PC) started to build the team, first recruiting CD, who had experience in inclusive practice and research into 'co-envisioning'. Following this, AH was contracted as a team member because of their experience as an advocate for people with intellectual disabilities. These experiences meant that AH provided valuable guidance on how to recruit a research associate with a lived experience of intellectual disability onto the team. AH's networks with other community and advocacy organisations meant that recruitment of a person with intellectual disability could be sent out to established networks relatively quickly. JK, who had experience as a self-advocate and community researcher, was approached as a potential candidate, and following a telephone call and face-to-face meeting, JK decided they would like to take the job as a research associate. Team member AH also had extensive experience working with people with intellectual disabilities, and on this project they worked closely with JK to plan for all support requirements related to working with both the team and other participants with intellectual disabilities. The team leader worked with all team members to determine individual preferences around personal support workers on campus and were open to having any preferred support person present with the team during workdays. The team themselves had existing skills in inclusive communications, both in writing and in generating Easy Read materials. This made the team communications able to be managed within the team and not externally sourced. AH provided clear guidance for the project leader around planning, scheduling and communication materials for the project and how best to manage work tasks set for all team members with lived experience throughout the duration of the project. PC and AH worked closely with each team member to set and plan workloads that suited individual skillsets, communication preferences and expectations.

This paper covers a period of one year of the project, when the team members worked together on-campus in an open-plan shared office. We all worked a range of hours per week on the project but were on-campus together fortnightly (for the first 4 months), then weekly. After morning team meetings, we would break into smaller groups, depending on whom was working on what research activity. We all worked together to complete a range of research activities for the project:

- Conduct focus groups with people with intellectual disabilities
- Conduct interviews with local government representatives
- Co-facilitate workshops with the local government
- Analyse and synthesise results from the focus groups and interviews
- Plan each next stage of the project and negotiate contributions

#### Inclusive Analysis of Data

We worked to ensure that all team members had the opportunity to contribute to each of the research activities. All but one of our focus groups and interviews were co-facilitated with a team member with an intellectual disability.

We also analysed and synthesised our focus group data together. We did this by firstly getting all recordings transcribed. In one of our regular team meetings, we discussed what we thought some of the themes might be, based on the experiences we had as co-facilitators of focus groups and interviews. We also discussed ways the team could come together to agree on the themes emerging from the recordings.

Team members PC and CD first began a round of initial coding of the data, generating a collection of key quotes and generating a list of possible themes. The team spent a morning together with these quotes written onto pieces of A3 paper. We discussed them and clustered them into themes. We then co-facilitated an analysis workshop that included our team as well as self-advocates with lived experience of intellectual disabilities from a local disability advocacy organisation. During this workshop, co-facilitated by our team member with intellectual disability, we used the walls of our meeting room to post a selection of quotes, written on large pieces of paper, on the wall. We all discussed each quote, and each participant in the analysis workshop helped us to categorise and prioritise the quotes within themes. The quotes were placed around the rooms into different categories, reflecting on what they meant for each of the workshop attendees. This was how we came up with the themed recommendations as findings from the research project that the team were working on together.

## 2. Materials and Methods

A number of papers have documented or reflected on their inclusive research approaches, processes using autoethnographic writing (Milner and Frawley 2019; Schwartz et al. 2020; Schwartz and Durkin 2020). Other autoethnographic research has explored the experiences of people with intellectual disabilities as students at university (High and Robinson 2021; Vroman 2019). The experiences of individual researchers with intellectual disabilities has been documented as auto-ethnographic research by White and Morgan (2012), and the process of building inclusive teams has been explored by Strnadová et al. (2014).

This paper uses the qualitative method of collaborative autoethnography, as described by Chang et al. (2016), to explore the experiences of an inclusive research team, including team members with intellectual disabilities, at an Australian university. We reflect as a group on how we worked together and how our team operated within the existing systems and structures of a university faculty. In this paper, we employ Chang et al.'s approach to the collaborative autoethnography of pooling stories, finding commonalities and differences and finding meanings in relation to sociocultural contexts (Chang et al. 2016).

We want to discuss what it means to have diversity of staff as well as students on campus. The reflections in this paper were captured in November 2019 as a series of group discussions and interviews between team members who had worked together for a year. The group discussions were intended to explore individual perspectives of working together and centred around the themes of inclusion, intellectual disability and universities as workplaces. The team also discussed their experiences as a collective, together, as a small inclusive research team operating within a larger university faculty.

Team members framed a list of open questions designed to explore each person's perspectives, what they learnt and what they would do differently next time, in a diverse team setting at a university. Notes were taken at each discussion, and the questions asked included:

- What has it been like for non-academics on the team to work at a university?
- What have we learnt working together?
- What has worked well?
- What would you do differently?

## 3. Results

The team reflected on their experiences, what it meant to be working at a university and what knowledge they take with them beyond this project. We share what has worked,

what hasn't worked, and what it is like to be a diverse team, including researchers with intellectual disabilities, within a large organisation.

We organised our reflections into themes. Following our reflections and sharing of stories, we share what we have learnt together as a list of five tips—because we hope that hearing our project experience will encourage other universities to build diversity within research teams and include people with intellectual disabilities. The tips are intended to encourage discussion about inclusive research approaches in universities and their organisations and answer some of the difficult questions about what inclusion really is, what limits inclusion and how to address this.

### 3.1. Reflections on What Worked Well

What initially was thought to be a limitation of the project—that it was being conducted in a university setting with no experience of inclusive research, and with no experience of including people with intellectual disabilities as staff members—became one of the project's strengths.

*JK: We are all from different backgrounds—not necessarily disability—and we all bring something special to the team.*

Each team member valued the structure and location of our team's project in different ways. For example, some of our team valued that the project was not located in a disability-focused centre or faculty; rather, it was an experience of university life without the label of disability:

*JK: This office isn't focused on disability-related work and have a different take on it. What I mean is, this office doesn't have the word 'disability' in it*

For the project's lead researcher, the lack of precedent of inclusive research was at first thought to be a potential difficulty when considering interactions with university operational, professional and academic staff. However, this perceived difficulty became an opportunity:

*PC: Because our faculty and school had not undertaken any inclusive research before, there were no rules to guide us—this worried me at first. But then, we realised that we could do our best work, and no one was limiting our scope on what was inclusive or how to do it—instead we looked to the lived experience within the team, of self-advocacy and advocacy, to guide us. It worked well because we built our own rules and ways of working together.*

*PC: We had very supporting professional staff, who worked with us to ensure that the needs of everyone in the team were met—this might include accessing assistive technology, supporting with administration activities, accessing the building, finding spaces for us to work together.*

All of team members, regardless of lived experience, found working in a diverse team a rewarding and valuable experience:

*JK: We are a dream team; I think when you are building a research team you have to have people who are on the same page with ideas and with the same outcome in mind.*

For the research lead, what also worked well was having everyone together on the same day each week:

*PC: We could plan for regular meetings, and everyone could be kept up to date on the project's progress and activities. I knew that Thursday was our project day. For me, I really appreciated everyone being together, and sharing the decision making on a regular basis. I would not have liked to be working remotely or managing the team individually—we really were together, working together.*

Additionally, what also worked well was that we all respected that each individual team member had preferred ways of working and communicating with each other. We



adjusted our communication accordingly. For example, we worked out that some team members preferred to have conversations about things rather than read through a document, so we planned discussions to work through decisions rather than requiring reading of materials. We also worked out how much information we could discuss in a staff meeting and what information was too much. Together, we worked out that having regular breaks was important to keep everyone focused and rested. We also worked out that working between 9 am–1 pm was the best use of everyone’s time on a Thursday. If people wanted to work longer, they could, but 9am–1 pm was our team time.

*JK: I have a lot of flexibility; I can have a break anytime I want.*

*JK: This was the first team where my manager totally understood the way that I like to operate; it took other employers a long time to adjust to the working style that I have.*

Time management was very important for the research lead, and one of the skills learnt was that when working in a team with diverse support, mobility and communication preferences, planning activities well in advance meant that support workers could be scheduled, and transport planned.

*PC: We established an understanding and respect for each other’s time availability and the time taken to plan for attendance and performance of key activities e.g., co-facilitating focus groups at various local government locations. It takes time to make sure that support staff are available, to organise transport and check accessibility of venues. For people with disability who rely on support staff and accessible transport to meet their job requirements, allowing for this forward planning is very important.*

### 3.2. What Was Difficult—What We Would Do Differently

One of the continuing barriers we experienced as a team was the expectation for us all to engage with the university’s inaccessible systems online. These included pay claim systems that didn’t work with screen-readers or voice-to-text technology. Although professional staff were extremely helpful in finding workarounds, such as hand processing pay claim forms, this was ultimately not sustainable and meant that support staff would complete this task on behalf of team members who relied upon voice to text.

Another example of the inaccessibility of the university systems was the compulsory online training courses that all staff were expected to complete. These courses were delivered on an online platform that was inaccessible for people who use voice-to-text technology. In addition to this, the content included complex and overlapping concepts, meaning that it took additional time to complete for team members who preferred to work with Easy English and Plain Language communication.

### 3.3. Barriers to Doing Best Practice Inclusive Research

We often talked together about the fact that our project was not diverse or inclusive until 3 months after the project started, after the grant was awarded and the project aims defined. Our reflection on this is that the way university research is funded, via non-recurrent project grants, presents a significant barrier to more inclusive research. Relying on non-recurrent project funds to undertake inclusive research means that research associates can only be employed after the grant has been won. This limits the ability to perform community-led research and restricts grant writing to academics employed on long-term fixed contracts or permanent positions, as their time is paid for at the time of the grant writing.

The team reflected on the dynamics of the team and how the team was built.

*PC: One thing I would do differently, as the manager of the inclusive team and project, and I would feel more confident about it now, is that I would employ more people with lived experience of intellectual disability on the core team. . . . in the intensive focus group and feedback parts of the research, such as when we are doing roundtables—I feel that expecting one person to represent diversity on the project, to come in part time, and to be*

*present to co facilitate, co-interview, co-chair in those busy times. . . . puts pressure on that team member because of the value and importance of their lived experience.*

### 3.4. Perspectives on the Label of Intellectual Disability

We talked about some of the things we learnt by having worked in a diverse team at a university, about working together with JK and conducting focus groups with people with intellectual disabilities:

*CD: The most striking thing for me working for the first time with people with intellectual disability has been the overwhelming discomfort with the label and facing the prejudice that is embedded [ . . . ] in this. JK's contributions to the work are insightful and very often profound. JK articulates the essence of things succinctly and keeps the project's integrity, values on track with clear and kind redirection where we need it.*

*CD: I have personally really struggled with the appropriateness of the label "intellectual disability" when I believe the contribution of JK as a core team researcher and the focus group participants is in fact the critical work. The rest need to adjust, learn and be humbled to these ways of seeing and being in the world.*

*PC: We did our best to make the project and our teamwork a success. Sometimes things got in the way—like a structure or a system. For example, budget limitations meant we had to do things differently, not employ as many people, but we recognised that part of the learning process is accepting that our inclusive research might not be perfect first time, and that we can improve and build upon the process we have learnt along the way.*

### 3.5. Reflections on Access and Inclusion in the Workplace

The team discussed what we learnt about how access and inclusion are framed in the workplace, in the physical built environment, communication approaches and in social settings.

*CD: The second thing I have learnt is the concept of accessibility extending well beyond the physical. This highlights the need for designers in the built environment to be far more educated.*

*AH: We found out early on that the campus wasn't accessible in some ways. The fire stairs couldn't house more than one person using a wheelchair.*

*JK: The online payroll system can be confusing and does not work with voice-to-text. I needed to have help to fill it in. We have got used to it now though.*

### 3.6. Inclusive Research Is Doable—Here Are Our Top Tips

As a team, we felt it was important to come up with our set of top tips to share with other researchers who are considering undertaking more inclusive research at a university. We developed these tips to demonstrate that inclusive research is doable and can be accomplished well in different ways. Our top tips are listed below and included as an illustrated graphic in Figure 1:

1. **Employ people with the lived experience of disability as members of the core research team.** We regard this as one of the most valuable and critical features of the success of our project. We all worked together, bringing together a range of skills—each team member had the opportunity to take the lead and share their skills and knowledge about inclusive research. The project we worked on can be found here: <https://www.uts.edu.au/node/284291/what-we-do-old/research/my-home-my-community> (accessed on 3 March 2022).
2. **Do what it takes to make it happen—be flexible, listen and be responsive.** Build expertise and experience into the team—this includes the lived experience of people with an intellectual disability, as well as experienced advocacy and support experts, to ensure that peer skill building takes place. Work out early on how people prefer to

work and communicate and adjust the team environment and processes to suit everyone. Partner with community organisations to bring additional inclusive research knowledge and expertise (we were grateful to be able to partner with the Council for Intellectual Disability (CID) for some parts of our project).

3. **Recognise that inclusive teams can work in all learning and research spaces—not just disability-specific ones.** There are many opportunities to utilise the benefits and increased impact of community-led, diverse teams across the university campus.
4. **Accept that it's going to look different for different teams.** Everyone has different ways they like to work and different skills to contribute, and personalities work differently together. Not only this, but every project will have different priorities and outcomes.
5. **Be open to not knowing "stuff" and/or not being in control.** It is okay to not be an expert in inclusive research straight away. Listening and surrounding oneself with experienced people (both self-advocates and advocates) is a great way to navigate what inclusive research can be.



**Figure 1.** Our team came up with five tips to guide the development of more inclusive research teams within university settings. These are all based on what we learnt collaboratively during the research project.

#### 4. Discussion

Our work together raised several questions about inclusion, research and the experiences of people with intellectual disabilities who have a job at a university. We decided to focus this paper on how we experienced teamwork in a university setting, the physical environments, structures and systems, to highlight how inclusive research has been undertaken. We have reflected on how existing university systems and processes either helped or hindered working together, and how different team members took the lead across different parts of the study.

What is clear from our reflections is that our different backgrounds worked very well together. For most of the team, this was their first experience of working in an inclusive research team, including the team leader. Effective management of the team and the project meant listening to the experiences and guidance of other members, including team members with a lived experience of intellectual disability. One of the unexpected strengths perceived by the team, and emerging from the reflective discussions, was that we were not part of a disability-specific centre.

The project was undertaken in the Faculty of Design, Architecture and Building and the School of Built Environment. The administrative, professional and supervisory staff around us had no prior experience being part of an inclusive research team. This lack of disability-related experience was initially seen as a disadvantage for the team, who were working without much guidance or precedent. However, interestingly, as the project progressed, not being a “disability” research centre was highly valued by team members, especially members of the team who had a lived experience of intellectual disability. The freedom given to the team by the university was valued by the team leader. This freedom

was possibly the result of a lack of established ideas and policies around what inclusive research should be and meant the team could decide what worked for them.

Together we identified some barriers that influenced how we worked together as an inclusive research team, as well as the potential to work on other inclusive research activities as funded projects. We learnt that the way research is typically funded in universities (as non-recurrent funds form competitive grants) can be a barrier to community-led research, and best-practice inclusive research (as described by Johnson and Walmsley 2003). Unfortunately, this indicates that community-led research projects, where communities themselves prioritise and decide upon what research is important for their community, will be less likely to take place in university sectors in the current research funding setting. It is only the academic with long-term employment at a university who can be paid to develop and apply for a grant, and who designs the project—up until the team is put together—and communities cannot be expected to give their time without being properly recompensed. Given the relatively privileged and ableist representation of university academics, a person with long-term academic employment is unlikely to be a person with an intellectual disability. The reality is that funds are unlikely to be able to be found to pay a person with an intellectual disability prior to a grant being awarded.

The Carnegie Community Engagement Classification is a global network of universities (in the US, Ireland, Canada and Australia) that has been established to evaluate and recognise best practices in community engagement by universities (Driscoll 2008). The Carnegie Foundation recognises the role that universities can play in embodying diversity and inclusion and encouraging community participation. The very existence of the Carnegie Foundation speaks to an opportunity for universities to expand practices that offer practical pathways to diversity and inclusion of researchers, and of research practices, as well as students. There is also an opportunity to identify structures, such as the project-limited funding structure described previously, that act as barriers to community-led research. Though there is a long, established and important history of inclusive research being conducted in universities, this has tended to be restricted to disability-focused institutes and centres. The next level to best practice will be the incorporation of inclusive practices and community-led projects being actively pursued and delivered across the full scope of university research being undertaken. This requires us to ask the question of how universities value community partnerships in relation to research teams, and will require deeper articulation and scrutiny of the questions asked by Grant and Ramcharan (2009, p. 32):

- *“What kinds of knowledge are directly attributable to inclusive research (intellectual capital)?*
- *How these knowledge claims can be assessed and authenticated (methodological capital)*
- *The benefits of the experience to individual service user researchers (individual capital)*
- *In relation to project teams, what forms of partnership (managerial and social capital) make inclusive research effective and whether good science and inclusive research can be integrated.”*

We also experienced some barriers in the built environment and online university systems. Although the immediate workplace was made accessible with appropriate assistive equipment (including voice-to-text software on computers), the team was frustrated by the inaccessibility of internal online systems and was confronted with how this limited the autonomy and agency of staff who use, and rely upon, screen readers or voice-to-text technologies. For example, the recruitment process itself was extremely cumbersome and digitally inaccessible, requiring professional staff to sit with the new staff member in person and work through the recruitment process. The system inaccessibility extended to many of the internal financial systems, making pay claims and expense claims something that team members who used screen readers could not accomplish independently, which is problematic if this means having to divulge passwords and logins.

These barriers prompted a lot of discussion within the team about what inclusion really is, how universities could do better and what role we could play as a small inclusive research team. We often discussed what our responsibilities were to support changes to structural inaccessibility. The team manager, as the only long-term employed researcher on the team, felt strongly that part of their role and responsibility as the project lead

was to represent the importance and possibilities of more inclusive practices. This was accomplished by being transparent and demonstrative about how successfully the team were working together, and by vocalising what processes were inaccessible and why change was important. When we had the opportunity to engage with any university department or network (e.g., marketing, finance, research support and media) about our experiences, we did so with transparency about why our project was significant, how we made it work and what parts of the systems at the university made doing so unnecessarily difficult.

There were also considerations to be made around the practicality of managing a project with a team of traditional and non-traditional academics, where most of the team were employed on a part-time and time-limited basis. Given the diversity of experience as well as communication and work preferences across the team, what worked well was dedicating a day per week on which we all worked together on campus. We hosted inclusive team meetings and planned upcoming research activities on this day. We learnt that long-term calendar planning in an inclusive team is important, and it is the only way to ensure that team members and those who receive personal care support could be expected to plan transport, attend meetings and focus groups and co-facilitate planned activities. We revealed that some research and project activities do have to be broken down into smaller parts, with regular breaks built in.

The list of top tips to guide the development of more inclusive research teams within university settings arose out of our reflections and discussions together. We asked ourselves what we thought would be useful to share with other researchers who might be considering inclusive research or were unsure how to approach employing people with intellectual disabilities as researchers at a university. The tips are informally worded and are intended to get people comfortable with the idea of taking small steps, iteratively learning and not feeling pressured to get everything perfect, especially the first time around.

## 5. Conclusions

This paper is intended to encourage discussion about inclusive research approached in universities and other organisations. Here, we reflect on our experience as a team and share what worked and what was difficult. We had the opportunity to work together on a project that was designed to support the inclusion of people with intellectual disabilities, and it meant that we got to think about some difficult questions about what inclusion really is, and what it is not, what limits inclusion and how we set about as a small team with lived experience of intellectual disability to address this.

As we expand our understanding of community-led research, and inclusive research across universities in general, it is important to consider that the application of the principles of inclusive research explored in this paper are not limited to people with intellectual disabilities. Rather, the concept of inclusive research can be expanded to include any community group, in particular communities who have historically been excluded from research conversations and decisions despite being the subjects of research. Developing more inclusive university systems, processes, software and communications can lead to universities being more inclusive of researchers from a wide range of marginalised communities, e.g., older people, people who have experience mental health conditions, or culturally and linguistically diverse communities.

We hope that our project experience will inform and encourage other organisations to build diversity within research teams and to include and employ people with intellectual disabilities.

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## Article

# Inclusive Research and the Use of Visual, Creative and Narrative Strategies in Spain

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**Abstract:** In recent decades, there have been many works on inclusive research that provide a clear framework on its meaning and the implications it entails. They also highlight the importance of addressing outstanding challenges, among others, to inquire after research strategies that respond to the diversity of situations in which people with intellectual disabilities find themselves. This article presents a research project carried out in Spain over a period of eighteen months by a team of researchers with and without intellectual disabilities. Specifically, we explore how the construction of enabling relationships, both dialogic and horizontal, requires giving greater emphasis to visual and creative methodological strategies, such as photographs, image-theatre, body-mapping, murals or visual presentations. The findings reported by the researchers and co-researchers have encouraged us to review some methodological premises such as our role as researchers or the type of relationships we establish. They also demonstrate the value of using a variety of collaborative enquiry strategies that recognise the agency of all researchers.

**Keywords:** inclusive research; collaborative groups; qualitative research; creative methodologies; people with intellectual disabilities

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## 1. Introduction

This article presents part of a research project developed in Spain by a group of researchers with and without intellectual disabilities on “The importance of social relationships and loneliness”.

The article was written by two academic researchers and is based on an essential idea: the principles that underpin research articulate how it develops and, therefore, the relationships that are built in it. Thus, it can be said that the research strategies we used support these principles and, within the framework of inclusive research, they should contribute to improving the lives of people with intellectual disabilities and help transform the type of unequal relationships that are established with them. It is important to bear in mind that the strategies and activities developed are not essentially participatory or emancipatory; consequently, it is necessary to review the experience of the people who use them, where they come from and to what extent they improve the academic research we have been doing.

This research is part of a project coordinated by the National Research Plan and Innovation Networks for Educational and Social Inclusion that aims to promote innovation and development by educational and social agents and entities in four regions of Spain. It is the result of collaborative work carried out over 18 months, after which the results have continued to be disseminated.

This article focuses on three of the research strategies used in the project—specifically narrative, visual and creative strategies—and reflects on how they can facilitate and promote dialogue and debate within the research group and contribute to collaborative research by providing more choice and control for people with intellectual disabilities.



## 2. Background

### 2.1. Inclusive Research

The term inclusive research is used to refer to a type of knowledge production that questions the consideration of people with intellectual disabilities merely as sources of data and demands their right to participate in decisions and spaces that concern them as citizens, including academic spaces (Walmsley and Johnson 2003; Nind 2014, 2016).

In a recent review of the term (Walmsley et al. 2018), inclusive research is defined as:

- “Research that aims to contribute to social change, helping to create a society in which excluded groups belong, and which aims to improve the quality of their lives.
- Research based on issues important to a group and which draws on their experiences to inform the research process and outcomes.
- Research which aims to recognise, foster, and communicate the contributions people with intellectual disabilities can make.
- Research that provides information which can be used by people with intellectual disabilities to campaign for change on behalf of others.
- Research in which those involved in it are ‘standing with’ those whose issues are being explored or investigated” (p. 758).

The term inclusive research encompasses a broad set of research approaches in which the type of relationships established within it—horizontal and collaborative—are fundamental. It refers to a set of approaches and methods that emphasise the democratisation of research processes (Nind 2014), in contrast to extractive and assimilative approaches that sustain unequal power relationships with people with disabilities (Milner and Frawley 2019). Thus, regardless of the degree of control that people with intellectual disabilities have in the research—as advisors, collaborators or leaders—it creates a space for life experiences to be discussed. As a collaborative practice, our research provides space for new content and dynamics to emerge within the group. Evidently, this presents challenges that do not appear in other types of research that follow traditional methods.

Research involves a broad range of acquired knowledge, abilities and strategies that have traditionally been part of the academic sphere. Firstly, in this context it is important to recognise that people with intellectual disabilities have not had access to this specific training. Furthermore, in some countries, such as Spain, there has been no overt support from funding agencies that value the inclusion of people with intellectual disabilities in research projects, something which adds more uncertainty to the meaning of specific pre-designed or pre-packaged research training.

According to Nind (2016), inclusive research is in itself a learning opportunity, addressing complex questions in complex ways, thus providing an opportunity to learn how to research by researching, taking care not to exclude those who may need the most support. Therefore, within the framework of each phase of this research project, the co-researchers have taken different kinds of decisions throughout the whole process, including what techniques or methods should be used to respond to the questions raised.

### 2.2. The Use of Visual and Narrative Strategies

As a dialogical practice involving researchers with and without intellectual disabilities, research activities should promote analysis and reflection within the group. Therefore, they must be meaningful and accessible for the participants and recognise the knowledge and experience of people with intellectual disabilities (Nind 2014; Holt et al. 2019; Fudge et al. 2019). In this process it is necessary to include a variety of strategies and activities that encourage dialogue and allow transition from the individual to the general, from the concrete to the abstract or from the personal to the social and vice versa (Nind and Vinha 2014; Bigby et al. 2014; Nind 2014, 2016; Murray 2019; Holt et al. 2019).

In short, we are talking about ways of learning how to research, types of research relationships and a form of co-production of knowledge that needs to be supported by a diversity of methods and visual, narrative and creative activities that ensure dialogue throughout the research process. As highlighted by several authors (Fulcher 1995; Booth

and Booth 1996; Aldridge 2007), the limitations of methods serve to legitimise the exclusion of people with intellectual disabilities. Therefore, it becomes necessary to use alternative methodological approaches rather than more traditional ones.

The use of visual and creative methods is not new. As Mannay (2016) points out, the preoccupation with visual and creative works in disciplines such as history, art and archaeology goes back a long way. “There is much to be learnt from the humanities, where art and artefacts have been thoughtfully considered by a range of scholars; and engaging with different fields and disciplines is fundamental in progressing visual studies” (p. 24).

The inclusion of images, physical objects or theatre during the research process does not aim to substitute narration but rather complement it. The introduction of visual and creative elements can be used to establish dialogue and facilitate mutual knowledge, e.g., about what we want to research or what we think about the issues that affect us as citizens (Martínez 2008). Thus, enabling access to the spaces and lives of the participant and leading to more personal communication. It can also provide different ways of understanding and knowledge that contributes to making the familiar strange and deepening what is known (Mannay 2016). In addition, having access to more resources, other than oral language, gives more control to participants to propose or organise the issues being addressed or to share previous work with other people (Serrano et al. 2016). As Goodley and Moore (2000) point out, when we carry out research with people with intellectual disabilities, such contextualisation allows the theoretical and political qualities of the actions to be revealed.

Recent work in inclusive research also supports the qualities outlined above. Photography or video was used to identify and analyse ideas relevant to people with intellectual disabilities requiring support in verbal communication (Booth and Booth 2003; Rojas-Pernia and Sanahuja 2011; Cluley 2016; Krisson et al. 2022). In some of these works, the images were pre-selected by researchers with the aim of eliciting dialogue and ensuring the participation of those who could not read (Mooney et al. 2019). In others, the images produced by the participants were shared with relatives and professionals, giving them the opportunity to learn about and reflect on the issues raised by people with disabilities and providing them with the possibility of returning to the topics discussed (Sitter et al. 2019; Kim et al. 2021).

In research where people with disabilities act as advisors or co-researchers, diverse strategies are incorporated throughout the whole process, including in the analysis of the data obtained. For Pallisera et al. (2015), photography and drawing were essential to conducting the interviews and focus groups, facilitating the participation of a group of young advisors between 17 and 22 years old. Sitter et al. (2019) refer to numerous creative activities (drawings, images and photographs from magazines) during the analysis phase of the research topics. The use of arts-based activities such as collage throughout the whole process encouraged dialogue and collaboration between its members with the eventual creation of a set of videos about the sexual rights of people with disabilities.

Photography, music or collage are also referred to by Kennedy and Brewer (2014) as valuable resources for learning about the beliefs, experiences and perspectives of the four people with intellectual disabilities involved in this research.

Less frequently, other works have been supported by creative resources such as theatre or body-mapping. The project carried out in CHANGE on affective relationships and sexuality used the theatre as a means to address embarrassing issues, elicit new topics or make the familiar strange (Garbutt et al. 2009). This is also the main resource used by a group of young people to explore the dilemmas they faced when taking a more active role in the transition to adulthood (Goddard 2015). As highlighted by the author, theatrical techniques that produce knowledge through interaction with others can contribute to the construction of a model of collaborative work between people with and without disabilities. For their part, Dew et al. (2019) used body-mapping to understand the planning experiences of adults with intellectual disabilities and complex support needs. Each participant created two body maps through a guided group process. Participants received a range of art materials and were invited to use symbols, images and text to fill in the inside and outside of the to fill in the inside and outside of their body schema.

On the whole, uses visual, creative and narrative resources that facilitate or promote participation in some phases or throughout the entire process.

Our research project developed in Spain by a group of researchers with and without intellectual disabilities on “The importance of social relationships and loneliness” uses different visual and creative research strategies and resources to create a collaborative relational space. As Nind (2016) points out, the authenticity of the relationships in the group, based on the recognition of personal experience and collective learning, determines the genesis and dynamics of the research group. In addition, to facilitate the participation and collaboration of all members of the group various strategies were developed using different materials and languages throughout the research process which involved design, data analysis and dissemination, thus resulting in participatory productions.

### 3. Study Context

This research is part of a project coordinated by the National Research Plan and Innovation Networks for Educational and Social Inclusion<sup>1</sup>, which aims to promote innovation and development by educational and social agents and entities in four regions of Spain.

The project on importance of social relationships and loneliness began in February 2017. The first information meeting was addressed to young people with intellectual disabilities, their families and some professionals from an association for people with disabilities. In this meeting the meaning of the proposal was discussed: to set up a collaborative research project made up of academic professionals and young people with intellectual disabilities. The two academic researchers also emphasised the inclusive nature of the research and the importance of selecting a research topic relevant to the group. One of the families gave a positive assessment of the project, while highlighting the necessary commitment involved in this kind of work. This provided further information on what the proposal entailed and also an opportunity for the young people attending the meeting to express their interest in taking part.

The framework of the research project was approved by the Ethics and Social Sciences Committee at the University of Cantabria (Spain). At the first meeting the participants were informed of the ethical conditions of the research. These were included in a written document which we reviewed together, a signed copy of which was given to the attendees. The document requested permission to take photographs and videos for the sole purpose of disseminating the research. Consent was obtained from all co-researchers. Subsequently, all members of the team decided to use our real names for the dissemination and publication of the results of the research process and anonymity was guaranteed for all people interviewed on the topic of social relationships and loneliness. Real names and photographs provided by the interviewees are not revealed under any circumstances.

Lastly, eight young people joined the proposal, four men and four women aged between 19 and 26 years old. It is important to point out that we while all have different experience and backgrounds it is essential that all voices are heard. Joining the research team was a personal decision. With regard to the co-researchers’ social and cultural backgrounds, it should be noted that they all lived in their family home, two were looking for employment and the rest were enrolled in some type of training programme aimed specifically at people with intellectual disabilities. All the co-researchers were able to express their concerns, ideas and feelings using spoken language. In addition, they could read and write and use ICT. They showed different levels of competence, and therefore, we used easy-to-read materials to facilitate access to information by all group members.

#### 3.1. Methodology

Over 18 months, the research team met every two weeks for two hour sessions in which decisions were made about what to research, the participants, the data collection strategies, the analysis of information or the dissemination of the results. Following the completion of the research, the team continued working together and produced some

academic texts collaboratively (Álvarez et al. 2022; Rojas-Pernia et al. 2020), among other activities.

The academic researchers made it clear at the first meeting that it was necessary to ensure from the first meeting that the whole team would participate in the decisions that were adopted. To this end, the sessions started by sharing work carried out in the previous session (via the website or one of the audios produced); some of the activities to be undertaken were anticipated (designed by the academic researchers or devised by the co-researchers); key concepts or ideas were organised on a whiteboard to make them visible throughout the session, and the information was repeated using different strategies; either an academic researcher or one of the co-researchers took responsibility for this task. To conclude the session, the issues or ideas relevant to the team were synthesised. All of the above helped to organise the research activity and make it more comprehensible.

As discussed in previous papers (Haya-Salmón and Rojas-Pernia 2021; Rojas-Pernia and Haya-Salmón 2021), this research revolved around four interconnected phases. The first phase was the creation of the team and consultation on the research topic; the second phase focused on designing the research process and data collection; the third phase was data analysis; and the fourth phase was the dissemination of the results.

From a methodological point of view, it is possible to identify two approaches. Firstly, our research was documented by the two academic researchers. This was performed using audio and video recordings and a field diary. In addition, the co-researchers recorded each session through voice notes in which a brief summary of the session and important issues were recorded. Photographs were also taken of the activities carried out. All this material, organised in sessions, was uploaded to the website<sup>2</sup> by the two academic researchers.

Secondly, different strategies, techniques and materials were used in order to promote listening and the participation of all members of the research team. We worked with personal objects, image-theatre, photography, audiovisual material and body-mapping. We focused on the use of some of these resources with the aim of sharing how they could help us get to know each other and encourage dialogue in the team. Consequently, the findings presented in this article are the result of the systematic documentation process carried out by the academic researchers over two years.

The documentation process we followed allowed us to think about techniques that would facilitate the participation of people with intellectual disabilities in the research team. Specifically, this article describes three techniques (objects, image-theatre and body-mapping) that rely on languages other than verbal language. Therefore, the visual methods we present in the results section are used as elements that facilitate inclusive research processes and collaborative inquiry within the team rather than tools for data collection.

### *3.2. Mediated Spaces of Reflection through Objects, Image-Theatre and Body-Mapping*

Three of the techniques used by the research team are described below. A brief description of the technique, the research phase in which it was used, the purpose of its use and reflections by the authors of this article are also included.

#### *a. Personal Objects*

As Mannay (2020) points out, the use of participant-selected objects can be an opportunity to explore their everyday lives as well as a very useful resource in social research. Whether the objects are produced by the participants or selected by them, the participants can lead the conversation and highlight or focus on what is important to them. Furthermore, as the author notes, “the artefacts metaphorically took the researchers to different times and places, and physically shifted the interview setting from the confines of the room” (p. 323).

As we said earlier, the first meeting was informative and was attended by some young people who had been involved in an organisation for people with intellectual disabilities from the region. As a result, some of the young people knew each other through the organisation, although not all of them had participated in the same programmes. For all of us, it was the first time we researched together.

The use of personal objects was introduced in the initial meetings during the first phase, the creation of the team and consultation on the research topic. The academic researchers suggested that each team member bring a personal object that was important to them, whatever they wanted. We had two objectives, to begin to discover ourselves and narrate to others and also to promote an interest in getting to know other people (what links us and what we share or do not share). To this end, we each selected an important personal object and shared it with the rest of the group. The objects that were selected were: a clown's nose, a playstation remote control, a loudspeaker, a cuddly toy, a photo album, a bracelet, a letter, another cuddly toy, a music CD and a book.

"This makes me feel a bit embarrassed, because for me this is already a bit childish". Finally, Elena (co-researcher) uncovered her object: "This is very important to me because it has photos of my first communion. That day was very important, I felt emotional, for me it is very important".

Belén (co-researcher): "My object is a letter ( . . . ) but it was a special moment for me because after many years of bullying, it was the first time, it was my first boyfriend, the first boy that paid attention to me . . . it brings back a nice memory". (Field Notes, s2)

As each person presented their object, other members of the team freely asked questions: Why is that object important to you? What do you use it for? What does it represent? How long have you had it? Memories are linked to people or situations that have been important in our lives.

Susana (academic): What do you think the things we have done have been useful for?

Belén: To get to know something about ourselves.

Susana: How has it helped you?

Ernesto (co-researcher): To know a bit more about the others.

Susana: Nearly everyone has said important things. Why? We go through each of the objects and link them to people that have been or are important in our lives. (AudioRecording, s2)

The objects took us from the past (a special moment, a hobby that we gave up or a person that does not share our life anymore) to the present (hobbies that we have now or new friends). The objects helped us to discover that some people in the group have things in common and that all of us have chosen objects that link us to other people.

#### b. Image-Theatre

Image-theatre is a type of Theatre of the Oppressed (Boal 1979, 2006) that uses non-verbal language to express the experiences of everyday situations. Non-actors can express their ideas, emotions or fears through theatre. The application of this theatrical technique in the context of social and educational research reveals numerous possibilities, increasing the channels and forms of expression and communication while allowing us to explore oppressive or unjust situations that people we work or research with may experience (Rigano 2021; Englhart 2004). Specifically, and within the context of inclusive research, we found inspiring examples in which the Theatre of the Oppressed and image-theatre are used by the co-researchers to denounce socially unjust situations that people with intellectual disabilities experience (Ignagni and Schormans 2016). Thus, according to Perry (2012), image-theatre may "provide participants with a lens through which they can witness instances of domination and oppression as they are enacted by themselves and by others in each moment" (p. 116).

We used the resource of image-theatre in different sessions during the first phase of our research with two main objectives: to use the body as an expressive element and as a means to investigate, reveal or denounce situations of injustice or oppression experienced by the participants.

Specifically, the resource was useful to start thinking about possible research topics. Thus, as described in the following example, image-theatre allowed the group to act out situations from their daily lives (from the present to the past) that were interesting in order to start talking about episodes in their lives in which some of the “characters” saw their rights being violated.

One of the group sculptures represents a break time in a school (Figure 1).



**Figure 1.** Group sculpture.

In the scene, one of the characters is a teenager who is crying. The character wanted “Not to be hit, not to be insulted, not to be made fun of and not to be called a nerd”. The fictitious situation allows some ideas to emerge about what this character experiences and how other young people and adults behave in such a context. Once the performance is over, the team stops to talk about what has been performed.

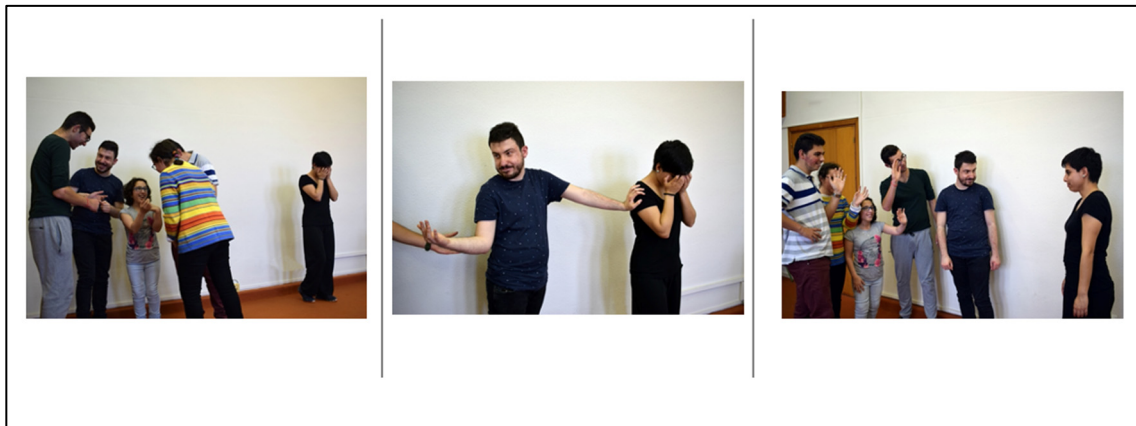
Nacho, one of the academics, states that out of the whole performance he focused on Santi’s statue because it represented an unjust situation. He asks the group if they agreed with him. Without hesitation they answer that it is an unfair situation.

“Do you think that it is an unrealistic situation?” Unanimously, they reply, “quite the opposite”. From that moment on, they began to recount situations they have experienced. Mónica (co-researcher) says that she was treated very badly and had to leave school. Belén (co-researcher) said that, for her, the situation went on for 12 years in two different schools. She points out that telling other people did not help her. Elena (co-researcher) points out that she has also experienced it.

Nacho asks why the situation is unfair. Elena replies that “people like us deserve to be in a good environment, free of bullying, without discrimination . . . just in a group”. “*why do people with disabilities deserve these situations?*” Some classmates react and correct Elena, stressing that we have the right to be well-treated (Field Notes, S1).

Three months following the start of the research project and with work already underway on the formulation of questions around the research topic, the photographs taken during the application of the image-theatre were used to represent our ideas and imagination on the importance of social relationships and loneliness (Phase 2).

At the request of one of the co-researchers, the photographs taken during the activity were incorporated into a PowerPoint presentation, which was used to discuss on our topic in several meetings (Figure 2). The images helped us talk about what we can communicate through the body or facial expressions or how we occupy space.



**Figure 2.** Sequence on the importance of social relationships.

These and other images were used for the dissemination of the results phase and for the preparation of the exhibition open to the public.

### c. Body-Mapping

Body-mapping reveals perspectives that would otherwise be oppressed or obscured. It is a way of representing first-person accounts and social relationships through the body.

As described by some authors (Jager et al. 2016; Gastaldo et al. 2018; Dew et al. 2019), body-mapping involves drawing a life-size outline of the body and decorating the outline with images, symbols and words in response to a series of semi-structured questions. More specifically, body-mapping draws the participants' attention to their bodies and their bodily experience, encouraging awareness and reflection on that bodily experience (Jager et al. 2016).

The body-mapping technique was used in the second phase of our research—designing the research process and data collection. The purpose was to enable those involved to indicate what they feel and where they feel loneliness. It is important to point out that the introduction of this technique resulted from the process of analysing the initial interviews with the participants.

Initially it was decided to use semi-structured interviews to explore the subjective experience on relationships and loneliness of young people with and without disabilities. The first two interviews with young people without learning disabilities made us realise that some questions were confusing: for the interviewees some questions were too abstract and their answers did not help us to understand their experiences, e.g., when we asked them how they feel loneliness.

Susana: We also said something about the interviews ( . . . ) What had we missed?

Santi: Some things were missing!

Mónica: We have to change questions 6 and 7, some of the terms.

Santi: Terms, and a close to end the interview.

Susana: ( . . . ) someone told us the questions were very difficult, we had to repeat them several times and give examples so that they would understand us. So those of us who were in the last session decided that Nacho and I should give the questions some more thought and come up with a proposal. (VRecording 12)

The body-mapping was a result of this interview analysis process. Before incorporating them, we decided to test them between ourselves and assess their suitability.

Susana: How do you see this activity and the questions we asked the interviewees?

Ernesto: Good!

Elena: Oh! I think it's complicated.

Santi: Would it be this activity?

Susana: The interview would be the one we prepared together, but do you remember that some questions weren't clear?

Santi: Yes!

Susana: So, we would do this in the middle: they would have to talk about a situation . . .

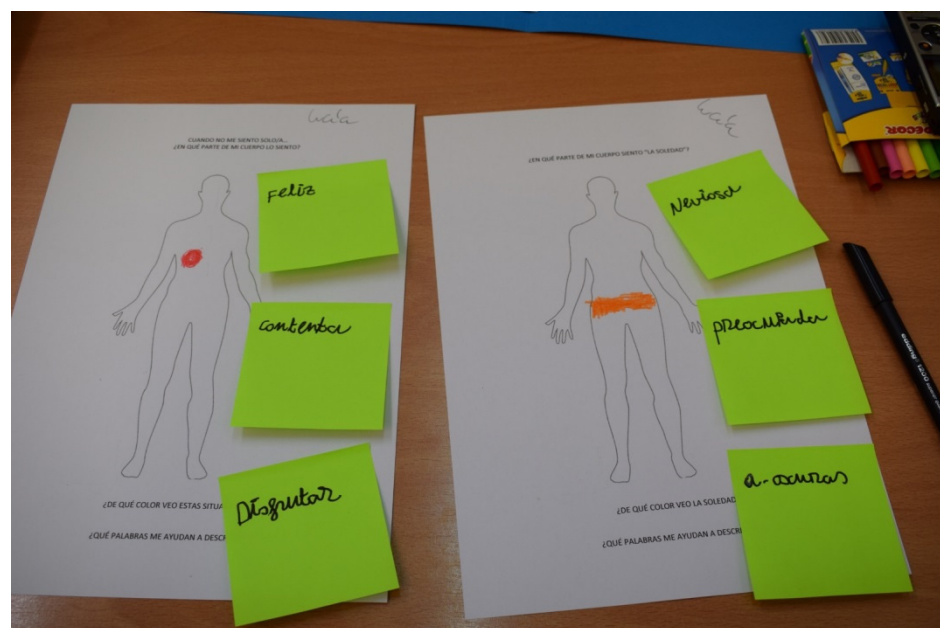
Santi: Oh OK! But without the post-its or the figures

Susana: No, no! With the figures and the post-its, and later we would bring the 60 figures and 60 post-its, whatever . . .

Santi: That would be great! But it's going to be complicated to sort all that out

Elena: That's right! (VRecording 12)

The team carried out five body-mappings (Figure 3). The use of cartographies provided the team with access to personal experiences (something which the interview questions did not achieve) and made it possible to draw what was difficult to put into words. The body-mapping technique “will give us twice as much information because we have the answers to the interview and with this other technique we get more information” (Santi), “so more people participate” (Gerardo, co-researcher), “without using words” (Santi), although “there are things that are difficult to say” (Elena).



**Figure 3.** Personal cartography example. Left: “When I don’t feel lonely—Where do I feel it in my body? What colour would represent it? What words would I use?” (Response: “happy, content, enjoy”). Right: “Where do I feel loneliness? What color would represent it? What words would I use?” (Response: “nervous, worried, in the dark”).

Overall, it can be seen that the methods used during our research on the importance of social relationships and loneliness made it possible for the following:

- Share personal knowledge within the group.
- Talk about the importance of looking after ourselves and others and, therefore, the need to know how to set limits.
- Return to important issues, remembering work carried out so far.
- Use personal experience to connect to social issues.
- Debate complex topics, identify ways of thinking and being in different worlds.
- Recognise the value of basic human rights.
- Organise the process followed.



- Share the research process followed or the work carried out with other people.
- Question the ways in which we traditionally carry out research and the extent to which methods distance us from the people being interviewed or observed.
- Continually reflect on the ways in which research limits and restricts our ability to talk, act and imagine.

#### 4. Discussion of the Results

Research processes that have participatory and dialogical qualities encourage democratic forms of learning for everyone. The research strategies used during all phases of the project, mainly narrative, visual and creative, facilitated the exchange of experiences, interests and curiosity in other people. Dialogue between members widened the options for expressing what is personal and connecting with what is social as well as gave more control to the co-researchers.

As we said before, we made clear that it was necessary to ensure from the first meeting that the whole team was involved in the decisions that were adopted. The issue is not so much a question of accessibility. Thus, while everyone should have access to information, inclusive research must ensure that researchers do not continue to reproduce outdated oppressive dynamics, even when the methods promote participation, and their ethical appeal could lead us to believe that their introduction changes the type of relationships that are built in research and the discourses they promote (Milner and Frawley 2019).

Therefore, it was necessary to develop ways of inquiring, debating or making proposals that recognise all voices from the outset. From the first session, different techniques were incorporated in order to promote forms of communication other than the spoken word, such as the use of objects or body language (theatre-image) to relate situations and relevant ideas to each of us. We were all able to share our experiences and share personal information and ideas about what was important to us.

Moreover, as a relational space, this way of working was maintained throughout the project. The development of the project was an opportunity to get to know each other, discover our strengths, value listening, practice asking questions, respect personal space and appreciate the attention of the people we work with. There needs to be a safe space for all members of the research team and for everyone to recognise that they have authoritative voices.

Thus, valuing research-inquiry strategies that emphasise visual language, for example recording our research process through photography, provides us with tools that help us all to think about the process itself and disseminate it. It is essential to be aware of the opportunities that each research meeting provides in order to be able to review how research is constructed.

As mentioned previously, photographs were taken throughout the research project. The images were taken by the academic researchers and by the co-researchers to document work processes. Some of the productions were used to document work on the website, but they were also very valuable in the dissemination of the results phase (phase 4). Specifically, they were used to record the whole process, which was formatted into a poster (see Figure 4), and for the preparation of the exhibition.

It is important to note that the academic researchers carried out a pre-selection of the images due to the number of photos they had (around 1500). Afterwards, they prepared a guide with questions (image functionality, aesthetic aspects and content) that helped us decide which images would be exhibited.



**Figure 4.** Poster of the research process used in the exhibition. (From left to right and from top to bottom: We have something to say/How did we conduct our research? Images, objects, theater, asking questions, looking for answers. Which concerns us? Looking around us. Working as a team: dialogue and discussion).

Similarly, research processes cannot merely feed the expert role of the academic researchers (extractive research). We believe that academic standards (implementation times, publication rules, etc.) may weaken the principles on which inclusive research is based. Therefore, it is necessary to ensure that there is enough time to stop and think about the ways in which we move forward in research in order for it to be truly transformative. As some works highlight (Ellis 2018), it is possible for research discourses and practices to move in opposite directions if we do not stop to think about it. We agree with Chalohanová and colleagues that “time is needed to relax into relationships that are allowed to build slowly and organically” (Chalochanová et al. 2020, p. 155).

What emerges is a way of working in which academic researchers need to show an attitude of receptiveness, permeability and genuine listening. We recognise a phenomenological attitude in which researchers learn from the situations that arise from what is constructed together, placing us in different positions in the research relationship. From there, it is possible to question, e.g., the use of the interview as the only strategy that can be used, and allow other ways of researching experience, such as body-mapping.

Finally, the productions made by the team and shared with other people later on in the exhibition, e.g., allowed professionals, students or families to think about the research topic, the results obtained and the work processes followed. Similarly, the creation of a space where visitors assessed issues raised in the exhibition and which the team could return to in later meetings was important in the process of personal empowerment.

Reflection on research methods increases knowledge about the ways we have been carrying out research and contribute to recognising the knowledge that emerges from collective learning and the co-production of knowledge. In line with Bigby et al. (2014) and Fudge et al. (2019), the diversity of methods and activities produced a fluid positioning of all collaborators. The contributions and control over the process and the results increased at every stage to the extent that they felt respected. They were progressively exercising more control.

The examples show how the use of different tools and methods is a constant throughout this research. Working with images from the activities we were developing allowed us to return to and discuss important issues, raise questions and share experiences. Objects, image-theatre, the images we made of the objects and the dramatised situations clearly enabled the participation of all members of the team. These images have shaped the biography of the project.

## 5. Conclusions

As we highlighted at the beginning of this article, the principles that underpin research articulate how it develops and the relationships that are built. The research strategies support the principles and, within the framework of inclusive research, these should contribute to improving the lives of people with intellectual disabilities and transforming the type of unequal relationships that are established with them.

We have identified a range of practices in which listening and a willingness to permanently learn from the people we research is essential (article 3 2021) and in which academic researchers support researchers with intellectual disabilities throughout the research process, thus maximising participation.

The development of research projects supported by visual, creative and narrative strategies contributes to imagining other avenues of inquiry. These works also highlight the need for funding agencies to take into account that collaborative research requires time. It is essential not to forget that co-production in its deepest sense is slow knowledge, where history matters.

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## Notes

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<sup>2</sup> <https://inclusionlab.unican.es> (accessed on 27 March 2022).

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## Article

# Doing Research Inclusively: Understanding What It Means to Do Research with and Alongside People with Profound Intellectual Disabilities

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**Abstract:** Positive developments in inclusion in line with ‘Nothing about us without us’ have rarely extended to people with profound intellectual disabilities. Advances in inclusive research are in danger of leaving this group (and their families and allies) on the outside, with researchers relying on proxies at best, or more often omitting this group as ‘too difficult’ to include in the research process at all. This paper argues that finding a way for people with profound intellectual disabilities to belong in inclusive research is important. Using examples, small stories and photographs, it explores and illustrates potential ways to research with and alongside those with profound intellectual disabilities that celebrate different kinds of agency and personhood and that support relational autonomy. The paper concludes that rather than starting from how inclusive research is currently conceived, the starting point should be a deep knowledge of people with profound intellectual and multiple disabilities. The way forward is likely to be an inclusive research culture that can accommodate ‘being with’ as core to its research approach. This will enable the voices of people with profound intellectual disabilities to inform the research in creating intersubjective knowledge together.

**Keywords:** inclusive research; participatory research; profound intellectual and multiple disabilities; belonging; intersubjectivity

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## 1. Introduction

Developments in inclusive research have done much to include the views and experiences of people with intellectual disabilities. In line with the call for ‘Nothing about us without us’ (Charlton 1998), many people with intellectual disabilities are now involved in research about them, not just as participants, but as instigators of ideas, researchers and authors (Walmsley and Johnson 2003). (See Bigby et al. 2014 for a history of the movement). The added value of research of this kind is well rehearsed (Nind and Vinha 2014; O’Brien et al. 2014; Walmsley et al. 2018).

These developments in inclusive research, however, have not embraced the call that ‘All Means All’ (Australian Alliance for Inclusive Education n.d.; UNESCO 2020) that is usually applied to inclusive education. People with profound intellectual and multiple disabilities are yet to belong in any meaningful way to the inclusive research movement(s) (Jones et al. 2020; Mietola et al. 2017; Ward et al. 2016) and are often excluded from research altogether (Kellett and Nind 2001). This means not just exclusion for individuals with profound intellectual disabilities, but the loss of the insights that could be gained from their involvement. When referring to people with profound intellectual and multiple disabilities, we mean people with high and pervasive support needs and multiple disabilities (and often life-limiting conditions), including intellectual impairment such that communications

will be idiosyncratic, not symbolic. However we stress (i) that people with profound intellectual and multiple disabilities have assets too and (ii) that they are also disabled by poor resources and care (see the discussion in Nind and Strnadová 2020 and Vehmas and Mietola 2021).

In this paper, we reflect on the important steps taken by researchers who have begun to include people with profound intellectual and multiple disabilities in research in ways that make them more than just the object of the researchers' gaze (Nind 2014). This is a reflective piece, reviewing the state of the art. We raise fundamental questions about the impact of the exclusion and inclusion of people with profound intellectual disabilities in research, arguing for a paradigm shift. We illustrate some of our points using 'small stories' (Bamberg and Georgakopoulou 2008), that is, brief stories that ground the self and identity in interactive engagement with people. 'Small stories' put forth arguments and confirm and challenge views. Ours combine pictures and words to animate the perspective of someone with profound intellectual disabilities, often enabling the reader to read body posture and facial expression. The small stories add something about what is going on as we take on the role of animator (while limiting how much we interpret). They deliberately communicate in very few words, reflecting that including people with profound intellectual disabilities challenges us in terms of modes of communication.

The paper is not what Davy (2019, p. 111, after Kittay 1999) would call a 'view from nowhere', but is situated in our joint positionalities. We are researchers spanning novice to experienced; we have been practitioners (teachers, a speech and language therapist, and an assistant clinical psychologist), and our understandings of people with profound intellectual disabilities come from decades of involvement as variously: professional, advocate, voluntary sector worker, ally, friend and, most deeply, mother.

## 2. Why People with Profound Intellectual Disabilities Are Left Behind

Inclusive research was not developed with people with profound intellectual disabilities in mind. It has at its heart exploring, celebrating and utilizing the resources that people with intellectual disabilities have that can make research more meaningful, credible and valuable to them (Walmsley and Johnson 2003). Advocates of inclusive research have asserted the need for research 'with', 'for' and 'by' the people the research is about and have rejected research merely 'on' them (Nind 2014). However, over time, the elements of 'with' and 'by' have tended to take precedence over research 'for' people with intellectual disabilities and assumed a new taken-for-granted status as how inclusive research should be. These features of recent history have culminated in a model of inclusive research in which the people for whom the research is 'for' or is conducted 'alongside' are required to be able to express their views about needed research and fulfill roles that academic researchers have traditionally occupied—colleague, interviewer, observer, seeker of patterns in the data, writer, disseminator and creator of impact. This means that they need to match what a conventional researcher knows and does. As Bigby and Frawley (2010) note, when reflecting on work with a co-researcher who resists such molding, this is neither fair nor reasonable. It is no wonder, then, that inclusive research has not been able to stretch its parameters sufficiently to enable people with profound intellectual disabilities to belong.

Walmsley and Johnson (2003, p. 10) see research 'as a microcosm of the wider community'. This makes the restriction of inclusive research to those whose intellectual disabilities are at the mild/moderate end of the spectrum unsurprising; it is typical of wider failures to include those at the other end of the spectrum. The exclusion of people with profound intellectual and multiple disabilities from inclusive research is part of wider marginalization; it reflects what Davy (2019, p. 101) refers to as, 'The modern Western notion of the self as an autonomous, self-contained centre of thought and agency [which] informs cultural understandings of "the good life"'. This reflects the predominance of a narrow conceptualization of citizenship as involving 'communicative competence' (Anderson 1999, cited in Vorhaus 2014, p. 618). Vorhaus (2014, p. 618) argues that this focus on communicative competence means that 'profoundly disabled people are . . . set up to fail the tests' of

full citizenship. This conceptualization of citizenship has underpinned policy imperatives around the increased involvement of people with learning disabilities in everyday life, particularly the ethos of normalization and social role valorization, which has been reproduced in inclusive research approaches, particularly in the UK (where people with intellectual disabilities employed by universities may be viewed as the pinnacle of inclusion). These high bars are evident in inclusive research, where people with profound intellectual and multiple disabilities are often excluded because their forms of communication lie beyond the technologies and practices of traditional, verbally based research roles, meaning that they ‘have had little or no chance to self-author their place within our historical record, nor to contest the many “unauthorized” representations’ (Milner and Frawley 2018, p. 386) in research accounts. They have been the ‘lost voices’ (Atkinson and Walmsley 1999, cited by Milner and Frawley 2018, p. 386) of qualitative research and may be the ‘most silenced’ (Mietola et al. 2017). We follow Vorhaus (2014) here in arguing that, just as this narrow form of citizenship needs redefining to include people with profound intellectual disabilities, so too must inclusive research be reconceptualized to be inclusive of people with profound disabilities.

We acknowledge that this is a challenge. There are structural (practical, methodological and ethical) (Tilley et al. 2020) and conceptual barriers to the inclusion of people with profound disabilities, even as research participants; the ethics procedures designed to protect vulnerable people are increasingly regulatory, often resulting in the exclusion of people with profound disabilities (Kellett and Nind 2001). Moving beyond inclusion as participants, as people have sought to firm up the structures that govern inclusive research to make it fundable, it has become less flexible; this systematically excludes people who cannot meet its requirements (Jones et al. 2020). This was a concern for Nind and Vinha (2014) when they advocated for keeping the phenomenon of inclusive research fluid, and this is why we use their more flexible term ‘doing research inclusively’ in the title of this paper. Without intending to do so, moves to pull some people inside inclusive research expose how people with profound intellectual disabilities are largely left sitting on the outside. As Seale et al. (2015) found, some definitions of inclusive/participatory research would not accommodate projects involving people with profound intellectual disabilities, but such projects ‘serve an important purpose in calling these boundaries into question’ (p. 491).

### 3. Why People with Profound Intellectual Disabilities Need to Belong

In this paper, we argue that current definitions of inclusive research have pushed the field forward, but are, in some ways, problematic because, in including some people, we have somehow excluded others. If inclusive research, like inclusive education, is a simultaneous process of increasing inclusion and decreasing exclusion (Booth 1999), we need an ‘inclusion/exclusion’ project ‘to encourage the keeping of both processes in mind’ (Booth 1999, p. 164). As Vorhaus (2014, p. 616) argues with regard to citizenship more broadly, ‘a profoundly disabled person may be unable to speak or contribute to a process of rational argument, but even when these capacities are absent, she remains a conscious agent, whose acts reveal human intentions and purposes’. This resonates with Carlson and Kittay (2010), who argued that we have moral obligations to people with profound learning disabilities. Only by engaging with these can we explore the nature and limits of concepts such as justice, rights, respect, care and responsibility to inform relevant policy, provision and practice. We add inclusive research to this list. Inclusive research is poorer if we fail to incorporate the experiences, intentions and purposes of people with profound intellectual and multiple disabilities. Society is poorer if we keep some people with intellectual disabilities and their families invisible (an invisibility lamented by Ryan 2021). We need research that explores how different forms of agency can contribute to and enrich inclusive research processes and findings.

Our desire to find ways to do research inclusively of/with people with profound intellectual disabilities is partly a recognition of their marginalization in society (Ockenden



2006)—they and their families are the excluded of the excluded (Lyle 2019). This has meant that research agendas have been underpinned by gross, negative and erroneous assumptions of impoverished lives (Ryan 2021). Assuming the quality of people's lives to be low results in discrimination with real-world consequences. This includes having a learning disability being used as a justification for placing DNACPR orders (Do Not Attempt Cardiopulmonary Resuscitation) on people's records without consultation with families or individuals (NHS England and NHS Improvement 2019). Instead, we follow Reinders (2008, p. 14) in arguing that people with profound disabilities can be understood 'as the rule of what it means to be human instead of the exception'. Without this, we lose the knowledge base held within these differently experienced lives.

Enabling people with profound intellectual and multiple disabilities to belong in inclusive research involves accepting that, while including them is hard, this is not a valid reason for exclusion. We illustrate this with the first of our 'small stories', showing that if something is hard in the lives of people with profound intellectual and multiple disabilities, then our work is to find a way around the barriers.

#### *Small Story 1*

Just once, Johanna (Catherine's daughter) went to an international conference. In this photograph (Figure 1), she was checking in the eleven bags that were all just for her. Clare Barnett came as an informal carer. Johanna was frisked soon after this just in case she had illegal substances hidden in her wheelchair.



**Figure 1.** Checking in at the airport ahead of an international conference.

If all means all, then we must address both micro and macro exclusions. As Grant et al. (2010, p. 160) have argued, this is 'one of the most vulnerable groups in society; and if society is to be judged by how it cares for its more vulnerable members, there is clearly much yet to be accomplished'. If the research community heard more from people with profound intellectual disabilities and their families, the benefits could be transformative. We might think differently about the costs in money, time, space and effort of including them (Brusch 2017) and appreciate the value of their lives. Community is not a problem to solve; instead, we need to build a community around our most vulnerable members (Block 2018). In this paper, we adopt Davy's (2019) feminist ethics of care approach, as this draws attention to the problematic, normative aspect of notions of vulnerability, dependency and responsibility.

#### 4. Advances in Doing Research Inclusively with People with Profound Intellectual Disabilities

In this part of the paper, we argue that doing research inclusively with people with profound intellectual and multiple disabilities is possible. If we can work out their involvement as participants who are able to share their experiences, then we can work out how they can accomplish further research roles. Moreover, meeting the challenge of meaningfully including people with profound intellectual and multiple disabilities in research can be a catalyst for developing approaches that are capable of hearing meaning in new ways, which, if clearly documented, will benefit the whole inclusive research community (Jones et al. 2020, p. 114).

The first step in doing research inclusively with people with profound intellectual disabilities might be to accept that the absence of verbal, symbolic language does not preclude meeting the criteria for inclusive research of Walmsley et al. (2018, p. 758)—research that stands with them, ‘that aims to contribute to social change’ and ‘create a society, in which excluded groups belong’, improving the quality of their lives, drawing ‘on their experience to inform the research process and outcomes’, recognizing, fostering and communicating their contributions, which ‘can be used by people with intellectual disabilities to campaign for change on behalf of others’. The recognized sticking point is about accessing their experiences and perspectives, but for this, we do not need to rely on words.

One key advance is the use of ethnography in an inclusive way with people with profound learning disabilities. As authors Catherine de Haas and Joanna Grace embark on doctoral research concerning belonging for people with profound intellectual disabilities and look to people and approaches leading the way, it is ethnography and, particularly, the work of Gleason (1989), Simmons and Watson (2015), Mietola et al. (2017) and Skarsaune et al. (2021) that provide a strong tributary. Ethnographers are interested in the different ways that people experience the world. The impairments of people with profound intellectual and multiple disabilities mean that they experience their world in a very different way from others. Working ‘alongside’ them in research is one approach to seeing the world from their perspective (Vorhaus 2016).

Altering our lens to look through the multisensory prism offered by sensory ethnography (Pink 2015) offers a good match for the possibility of ‘being with’ people with profound intellectual and multiple disabilities, moving beyond a focus on vision, taking into account the interrelated nature of the senses to improve data quality and depth (Pink 2015). This is innovative and reflexive, and it moves beyond traditional verbally based research methods. In applying this to research with people with profound disabilities, Simmons and Watson (2015) emphasize using ethnographic methods informed by phenomenology to develop a deeper understanding of the lived experiences and agency of school children experiencing profound intellectual and multiple disabilities. Simmons (2020, p. 32) created ethnographic ‘vignettes’—‘rich and prosaic renderings of fieldnotes about social interactions . . . [with a] story-like structure’. By investing prolonged time in understanding his participants through being with them and talking with those who knew them intimately, Simmons achieved research ‘on’ them that was also ‘for’ and ‘alongside’ them. (NB: This is our claim and pre-occupation, not his.) This meets the new criteria for inclusive research proposed by Walmsley et al. (2018, p. 758) of “‘standing with” those whose issues are being explored or investigated’. This approach is also present in Vehmas and Mietola’s (2021) ethnography of Finnish group homes for people with profound intellectual and multiple disabilities and Skarsaune et al.’s (2021) ethnography exploring the relationship between people and professionals and the phenomenon of self-determination. Somewhat bravely given the barriers, Skarsaune et al. (2021) include what might be the perspectives of two participants with profound intellectual and multiple disabilities, acknowledging the epistemic risk of doing so in balance with the obligation to try to represent such “voices” (following Vehmas and Mietola 2021).

### *Small Story 2*

Our second small story is told with a photograph. It shows that, just like any other aunties, Johanna, the daughter of one of the authors (Catherine), enjoyed playing with her nephew. We can see this in Figure 2. This shows that people with profound intellectual disabilities are ‘people first’ too.



**Figure 2.** Johanna, the daughter of one of the authors (Catherine), enjoyed playing with her nephew.

Bigby et al. (2012, p. 453) argue that including the ‘direct voices’ of individuals with severe to profound intellectual and developmental disabilities is difficult given that ‘their thoughts, feelings, and inner mental states cannot be directly accessed’. They cite Kellett and Nind (2001), who, two decades ago, observed that ‘we do not yet have models for involving people with profound learning disabilities as real partners in research’ (p. 52). However, we have come to understand that such direct access is a myth, as all communication is co-constructed, and inference is an ordinary part of the communication process and is not

peculiar to communications with people who are nonverbal (Grove et al. 1999). Moreover, in research, voices in any mode are constructed by the researcher for research purposes (see, e.g., Jackson and Mazzei 2009). We argue instead for constructions of voice becoming a transparent and considered part of the research. Regardless of whether we agree, the communications of people with profound intellectual disabilities are pre-intentional (see the discussion in Simmons and Watson 2015), and their communications can be systematically interpreted by a parent (Forster 2020) or another person who knows them well. This is in contrast to viewing parents as too close to the situation (Ware 2004), effectively silencing both (Kittay 2010). Kittay (2010, p. 401) argues that ‘the intimacy of a parent and child and the parent’s caring labor gives us not a lesser grasp of moral truth but a greater one’.

Concerns about inferring the perspectives of people with profound intellectual disabilities are rooted in ideas about the ‘self-representing subject’, ‘seen as autonomous, articulating their authentic self and interests . . . , whereas speaking for the other is automatically deemed suspicious because this form of representation is mediated by the positioning of the speaker, their biases, privilege, and context’ (Davy 2019, p. 109). Davy’s concept of relational autonomy supports a view that the role of engaged others in helping the individual to live in and make sense of the world, including translating, interpreting and communicating their perspectives, is part of someone’s authentic autonomy, rather than something to be feared as undermining it. Kittay (2019) similarly reminds us that independence is an illusion, and this applies to communicative competence, too; we all rely on others to interpret, and through the reciprocity of close interactions, we can achieve ‘intersubjectivity’ (Stern 2005), which is understood as ‘the ability to share in another’s lived experience’ (Skarsaune et al. 2021, p. 318).

Advancing the inclusion of people with profound intellectual and multiple disabilities in research requires an inclusive stance on humanity, research and communication. In her co-constructed storytelling, Grove (2016) uses any expressive ability a person has, such as a movement or a sound, to enable a group of people tell a story together. Switches, objects of reference and symbols (Goldbart and Ware 2015) are resources for communication, but a stronger resource is the attitudinal shift from thinking in an individualistic way about people to thinking about how we relate to each other (Vorhaus 2021). Whenever Catherine spends time with groups of friends who have children with profound intellectual and multiple disabilities, she is filled with wonder by the capacity of humans to be interactive and find means of communication.

‘Being with’—as described by Forster (2020), partly based on Intensive Interaction (Nind and Hewett 2005)—could be key to doing research inclusively. ‘Being with’ people with profound intellectual disabilities is based on the attachment between people who share meaning, interest in each other and myriad emotions. It is dialogical and rich, with multiple turns over time, not single commands, and questions. If paid care staff in the Hanging Out Program (Forster 2020) could learn this way of being alongside a person with profound intellectual and multiple disabilities, so can researchers. While people with a purpose, such as teachers and teaching assistants, struggle with being still and ‘being with’ (Goodwin 2020), as a parent, Catherine feels that is exactly how she and Johanna (her daughter) were together, relaxed and enjoying each other’s company, even during tasks. Catherine would go as far as saying that Johanna taught her how to just be. ‘Being with’ is not another task, but a mode of being. In a study of quality in inclusive research, Nind and Vinha (2014) found that some of the most established inclusive research teams had established a way of being; they could just be people together alongside doing research together. A research culture that can accommodate ‘being with’ as a core element will hear the voices of people with profound intellectual disabilities by enjoying their presence and letting this inform the research in creating intersubjective knowledge together.

### *Small Story 3*

Kate knew immediately when she met Johanna how to be alongside her and have fun, together. Their immediate connection and engagement with each other were evident (see Figure 3) and meaningful. Kate could adapt herself as a communication partner to



Johanna's communication with a little guidance from Catherine, her parent. Johanna was stretching out on the floor having a break from her wheelchair during a coffee break of Jo Grace's Sensory Stories Training weekend. Jo and Kate came over to say hello; Catherine said that if you lie down next her, she will love it, especially if you clap hands with her. Kate felt comfortable doing this even though she had not spent time with anyone with disabilities since she was a child.



**Figure 3.** Johanna and Kate ‘being with’ each other.

In their book on belonging for people with profound intellectual and multiple disabilities, Nind and Strnadová (2020) bring together accounts from researchers with a readiness to push the boundaries on inclusion. McCormack (2020) used a life story approach, which, working with families and technology, she was able to do inclusively and accessibly. Tilley et al. (2020) enabled a profoundly disabled participant to deposit her life story material in an archive of the lives of people with intellectual disabilities by working with this individual alongside her family, practitioners, academics, archivists and solicitors. Goodwin (2020), while making no claims to doing research inclusively, used a creative art installation—‘golden tent’—to provide an immersive environment for staff and pupils to ‘be’ together, while Warwick (2020) supported a person with profound intellectual and multiple disabilities to use a wearable camera to shift the gaze of the research to her gaze and to see

the meaning in her activity from her (literal) perspective. This is an eclectic assortment of examples that show inclusivity at different levels of granularity—from design issues to micro methods. What they have in common is the researchers' determination that the life experiences of people with profound intellectual disabilities merit our efforts to seek to understand and share them. Their research was 'on' persons in this group but always seeking to be alongside them, appreciating that they can contribute significantly to research outcomes.

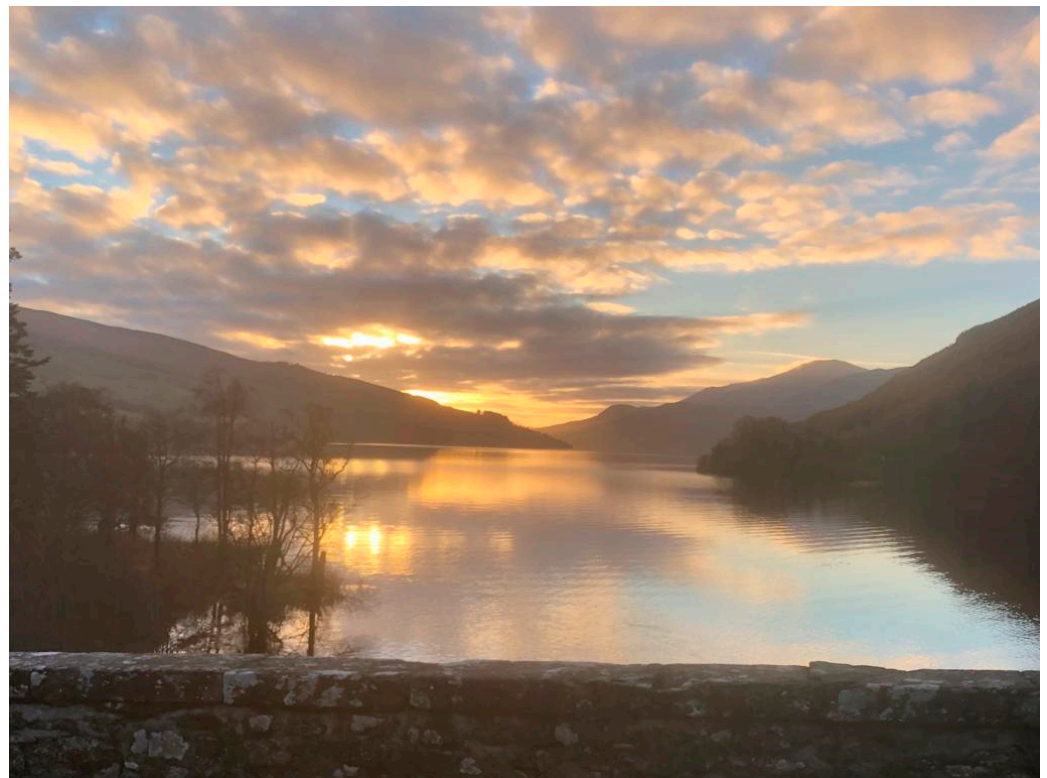
For some researchers, including people with profound intellectual and multiple disabilities is a creative endeavor of opening ourselves up to be surprised by things that we would otherwise have missed (Goodwin 2020) and being willing to use mediated approaches (Cluley 2016). People's capabilities in research have been revealed through their laughter (Brigg et al. 2016; Johnson et al. 2012) and their responses to music and other art forms (Macpherson et al. 2016; Vorhaus 2016; Warwick 2020). Ethnographers working with people with profound intellectual disabilities use careful observations to allow the person to 'speak' for themselves (Watson 2020). Interpretation is handled so that the reader can see what the researcher saw when they were with the person with profound disabilities. Researchers check their interpretations of communications, situations and cultures with people who know the person well (see also Ware 2004). Lyle (2019) argues that knowing someone with profound disabilities well requires being with them for two to five years. As with any inclusive research, there are strong indications that long-term immersion is beneficial or even necessary.

This is a prompt to recognize the many practical and ethical risks in doing research inclusively with people with profound intellectual and multiple disabilities. Inevitably, we warn against attempts from under-skilled researchers or researchers working in time-pressured conditions. We advise critical pauses to pose the difficult questions about whether this really is the way to proceed, whether the process is really 'being with' and 'standing with' and whether an interpretation stands up to scrutiny. However, we must not let risk aversion paralyze us and prevent positive risk taking and possibility thinking (see Seale et al. 2013).

#### *Small Story 4*

Each of us has a unique view of the world. If an academic researcher and a person with profound intellectual disabilities were to look at the scene in Figure 4, one person may enjoy the wide expanse of the hills, and another the light effects. By being in each other's presence, their enjoyment of the scenery can be enhanced, as each pays attention to the other's perspective. Our insights may be shared, and collaboration becomes possible. A person with profound intellectual disabilities may, with their reaction, draw our attention to something that we would otherwise miss.

Doing research inclusively of/with people with profound disabilities involves us as researchers in expanding our capacity to see and listen. We can learn from the work of Olsman et al. (2021) on families as witnesses, practical tips on listening from Goodwin (2013) and creative methods for hearing voice from Evans (2021). We can learn from co-design techniques (Neidlinger et al. 2021) and from seeing the person with profound intellectual disabilities as the teacher (Ward et al. 2016). Doing research inclusively of/with people with profound disabilities also involves reconceptualizing the research partnership (Seale et al. 2015; Tilley et al. 2020). More dialogue is needed to move the flow of ideas forward (Nind and Seale 2009; Seale et al. 2015), as schools are attempting to do (Colley et al. 2022). People with profound intellectual disabilities are capable of being responsive to their environment and of forming deep relationships with people they know well (Kittay 2010). This means that they can play a role in a research partnerships or teams where each person has a unique, interdependent role.



**Figure 4.** Different ways of seeing.

## 5. Conclusions: The Need for a Paradigm Shift

We need to move from focusing on the challenges of doing research with people with profound intellectual and multiple disabilities to considering what we gain by embracing new possibilities. We argue here that when embarking on new research on and with people with profound disabilities, researchers should not start by attempting to modify currently accepted models of inclusive research. Instead, we should begin from a deep understanding of people with profound intellectual and multiple disabilities. This allows us as researchers to tap into the meaning contained within and around people's lives while striving to realize their contributions, recognizing that all people hold valuable knowledge. This would allow us to conduct research underpinned by epistemic justice (see Collis 2021; Walker 2019).

People with profound intellectual and multiple disabilities are human not because of a list of psychological or cognitive capacities, but because of how they are in the world and how they interact with others and are cared for by others (Kittay 2010). This focus on personhood directs us not to tweak often verbal inclusive research practices, but to shift our thinking fundamentally. Inclusive research in the field of intellectual disabilities in the UK has deep connections with the self-advocacy movement; both inclusive research and self-advocacy celebrate the power of people's voices and choices. However, just as the self-advocacy movement has left people with profound intellectual disabilities and their families with a sense of not belonging (Palmer and Walmsley 2020), so too has inclusive research. There is a risk that in emphasizing the capacity of self-advocates and self-advocacy, people with profound disabilities are excluded on the grounds of cognitive incompetence (Davy 2019), mirroring the exclusion of people from true citizenship described by Vorhaus (2014). This may be a little unfair to self-advocates and their allies who do seek to speak *with* people with profound disabilities, which we, like Davy (2019), recognize makes 'self-representation' collective rather than individual. Nonetheless, we may need to look elsewhere when addressing 'all means all'.

A more solid foundation for doing research inclusively of/with people with profound intellectual disabilities involves genuine engagement with the relational concepts of self described by Davy (2019). Here, dependency and vulnerability are the norm; they are



‘basic features of the human condition’ (Davy 2019, p. 102). This allows us to dispense with notions of the ‘autonomous individual’, instead acknowledging *all* people as ‘situated and embodied’ and as requiring care in order to engaged autonomously in the social world (Davy 2019). We concur that agency and autonomy can only emerge relationally, and propose that the place of people with profound intellectual disabilities in research is as much about care as it is about autonomy. We need to resist seeing people with profound intellectual disabilities as a deviation from what it means to be intellectually disabled and from what it means to be human. Our position is one of optimism. We believe that by freeing ourselves of the preoccupation with autonomous or verbal voice, and by making explicit the issues involved, we can begin to make use of the conceptual and methodological tools at our disposal to do research inclusively with people with profound intellectual disabilities. We are confident that people with profound intellectual disabilities have knowledge to share and that, by being open to this, we all have much to gain.

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## Article

# Relationships of People with Intellectual Disabilities in Times of Pandemic: An Inclusive Study

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**Abstract:** (1) Background: Since 2012, our Inclusive Research Team has developed several studies on various topics that interest the co-researchers with intellectual disabilities. In 2021, throughout the COVID-19 pandemic, the co-researchers decided to investigate the impact of the pandemic on the relationships of people with intellectual disabilities. The aim of this article is to disseminate how this inclusive study was developed and to explain its results; (2) Methods: Co-researchers and academic researchers met six times to make different decisions: decide on the research topic; discuss the topic; prepare an interview script for people with intellectual disabilities; analyse the data obtained; and decide how to disseminate the results of the research. The co-researchers interviewed 10 people with intellectual disabilities and participated as facilitators in 3 focus groups; (3) Results: During the pandemic, digital devices have enabled people with intellectual disabilities to maintain their social relationships. However, the lack of access or support in using them, as well as the restrictions imposed on people with intellectual disabilities living in institutions, have presented significant barriers to maintaining their social relationships; (4) Conclusions: This article shows the difficulties people with intellectual disabilities face in maintaining successful social relationships in times of pandemic, and how we undertook research in an inclusive, virtual manner.

**Keywords:** intellectual disabilities; inclusive research; pandemic; relationships

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## 1. Introduction

### 1.1. The Advisory Committee of the “Diversity Research Group”

In 2012, the “Diversity Research Group” constituted an Advisory Committee made up of 10 adults with intellectual disabilities. The objective was to record their opinions and experiences on the transition to adult life, the subject of the research project that was being developed at that time. In this way, a collaborative relationship began in which people with intellectual disabilities advised the researchers and helped them make decisions in the different phases of the study. The richness of the process and the results of this incipient collaboration (Puyaltó et al. 2016) led the group to continue with this collaboration and to increase both its intensity and frequency, developing the three main forms of collaboration recognized in inclusive research (Bigby et al. 2014): advisory actions (for example in a research on transition to adulthood, see Fullana et al. 2016; Pallisera et al. 2015); co-research (for example, in research on independent living, see Pallisera et al. 2017), and leadership of some of the research processes developed (such as life as a couple, see Puyaltó et al. 2019). Rooted in the participatory and emancipatory research paradigms, the inclusive research model (Walmsley 2001, 2004; Walmsley and Johnson 2003) encourages research conducted by people with disabilities and argues that people with relevant experience in relation to the studied topic should be included in the research and their participation facilitated in all

phases of it, as a necessary way as a way of respecting their right to actively participate in matters that concern them.

The working procedure followed by the Advisory Committee (AC) is based on monthly meetings (bimonthly in some periods), lasting about three hours, on Thursday afternoons, at the university. Each meeting begins with an informal time of approximately one hour, so that all the participants (researchers and co-researchers) can catch up and have a snack together before starting work. During the meetings, the researchers offer different forms of support to the co-researchers, depending on the objective of each meeting and the type of collaboration carried out: preparation of the meeting material in an accessible format, preparation of accessible minutes, facilitation of the debate sessions, and joint preparation of materials for dissemination of the work carried out, among other forms of support. Most of the meetings have been video recorded by the researchers with the consent of all the co-researchers, something which has made it possible to document the entire process. A total of 35 people has formed part of the AC over almost 10 years. Each academic year, the Committee is composed of between 10 and 12 people. Participation is voluntary, and participants decide about their continuity in the AC depending on their interest and availability.

### *1.2. The Impact of the COVID-19 Pandemic on Personal Relationships*

The World Health Organization declared COVID-19 a global pandemic on 11 March 2020. Measures such as mobility restrictions and social distancing were adopted in all countries. The government of Spain declared a State of Emergency (Real Decreto 463/2020 2020) as a mechanism to legally impose home confinement measures. Daily life was greatly disrupted, especially between 15 March and 21 June 2020. Since then and during the first six months of 2021, contagion control measures were maintained, entailing restrictions in terms of the number of people in social gatherings and mobility restrictions in the worst moments of the pandemic.

This situation affected university life and, therefore, the activities of the AC, which was affected both in its way of working and the research topics undertaken. The collaboration between the research group and the AC was uninterrupted, but all the activities (the meetings and the application of the instruments) took place online. This adaptation was not without a series of difficulties. These are described in the “Materials and Methods” section of this article.

During the period of confinement, the AC decided to undertake two items of research related to the effects of the COVID-19 pandemic on their lives. The first of them took place from March to July 2020, in a collaborative, inclusive manner (Walmsley et al. 2018), and aimed to explore the impact of the pandemic on the rights of adults with intellectual disabilities. The second, held between February and October 2021, focused on the impact of the pandemic on the personal relationships of people with intellectual disabilities.

From the beginning, concern regarding the impact of the pandemic on the lives of people with disabilities has motivated the issue of resolutions by international organizations. Some of these refer directly to the issue of interpersonal relations (European Union Agency for Fundamental Rights (FRA) 2020; United Nations 2020a, 2020b; UNICEF 2020). The United Nations (2020b) highlights the negative impact of the pandemic on the social inclusion of people with disabilities, both in their participation in the community and in the establishment of personal relationships with their peers. Concern for the well-being of people living in institutions merits special emphasis, due to the seclusion and resulting social isolation that they suffered throughout the pandemic (United Nations 2020a).

A large amount of research has been undertaken that addresses the impact of the pandemic on people with disabilities. The voice of people with intellectual disabilities has hardly been considered in this line of research, with some exceptions; Among the studies that do provide the perspectives of people with intellectual disabilities, we should highlight those of Embregts et al. (2020); Drum et al. (2020), Amor et al. (2021) and McCarron et al. (2020). In the Netherlands, Embregts et al. (2020) explore the experiences of six

people with intellectual disabilities during the emergency period, highlighting the increase in their feelings of loneliness, personal discomfort, and the loss of relationships. Drum et al. (2020) surveyed 2469 adults in the US, 930 of whom have intellectual disabilities, autism, epilepsy, or brain damage. Overall, 66% of those surveyed experienced anxiety or depression due to the pandemic, and 20% reported not being able to access support services. Emotional issues grew among respondents over time as the pandemic continued and lack of services/supports made these problems more acute. McCarron et al. (2020) present the findings of Wave 4 of IDS-TILDA, a longitudinal study conducted in Ireland since 2008 which aims to identify the principal influences on successful ageing in people with intellectual disability in Ireland. Wave 4 of this study coincided with the pandemic period and included a COVID-19 questionnaire that was administered to 710 participants with intellectual disability. Some of the main findings indicate that more than half of the participants (55%) indicated stress or anxiety due to pandemic and that the most common cause of it was not being able to do usual activities, not seeing friends/family, loneliness/isolation, and fear of getting COVID-19. Even though people living independently or with family were more likely to report missing friends than those living in residential care or community group homes. Finally, Amor et al. (2021), also explored the perceptions of 582 people with intellectual disabilities during the lockdown in Spain through a questionnaire in which information was collected in relation to: access to information, emotional experiences, effects on living conditions and access to support. The participants reported difficulties on an emotional level, as well as problems to continue working or training. In research as a whole, it can be observed that the subject of relationships has hardly been studied in the research on the impact of COVID-19 on the lives of people with intellectual disabilities.

The objective of this article is twofold: on the one hand, to disseminate how we carried out this inclusive study; and on the other, to provide information on a significant issue for people's lives, focusing on the barriers they have encountered to maintaining their personal relationships and to make proposals for improvements.

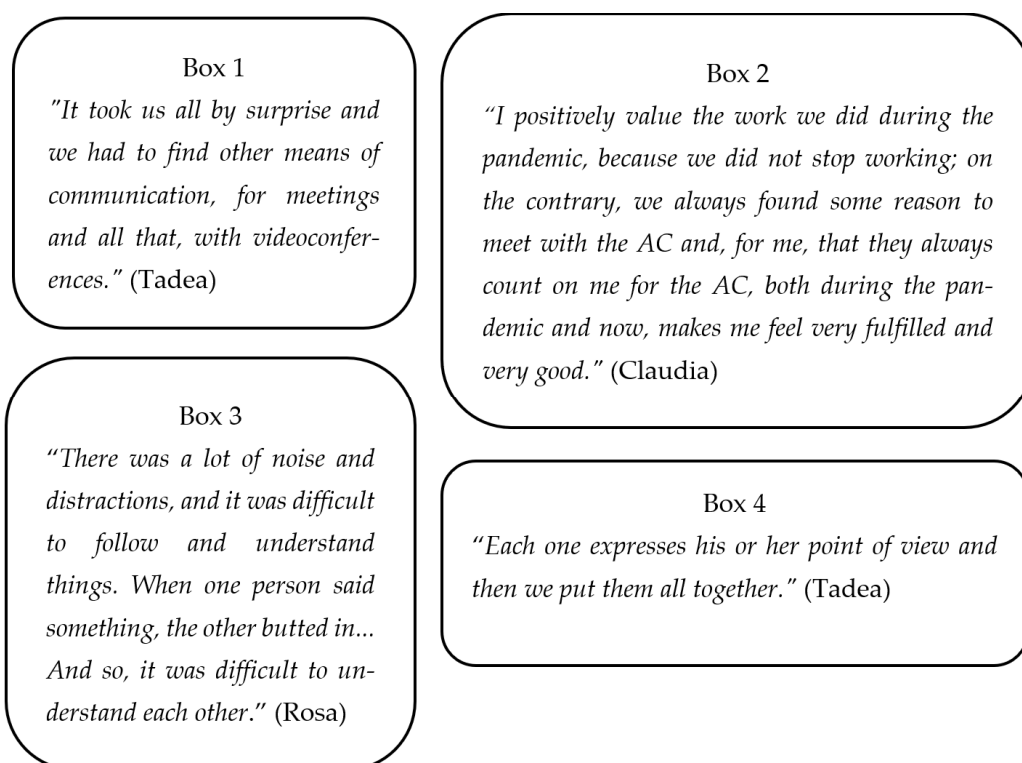
In this inclusive study, the role of the academic researchers has been to support the co-researchers throughout the research process. They were supported in choosing, exploring, and discussing the topic, collecting data on the topic through interviews and discussion groups, and analysing the results obtained. The academic researchers were also responsible for organizing the working meetings held with the co-researchers. This article was written mainly by the academic researchers after holding two working meetings with the co-researchers at the end of the research process with the aim of including their voices in this article. In the first meeting, after positively evaluating the possibility of publishing this article and its implications, the co-researchers reviewed the research process carried out and assessed different elements (study topic, methods used, current situation regarding the study topic, etc.). Their evaluations were later analysed by the researchers and included in the article in the form of vignettes. In the second meeting, the researchers presented the different sections of the article to the co-researchers in an accessible format in order to assess their content. They were also shown their contributions in the different sections so that they could decide whether they agreed to include them. Finally, they decided if they wanted to use pseudonyms and if they wanted to participate as authors of the article. The co-researchers agreed with the information provided in the article, they decided to include all the vignettes proposed by the researchers that included their points of view; and they chose their own pseudonyms—these appear in the vignettes that expose comments made by the co-researchers on different topics, such as the methods used in the research ("Materials and Methods" section) or the importance of researching on interpersonal relationships in times of pandemic ("Discussion" section).

## 2. Materials and Methods

Between September 2020 and June 2021, 11 co-researchers, 6 women and 5 men, aged between 18 and 60, formed part of the Advisory Committee (AC) of the Research Group.

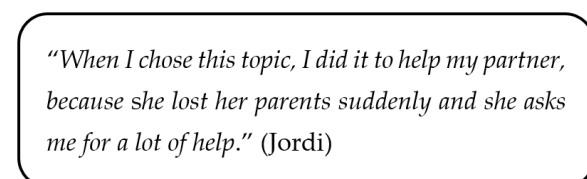
Three of these people joined the Advisory Committee for the first time. The AC had the support of five researchers and a master's student, who were in charge of facilitating the work sessions, taking a note of the agreements reached, helping in the elaboration of the information collection instruments, and providing support to the processes of information gathering and data analysis.

The research was carried out between February and October 2021. Due to the restrictions derived from the COVID-19 pandemic, the work was carried out online, which meant a different way of working compared to what used to be the normal operation of the AC (Figure 1, box 1). The videoconference meetings had the virtue of maintaining the activity of the AC during the time of restrictions (Figure 1, box 2), although technical problems had to be solved (connection, audio, etc.) (Figure 1, box 3) that conditioned some decisions, for example, to work on some phases of the process in small groups in order to facilitate communication between the co-researchers (Figure 1, box 4).



**Figure 1.** Co-researchers' opinions 1–4.

The process began with a meeting in which possible topics for research were discussed. In this first meeting, the co-researchers were presented and, through a discussion facilitated by one of the researchers, the concerns, themes, and questions that could be the subject of a more in-depth analysis through an inclusive research process were explored. The AC decided to focus its work on social relationships and friendships and how these relationships were affected by the pandemic (Figure 2).



**Figure 2.** Co-researcher's opinion 5.

The second meeting aimed to explore the experiences of the co-researchers on the research topic. For this reason, two groups were organized working in parallel, with the support of three researchers. Each group was set up as a focus group and they debated about who they usually interact with, what is the role of friends, what difficulties they find in establishing friendships and what or who helps them to establish and maintain these relationships. Part of the debate was dedicated to analysing how the restrictions due to the COVID-19 pandemic were affecting family, friendships, and relationships with partners. The role of new technologies in the pandemic situation in terms of maintaining social relations was also explored. After this analysis, the two working groups showed interest in knowing what other people with intellectual disabilities thought about this issue, so the possibility of conducting interviews was proposed. It was agreed that two people from each group would be in charge of preparing a script for an interview.

In a third meeting, 4 co-researchers with the support of 4 researchers prepared the interview script that included topics such as the type of relationships the person has, the difficulties and supports to make friends, the impact of the pandemic on their own relationships, and the use of new technologies to interact. The team jointly decided on the procedure for collecting the information, including the informed consent of the participants.

Throughout the agreed period, the same 4 co-researchers were in charge of conducting the interviews with some of their acquaintances. They contacted them via WhatsApp and phone calls to inform them about the research and to ask if they would be interested in participating in a virtual interview. Most interviews were carried out through the WhatsApp application audio recording tool. Each co-researcher recorded the questions in audio and sent them to one of his acquaintances with whom he or she had previously agreed to conduct the interview (Figure 3). Before starting the interviews, each participant was informed of the purpose of the research and that his or her anonymity would be guaranteed. Participants were also informed that they were free to answer only the questions they wanted to and could leave the interview at any time if they so wished and their responses would not be used for the project. The person's consent to participate was orally recorded, due to the virtual format. Data were collected from 10 people with intellectual disabilities aged between 18 and 60 years old, of whom 3 lived in group homes and 7 with their parents. The recordings were sent to two of the researchers, who did the transcription of the audio interview tapes. A third researcher analysed the interviews through thematic analysis (Nowell et al. 2017). It was performed question by question. The answers to each question were categorized by topic and summarized in bar charts to facilitate subsequent analysis and discussion with the Advisory Committee.

Co-investigators positively valued conducting interviews with people with ID:

*"I think the interviews were very successful, in the sense that they (the people interviewed) even asked us if we had any more questions. The topic fell short."* (Jordi)

Conducting the interviews was a personally rewarding endeavour for some co-researchers:

*"I thought that the people I interviewed would not participate and, in the end, it went very well, they really enjoyed collaborating and I was able to find out their opinion on this matter. I liked finding out the opinion of people of different ages and with different points of view."* (Claudia)

**Figure 3.** Co-researchers' opinions 6, 7.



In a fourth meeting, the results of the 10 interviews with the co-researchers, who worked in two groups, were presented and analysed. Specifically, the researchers presented the main topics that came up in each question of the interview, indicating in bar charts how often each topic was repeated by the interviewees. Presenting the results in this way made easier for the co-researchers to analyse and discuss the results. During this analysis process, the researchers took note of which topics the co-researchers considered most relevant. These topics were: the value of friendship, the difficulty of making friends without a disability, the importance of new technologies for maintaining relationships, the difficulty of living without physical contact and the lack of freedom to move and see your beloved ones. At the end of the meeting, the researchers proposed to explore the research topic a little more and the idea of holding a focus group with other people with intellectual disabilities arose. Through conducting focus groups, it was intended to obtain more information and, in this way, improve the validity of the results found to date. Two co-researchers showed interest in participating as facilitators of these groups.

The researchers contacted three groups: two groups of self-advocates and a recently created inclusive research group. An accessible e-mail was sent to these groups to explain the aims of the research and request their collaboration in participating in a virtual focus group. All three groups accepted the invitation. In focus group 1, 9 people who made up a group of self-advocates participated. Focus group 2 was carried out with another group of self-advocates in which 11 people participated, and focus group 3 with an inclusive research group made up of 7 co-researchers. Each focus group was facilitated by one of the co-researchers, with the support of two or three researchers (Figure 4). The three focus groups were carried out via videoconference, the same topics were discussed as in the interviews, and the consent of the participants was obtained from all of them, in oral format due to the videoconference process itself. The same procedure was followed to request consent as in the interviews. Once finished, two researchers did the transcription followed by thematic analysis. This analysis was presented and discussed with the Advisory Committee in the fifth meeting.

The role of facilitator of a focus group was a totally new activity for the co-researchers:

*"It was a bit difficult for me to moderate the focus group. At first, I was a bit shy because I had never done it before and also, I did not know any of the participants. That is why at the beginning you (the researchers) had to help me a little bit, but then I started to get the hang of it."* (Claudia)

Regarding a focus group that was carried out with an inclusive research group from another city, Claudia comments:

*"I liked joining this focus group because we already knew the points of view of the people in our city, because we had already done the interviews, and with this focus group we were able to learn how people from other parts of Spain experience this issue"* (Claudia)

**Figure 4.** Co-researcher's opinions 8, 9.

Finally, in order to discuss the results of the focus groups and prepare this article for publication, two working meetings were held with the co-researchers. In meeting 5, 3 co-researchers, with the support of 4 researchers, analysed together the main topics extracted from the focus groups. In that case, to guide the discussion, the summary of the topics

was accompanied by some excerpts from the focus groups. This procedure made it easier for co-researchers to analyse and discuss topics that seemed most important to them. On this occasion, the co-researchers considered that much importance should be given to the situation experienced by people with intellectual disabilities living in group homes during the pandemic. Thanks to the contributions made by the co-researchers during the analysis of the interviews (meeting 4) and the focus groups (meeting 5), the researchers were able to establish a list of final categories and main topics, which are included in Table 1. After discussing the results of the study, co-researchers evaluated the possibility of publishing an article and the research writing process developed. From this meeting, the researchers were able to make headway in the draft of the article incorporating the contributions of the co-researchers.

**Table 1.** Main topics and categories derived from the analysis of the interviews and focus groups.

Main Topics	Categories
1. The relationships of people with intellectual disabilities before the pandemic	<ul style="list-style-type: none"> <li>• Relationship circles</li> <li>• Benefits of relationships</li> <li>• Limitations and challenges of relationships</li> </ul>
2. The opportunities and threats to relationships in times of pandemic	<ul style="list-style-type: none"> <li>• Restrictions to maintain relationships</li> <li>• New ways of communicating</li> <li>• The need of physical contact</li> </ul>
3. The impact of the pandemic on the relationships of people with intellectual disabilities who live in group homes	<ul style="list-style-type: none"> <li>• Restrictions in group homes</li> <li>• Social isolation</li> <li>• Human rights violation</li> </ul>

In the sixth meeting, the researchers presented the different sections of the article to the co-researchers in an accessible format in order to assess their content. They were also shown their contributions in the different sections so that they could assess whether they agreed to include them. Finally, they decided if they wanted to use pseudonyms in the vignettes that show their opinions and if they wanted to participate as authors of the article.

Table 2 summarizes the process followed to develop the research and prepare this article.

This research was part of a larger project that was ethical approved and authorized by the Spanish State Research Agency who funded the project (protocol code EDU2017-84989-R). Accessible information about the research was provided to all participants and, once they agreed to participate, they gave their consent. Due to the pandemic situation, the informed consents were recorded orally. Data protection legislation was followed throughout the study (Spanish Organic Law on Data Protection 3/2018 and the Regulation (EU) 2016/679 of the European Parliament and the Council, 27 April 2016).

**Table 2.** Synopsis of the process followed to carry out the research and prepare the article.

Activity	Participants	Tasks and Agreements
Advisory Committee Meeting 1	11 co-researchers, 5 researchers and 1 student.	Presentation of the Advisory Committee Exploration of themes: It was agreed to investigate the impact of the pandemic on the social relationships and friendship of people with intellectual disabilities.
Advisory Committee Meeting 2	11 co-researchers, 5 researchers and 1 student.	Discussion in two groups on the topic of social relationships and friendship.
Advisory Committee Meeting 3	4 co-researchers, 3 researchers and 1 student.	Preparation of an interview script Agreement on the data collection process.
Application of the interviews	4 co-researchers	Conducting the 10 interviews.
Analysis of the interviews	3 researchers	Transcription and analysis of thematic content of the interviews Synthesis of the results through bar diagrams.
Advisory Committee Meeting 4	10 co-researchers, 5 researchers and 1 student.	Discussion in two working groups on the results of the interviews
Focus group 1	Participants: 9 people with intellectual disabilities (7 women and 2 men). Facilitators: 2 researchers	Discussion on how the pandemic was affecting social and friendship relationships
Focus group 2	Participants: 11 people with intellectual disabilities (7 women and 4 men) Facilitators: 1 co-researcher, 1 researcher and 1 student.	
Focus group 3	Participants: 7 people with intellectual disabilities (5 women and 2 men). Facilitators: 1 co-researcher, 2 researchers and 1 student.	
Analysis of the focus groups	2 researchers.	Transcription and analysis of the information obtained through the three focus groups
Advisory Committee Meeting 5	3 co-researchers and 4 researchers.	Discussion on the results of the focus groups Review of the research process followed. Appraisal of the study (theme, methods used, etc.). Appraisal of the current situation
Advisory Committee Meeting 6	4 co-researchers and 4 researchers	Review of the article and suggestions for improvement. Decision making on the authorship of the article.

### 3. Results

The aim of the research was to determine the opinions of people with intellectual disabilities on the impact of the pandemic on their social relationships. The results presented below derive from the analysis of the information obtained in the three focus groups and in the 10 interviews conducted by the co-researchers. These results are organized around three main themes: the relationships of people with intellectual disabilities before the pandemic, the opportunities and threats to relationships in times of pandemic, and the impact of the pandemic on the relationships of people with intellectual disabilities who live in group homes. To illustrate these issues, verbatim quotes from people with intellectual disabilities are included. All participant names have been changed to pseudonyms.

#### 3.1. Pre-Pandemic Relationships

The people interviewed and those who participated in the focus groups revealed that the people with whom they usually interact, beyond the family nucleus, are friends

with disabilities with whom they share leisure, work, or training activities, and with the professionals who work in organizations that provide them services. Most participants agreed that friends are a valuable source of help. Of the 10 people with intellectual disabilities interviewed, 8 thought that friends can help to understand situations. Three people considered that, in addition, friends help to have fun and overcome problematic and/or conflictive situations. According to the participants of the focus groups, friendship also teaches you to take care of others and be interested in them and put yourself in their place. They agreed that friends help to have fun and be happy. All the participants emphasised that friendship is based on reciprocity.

*Lucy: My friends help me, and I help my friends. They ask me how I am, how my family is and so on. Also, if sometimes I don't know how to say something, they help me. (FG2)*

All the participants reflected on the difficulties they find in establishing friendships. Most of the people interviewed highlighted the fact of not feeling accepted by others (9 out of 10), feeling different and little understood (8 out of 10). Half of the people interviewed considered that people with intellectual disabilities tend to be seen as inferior by the rest of society.

*Rose: Well, before I had a hard time relating, making friends, and for people to accept me, regardless of whether I had a disability or not, because many people did not understand what I was explaining ( . . . ). Just because of having a little disability, people have a hard time accepting it. (Interview 9, 27 years old)*

In the focus groups, it stood out that difficulties in establishing friendships with people without disabilities may be due to other factors such as: having attended a special school and having only related to people with disabilities; the lack of trust that people with disabilities themselves experience towards people without disabilities—especially those who have been victims of bullying; the fear of feeling rejected; and the lack of knowledge and understanding that people without disabilities have about intellectual disability.

*Arturo: I interact with the monitors at the centre, with friends, family... with friends from here in the town, no, because I get along very badly with them. I get along better with those in the occupational centre, because they are (people) with disabilities, just like us. Because the non-disabled mess with you, you know? That is why I interact with people from the occupational centre, or with the family: people who love me. (FG3)*

*Paula: It is true that we relate more to our environment than to other people. Because they don't know how to act with us. So, it is a bit difficult to make friends with people who do not have disabilities. You need to realise that those of us with disabilities do not have friends who do not have disabilities. (FG3)*

### 3.2. Relating in Times of Pandemic: An Opportunity or a Threat?

The pandemic has had a direct impact at different levels on the friendships of people with intellectual disabilities. Some people interviewed emphasised that the pandemic has caused important restrictions, such as not being able to see friends (5 out of 10), their partner (3 out of 10) and some relatives (4 out of 10), especially when they are not part of their own circle of cohabitation.

Regarding the way of relating, online communication was highlighted as one of the main changes that the pandemic has brought about. The physical distancing imposed during home confinement led to increased use of mobile devices and computers in order to maintain contact and communicate with others.

Participants in the focus groups and interviews explained that they had to learn to use applications and platforms such as WhatsApp, Meet, Skype, or Zoom. They positively valued that this learning, in most cases, facilitated by family members and support professionals, allowed them to maintain contact with their friends and family, and continue with their training online.

Gina: *Yes, yes, they have helped me, especially in the foundation to know how a Meet works, or a Zoom or at home they have also been helping me: "look, this is used like this or this like this". To know how to communicate, because in the future I know how to do it better, know how to use them better and not depend so much on other people. (Interview, 27 years old)*

Even so, they stressed that this has not represented a learning opportunity for all people with intellectual disabilities since not all have devices that allow them to access these types of applications and communication platforms, or if they do, they do not all have the necessary support to learn to use them.

Paula: *There are friends from the centre who we cannot see, because they do not have electronic devices. And this is a barrier. Or they don't have an internet connection. Or their parents are older and cannot help them. (FG3)*

In any case, most of the participants agreed that, despite the fact that technology has allowed them to maintain their friendship and partner relationships, they have not been able to meet the need to maintain physical contact with the people they appreciate. In fact, various participants agree that, in the wake of the pandemic, relationships have become considerably dehumanized and have cooled. This has caused distress in some cases and in others, it has posed new challenges such as that of being able to once again experience physical contact with people who were close.

Natalia: *Virtually, you can see your friends and talk to them, and that's fine... But you only see their faces, you can't touch them or hug them... This made me sad. (FG3)*

Martin: *The truth is that it makes me feel strange to be touched after so long... (FG1)*

### 3.3. Living in Institutions in Times of Pandemic: The Impact on Social Relationships

Although most of the people who participated in the interviews and focus groups live with their families, some live in group homes with other people with disabilities and their support professionals. In these cases, people reported having suffered the effects of the restrictions derived from the pandemic, as well as those imposed by the organizations where they live.

People living in group homes explained that their home confinement was longer than that of the general population. In fact, some of them were confined to group homes for—more than a year—the general population was confined for approximately three months—and with limited mobility to essential activities, such as going to the doctor and other specific actions. This restrictive measure was established during the beginning of the confinement and according to the participants it was imposed to protect them and the support professionals from possible infections. One of the effects of this measure has been social isolation and restriction of freedom of movement.

Joseph: *I have not been able to see my partner for a year. She lives in another group home. (FG1)*

Miguel: *(The confinement) has affected me emotionally, I miss my partner, my family and my friends who do not live in the group home. I hope everything returns to normal... (Interview, 60 years old)*

The participants explained that their activities were also stopped in the day centres, although this was only done for those people who resided in group homes, which meant that the possibilities of social interaction were even more limited for them.

One of the consequences that the pandemic has had for residents of group homes is that activities outside the group home had to be carried out in groups with the accompaniment of a support professional. For the research participants who lived in group homes, this has meant an increase in the already usual restrictions of the institutions since it has led to the loss of contact with friends and family and the loss of autonomy to be able to carry out activities with them. All this has caused a feeling of distress in the residents of the group

homes, who denounce that they have regressed in the exercise of some of their rights, such as making their own decisions or moving freely.

During the last meeting with the Advisory Committee (Meeting 5), two co-researchers living in a group home highlighted the fact that, a year and a half after the pandemic began, some of the results obtained, and described above, on the restrictions on interaction that people with intellectual disabilities experience in the institutions are still in force. This continues to occur despite the fact that almost all restrictions—except for the use of a mask in closed spaces—have now been withdrawn by the administration. In this sense, the co-researchers report that they continue to experience difficulties in meeting their partners and in moving freely outside their home.

*Jordi: They still won't let us go out alone. They only let us out to come to the university. We have to be accompanied by monitors, like dogs. ( . . . ) They are taking away the freedom we had, that's how I see it. (Meeting 5)*

According to the co-researchers, these restrictions not only have negative consequences on their freedom, but also contribute to people with intellectual disabilities being singled out and stigmatized against by their communities.

*Jordi: Now they talk about us behind our backs, because we go everywhere with a monitor. Before they would stop you on the street and talk to you, but now they look at us badly because we are accompanied. (Meeting 5)*

*Rosa: Sometimes people say "look, she is stupid..." (for going in a group with a monitor). Not before, but now they look at us on the street. (Meeting 5)*

#### 4. Discussion

The situation arising from the COVID-19 pandemic has imposed restrictions on society as a whole in relation to physical encounters, and has required the use of technical resources for communication that have had a significant impact on people's lives. In this context, people with intellectual disabilities have seen their opportunities to meet, organize, debate and report violations of their rights restricted. The objective of this study was to explore the impact that the pandemic had on the relationships of people with intellectual disabilities and to provide information on how this inclusive research was developed. According to Amor et al. (2021), it is necessary to listen to the voice of people with intellectual disabilities so that they express their needs and experiences regarding the COVID-19 pandemic.

One of the main findings of this study is the impact that the pandemic has had on the way of maintaining contact with other people. The participants of this study highlighted the need they had to use digital tools to be able to communicate with their friends and family during confinement. Although they valued their learning very positively, the use of technology did not represent a relationship opportunity for all people with intellectual disabilities, since not all had the necessary technological material or support to use it. In addition, the participants also pointed out that, although they were able to maintain contact with some people online, this contact was cold and dehumanized. Seeing friends and loved ones in person, or hugging and kissing them, are some of the things they missed the most. For most participants, physical contact is essential for relationships.

Another result that should be noted in this study is the social isolation that the participants in this study reported having suffered from not being able to see friends, partners, and/or some relatives, coinciding with the results of the research by Embregts et al. (2020) and McCarron et al. (2020). Additionally, in Amor et al. (2021), participants reported missing someone during the lockdown. In addition, the participants of this study also reported the loss of their work, occupational or training activity as another aspect that greatly affected them. This coincides with the accounts of those interviewed by Embregts et al. (2020) and those surveyed by McCarron et al. (2020) and Amor et al. (2021).

One of the significant effects of the pandemic has undoubtedly been on the mental health of the population. More than half of the participants in research undertaken by McCarron et al. (2020) and Drum et al. (2020) experienced anxiety or depression due to the

pandemic and its restrictions and, as Drum and colleagues pointed out, these emotional problems could continue to increase. In our study, emotional or mental health problems were not directly mentioned, however, the participants expressed their unhappiness at the fact that, almost two years after the onset of the pandemic, people with intellectual disabilities who live in group homes continued to have both relational and social restrictions, in addition to restrictions with mobility and social participation, in their day to day lives, despite the fact that the administrations already made measures more flexible for the population as a whole. A displeasure that is strictly related to a significant setback in the exercise of their basic rights, such as the right to mobility, assembly or independent living. Furthermore, it has been demonstrated that isolation and loneliness can be related to depression (Aanes et al. 2010), while, on the contrary, participation in society is related to low levels of depression, stress or anxiety (Ward et al. 2013). These data are relevant if it is taken into account that people with intellectual disabilities constitute a group with a high prevalence of mental health disorders, which is why they may present a greater need for help and/or support than the general population (Amor et al. 2021).

In Spain, research on the effects of the pandemic and confinement on the lives of people with intellectual disabilities has been very limited compared to existing international studies (Amor et al. 2021). Furthermore, no Spanish studies were found that analyse the effects of the pandemic from the perspective of people with intellectual disabilities themselves. As stated by Amor et al. (2021), the lack of research in this regard is worrying, since Spain was one of the countries most affected by COVID-19 in 2020. In addition, specifically the impact that the pandemic has had on the relationships of people with intellectual disabilities has been very little studied, unlike its impact on labour inclusion, access to education, health, or information, among others. Additionally, although the emotional impact of the pandemic has been studied, its influence on social isolation, loneliness, loss of friends, and difficulties in maintaining relationships encountered by people with intellectual disabilities has hardly been analysed. This is especially worrying considering that, as previous literature warned, people with intellectual disabilities tend to experience greater social isolation as well as significant barriers to establishing and maintaining satisfactory social relationships (Gilmore and Cuskelly 2014; Callus 2017). According to Duggan and Linehan (2013), some of these barriers are due not only to the lack of natural supports (family, friends, or neighbours) or the difficulty of making friendships, but also to the lack of involvement of service professionals in supporting people with intellectual disabilities to improve their social networks. In this regard, Sullivan et al. (2015) point out that the attitudes of professionals and their overprotective behaviour towards people with intellectual disabilities must be considered. They also emphasize the importance of professionals being aware of the extent to which the organization can limit or facilitate the opportunities of people with intellectual disabilities to establish satisfactory social relationships. These results and those of our research could indicate that the pandemic could have worsened a long-standing issue: the lack of support that people with intellectual disabilities experience to establish and maintain valuable relationships and participate in their communities.

This study makes an addition to the limited research that explores the perception of people with intellectual disabilities regarding the effects and consequences that the pandemic has had on their lives. It is relevant to consider the impact of COVID-19 on the relationships of people with intellectual disabilities if we take into account that the participants mentioned that friends were a valuable source of support, both to overcome complicated situations and to promote and maintain good emotional health. In this sense, the results of this research show that some people with intellectual disabilities continue to experience difficulties in overcoming the social isolation that the pandemic has caused in many cases, either due to lack of access to technologies that facilitate communication and/or the lack of support to use them, or because of the strict restrictive measures that are being applied to people with intellectual disabilities who live in residential institutions, such as group homes. In all these cases, there is a patent lack of support that should respond better

to the needs of people with intellectual disabilities and that would guarantee the exercise of their rights, especially in times of pandemic. Following on in this line of argument, we consider that it is an urgent matter to investigate the situation experienced by people with intellectual disabilities who are institutionalized, in group homes and residences (Verdugo et al. 2009; Huete et al. 2015; Puyaltó and Pallisera 2018), and specify what type of support is necessary to avoid their isolation and guarantee their rights, in a context in which the risk of contagion is imposed on their routines. According to the European Commission (2009), institutionalization refers to any residential care where: “users are isolated from the broader community and/or compelled to live together; these users do not have sufficient control over their lives and over decisions which affect them; and the requirements of the organisation itself tend to take precedence over the users’ individualised need” (p. 9).

This research was promoted by co-researchers with intellectual disabilities with the support of researchers. The impossibility of holding meetings in person during the development of the research forced all participants to adopt an online work format. The online situation led the research team to explore new ways of working, such as dividing into small simultaneous work groups or using WhatsApp to conduct interviews, among others, which were positively valued by co-researchers. These strategies coincide with those proposed by Miller and Heumen (2021) to successfully conduct inclusive research online. They highlighted the importance of using online platforms with which the co-researchers are familiar, offering them support in the use these platforms, adapting the format and timing of the meetings, or using accessible data collection strategies, as was performed in this study. Even so, it is necessary to remember that, in our study, all the co-researchers had access to the technology and received support regarding to use it, so the barriers they encountered to participate in the study were minimal.

In relation to the subject of this research, the co-researchers emphasized the importance of personal relationships and the seriousness of social isolation; a feeling of loneliness that some of the co-researchers claimed to have felt. Co-researchers also reported that the restrictions imposed during the toughest times of the pandemic are still in force for many of them, especially those who reside in institutions, and that it is necessary to report the rights they have lost, such as being able to go alone to different places, being able to choose which leisure activities to carry out during their day to day lives, or going to friends’ houses to eat, among others. In any case, they considered that participating in this research has allowed them to better understand the situation they are experiencing and, in some cases, make decisions about their lives based on the knowledge acquired (Figure 5).

*“Doing this research has helped me make decisions about my life, such as not wanting to go live in a group home, for example.” (Claudia)*

**Figure 5.** Co-researcher’s opinion 10.

Some co-researchers valued this inclusive research experience as an opportunity to make their role as researchers and the situations that people with intellectual disabilities have experienced during the pandemic known to society (Figure 6). In general, the entire team agreed that inclusive research has had an impact that goes beyond traditional research. Not only it allows us to share experiences and opinions between academics, non-academics and people of different ages and backgrounds, and learn from each other, but also to socialize and feel understood during a difficult time such as a pandemic.



*"(Spreading awareness of this research) is important for people to see that we can conduct research, and also for them to see how we lived during the pandemic." (Rosa)*

**Figure 6.** Co-researcher's opinion 11.

Finally, the co-researchers expressed the desire and willingness to continue conducting research (Figure 7). Some of the topics that interest them are community participation and the freedoms they possess and/or do not possess. They are aware that, as far as possible, conducting the research in person would be more suitable, since it would allow them to see each other, communicate and understand each other better.

*"With the experience we now have, if we conduct further research, it will surely turn out better, because the more times you do things, the better they turn out." (Jordi)*

**Figure 7.** Co-researcher's opinion 12.

The research carried out has some limitations. First, the small number of people who participated in the interviews and focus groups. Altogether, there were 37 people, a small sample of people with intellectual disabilities. In addition, the sample does not include people with greater support needs, so the consequences of the pandemic in the personal relationships of this sector of the population have not been addressed by this research. Despite these limitations, we wish to point out that the aim of this inclusive research did not seek to generalize the results. It started from an interest of the advisory committee itself and contributed to the participants exploring their situation and that of other people with intellectual disabilities, becoming aware of the consequences of the pandemic on their social relationships. The process aroused their interest in disseminating the results, as a result of which the article presented has been written.

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## Article

# Experiences of Inclusive Action and Social Design Research with Social Workers and People with Intellectual Disabilities

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**Abstract:** In this study, we report on a two-year experience of inclusive participative action and social design research consisting of intensive collaboration between social workers, people with intellectual disabilities and researchers. Action research and design research are attunable and lend themselves to an inclusive approach aimed at knowledge development and change in practice. Social workers and people with intellectual disabilities were involved in a community of development. They became owners of the subject matter and the answers and solutions they designed. We conclude that an inclusive approach lends itself well to combining or even merging action research and social design research. Inclusive participative action and social design research cannot be standardized since it contains a particularly emergent process. Hence, it requires flexibility and creativity in finding ways to create an inclusive process of co-creation.

**Keywords:** action research; design research; inclusion; social workers; intellectual disabilities

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## 1. Introduction

In this study, we report on a two-year experience of inclusive action and social design research consisting of intensive collaboration between social workers, people with intellectual disabilities and researchers. The goal of this project was to deepen and nuance the knowledge on how social workers working with individuals with intellectual disability can promote social inclusion. In this article, we present this project as a case study to report on the experiences we gained applying an integration of inclusive research, action research and social design research. First, an elaboration on notions of inclusive research is provided. Then, we describe the research design and the methods we employed to give shape to inclusivity and the road towards desired outcomes.

### *Inclusive Research, Action and Design Research*

Inclusive research is gaining ground in Western countries, including in the Netherlands (Grant and Ramcharan 2007; Riches and O'Brien 2017; ZonMw 2021). Researchers have embraced inclusive research and policy and funding bodies increasingly demand stronger involvement and influence of people with disabilities; this is also influenced by advocacy organizations ("nothing about us without us") and the UN Convention on the Rights of People with Disabilities (UNCPRD) (Sherlaw and Hudebine 2015). Adopted on 13 December 2006, the UNCPRD considers "persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them" (United Nations 2006). In the Netherlands, this has been laid down in the implementation plan, which holds that people with disabilities in their role as citizens, consumers and stakeholders are actively involved in the formulation and evaluation of policies (VWS 2017, 2018). In the field of

scientific research, this movement has resulted in a wide variety of participative and inclusive research designs (Frankena et al. 2015; Nind and Vinha 2014; Strnadová et al. 2016). Milner and Frawley (2019) call this a third wave of inclusive research that moves beyond “research on” and “research with” to “research by” people with disability.

Inclusive research is associated with labels such as participatory, collaborative, and interventionist research, co-design, community design and social innovation (Chick 2012; Joore et al. 2021; Nind 2014, 2017). Inclusive research, participative research, participative action research and emancipatory research constitute an extensive family of overlapping approaches (Nind 2014).

Walmsley and Johnson (2003, p. 16) introduced the term “Inclusive Research” with respect to people with intellectual disabilities, which encompasses three principles upon which inclusive research is based:

1. The research must address issues that really matter to people with intellectual disabilities and that ultimately lead to improved lives for them.
2. The research must access and represent their views and experiences.
3. People with intellectual disabilities need to be treated with respect by the research community.

From these principles, derive distinguishing characteristics that research is owned, but not necessarily initiated, by people with intellectual disabilities, that research enables people to exercise control over the process and outcomes, that research furthers the interests of people with intellectual disabilities, that it produces accessible outputs, that researchers are on their side and that it is collaborative. Inclusive research embraces participatory and emancipatory approaches to research (Walmsley and Johnson 2003, p. 64).

Action research lends itself well to emancipatory processes and goals. With its many faces, action research holds inquiry undertaken by or with insiders to an organization or community, but never to or on them (Anderson and Herr 2015). It emphasizes people’s lived experiences, individual and social change and the co-construction of knowledge. In doing so, epistemic justice is effectuated (Byskov 2021). Ultimately, it leads to a more just situation for the stakeholders (Greenwood and Levin 2007; McIntyre 2008). In effect, action research presupposes an inclusive approach and, despite a dearth of clarity as to what exactly inclusive research is, much experience has hitherto been gained (Bigby and Frawley 2010; Frankena et al. 2015; Garcia-Iriarte et al. 2009; Morgan and Moni 2013).

We would like to add social design research to this family of approaches. Design thinking is an iterative methodology that inspires a human-centered approach to design and can be divided into five key steps: empathize, define, ideate, prototype and test. Social design research focuses on the design and testing of generic solutions to problems. It is driven by the desire to solve field problems in collaboration with those concerned. Social design research aims at social change, for instance: improving social work practice by means of designing solutions (Van Beest et al. 2017; Margolin and Margolin 2002). It does not primarily seek truth, however it endeavors improvement of the social work practice (Van Aken and Andriessen 2011). Hence, social design research principally departs from the perspective of the stakeholders, for instance that of the social worker and people with intellectual disabilities. Action research is by definition participatory and pursues knowledge development and social change in practice. This implies personal and collective “professionalization” of the participants that is akin to the emancipatory praxis—interaction action and reflection—and critical consciousness (Anderson and Herr 2015; Freire 1970; Hammen-Poldermans 1975).

Inclusive research involving people with intellectual disabilities has evolved from a focus on process and ethics to being more concerned with outcomes: first- and second-generation inclusive research (Nind 2016; Strnadová and Walmsley 2018; Walmsley et al. 2018). Both foci remain valuable and should be pursued.

Process, outcomes and research with and by people with intellectual disability can, and should, concur in action and design research. It is not a matter of research on, research with or research by, but rather a matter of allowing the mixture of and dynamic between

each three “waves”, since positionalities of the researcher and the modes of participation may vary during the project (Thomson and Gunter 2011).

The aim of our research was to bring about changes that contribute to a more inclusive social work practice. For the purpose of this article, we focus on the methodology used and share the experiences of carrying out inclusive action and social design research with people with an intellectual disability and social workers.

## 2. Materials and Methods

### 2.1. Study Design

We conducted a two-year inclusive approach merging participatory action research with social design research and using the theoretical lens of method configuration (Joore et al. 2018, 2021; Margolin and Margolin 2002; Nind 2014; Van Turnhout et al. 2017). As for the social design process, we were inspired by design thinking and the closely related double diamond model (Veer et al. 2020).

Participatory action research and social design research are brought together in the model of a *Community of Development* (CoD) (Wilken et al. 2021) that we applied in this project. The CoD is based on the model of community of practice (CoP) put forward by Wenger (Wenger 2010). A community of practice can be viewed as a social learning system in a social context in which a dual process of meaning making materializes. This duality consists of participation and reification. The first involves active involvement in activities, conversations and reflections. The latter involves producing physical and conceptual artifacts such as words, tools, concepts and methods. The community of development includes both participation and reification, but links this dual process to four goals, namely, producing knowledge, designing a solution, bringing about (social) change and personal and collective professionalization of the participants (Van Beest et al. 2017). The CoD further distinguishes itself from the CoP by highlighting (social) solution design and by substantiating the process and results—artifacts—with research. That is why the CoD constitutes a vehicle that fits seamlessly into what we call inclusive action and social design research.

In a CoD, one of the principles is that all relevant stakeholders are represented. In the case of this study, people with an intellectual disability and social workers were the key participants. CoDs are supported by a researcher and a facilitator. The researcher focuses on the research process (data collection), the facilitator is responsible for managing the group dynamics; both prepare the CoD meetings together, attend the meetings, provide (visual) reports of each meeting to participants and reflect on the meetings with each other as well as with the participants.

In our research project, we have embraced the idea of method configuration as it lends itself well to intensive participatory action and design research in which planning and emergence or, as Van Turnhout et al. (2017) call it, “spontaneity” coincide. The rationale behind method configuration is that enhancing validity requires more than applying one or a few methods. Woolrych et al. argue that methods consist of “loose incomplete collections of resources which you configure, adapt and complement to match specific project circumstances” (2011, p. 940). They explain method configuration by the analogy of culinary dishes: “The method, like a recipe, is at best a guide to action. As with culinary dishes, [action research projects] a focus is needed more on what gets cooked, and how it gets cooked, and not just on how recipes suggest that it could [or should] be cooked” (Woolrych et al. 2011, p. 940). The culinary dish and a recipe’s ingredients are a metaphor for the research goals and the resources. The methods we employed consisted of dialogues, unstructured interviewing, focus group sessions, participatory observations plus design thinking and double diamond principles. The resources included paper ball showers, musical chairs, prompting questions, scaling questions, brainstorm techniques, empathy mapping, collective analysis utilizing an ecological model of social inclusion, preliminary conversations with participants with an intellectual disability to support them in preparing for the CoD meeting and their participation, evaluation of group dynamics and the research

process with CoD participants, visualizations of each CoD meetings, pitches, et cetera. These resources derived from the design thinking method, the double diamond approach, participatory action and social design research methodology. The deployment of these methods and resources was contingent upon the process in which the CoD found itself.

The double diamond model is a variation on existing divergence and convergence models and is depicted as two tilted squares representing the four stages: discover, define, develop and deliver (Veer et al. 2020). The first diamond depicts the stages discover and define; the second diamond depicts the stages of developing and delivery. Both diamonds represent broadening or expanding possible solutions, defining the friction more precisely and making choices. After the defining stage, a number of directions for solutions are devised, followed by finally developing a solution with the highest potential for ensuring a promising and validated solution. The results section is outlined along the double diamond stages.

## 2.2. *Involving People (Phase 1)*

The first phase of the study lasted over a year and consisted of forming two separate CoDs, each located in a different region (Amsterdam and Wageningen), where people with intellectual disability, social workers and others involved in the local practice participated.

In Wageningen, social workers set up a sheltered employment project named The Football Workshop, which is accommodated in the local football club. People with intellectual disabilities called “football workers” support the volunteers, who perform maintenance work at the club; they organize training sessions and play weekly football home and away matches against teams from the local community and beyond. The Amsterdam context concerns a metropolitan area, where people with intellectual disabilities receive ambulatory support.

Snowball subject recruitment was used for participant enrollment. We were able to draw on a broad regional network of social workers and people with moderate to mild intellectual disability, including people trained as experts by experience. “An expert by experience is someone who has had direct experience of living with a diagnosis or status, and of receiving care, support and/or treatment as well as the potential exposure to restrictive interventions. As a result of this lived experience, they possess a unique insight and understanding that allows them to think, feel and act in ways that brings an ‘added value’ to whatever form of partnership working they are engaged in” (Hollins 2019, p. 3). In addition, we argue that their life experience is enriched by the experiences of others and that they have learned to transcend their individual life experiences. Generally, they have completed training to employ this knowledge, for example, as peer workers, consultants, lecturers or researchers.

Selection criteria for the recruitment of service users and experts by experience included being interested in the subject matter of social inclusion, being motivated to participate in the project, willingness to and being capable of sharing life experiences and being prepared to act as a “critical friend” to the other participants (Embregts et al. 2018). As far as the social workers were concerned, selection criteria for the recruitment were: (a) being employed as a social worker working with people with mild intellectual disability, (b) having an interest in the subject matter “inclusion” and (c) motivation to bring about change in the social work field aimed at promoting inclusion.

To communicate what the study entails, questions needed to be answered such as: what is the study about and what does a community of development entail, what activities take place in these CoD meetings, where and how often do we meet, who are the other participants, what is my role, what influence do I have, what is expected of me during and in between the CoD meetings and what is in it for me? To answer these questions, we offered a flyer in accessible languages, organized physical meetings—one to one or in small groups—and with the help of the feedback from social workers and people with intellectual disabilities we created a visual representation of the information for people with intellectual disabilities. The visualization needed to comply with accessible language

criteria and should not be childish. After several adjustments and the final approval of social workers and experts by experience it was ready for publication.

### 2.3. Execution (Phase 2)

A total of twelve meetings per CoD were held over a period of two years, at intervals of seven to eight weeks. The CoD Amsterdam and the CoD Wageningen were composed of social workers and service users. The CoD Amsterdam and the CoD Wageningen comprised eight and five participants, respectively, each containing two experts by experience.

Data collection consisted of audio recordings of all CoD meetings ( $N = 24$ ), visual records of each meeting—each time these were shared with the participants for verification—and all tangible results produced in the meetings such as photos of activities during the meetings, photos of notes on white boards, empathy maps, mind maps, brainstorm papers, sketches and analyses. The visual reports also contained a limited amount of written language, which succinctly explained the observations of the researcher and facilitator.

### 2.4. Analysis, Sharing and Interpretating Data (Phase 3)

Analysis was carried out in several ways. Firstly, data from audio recordings of the meetings of the CoDs were coded. Secondly, a descriptive analysis was made. This approach to data collection and sharing serves the hermeneutical process and ownership of those involved as well as democratic validity (Anderson and Herr 2015; Guba and Lincoln 1989). Due to COVID-19 measures, results from the first analysis were shared visually with the participants of the CoD during a digital meeting. The first analysis indirectly linked to designing a solution. It was principally aimed at answering an associated research sub question on the behavior of social workers that fits inclusion-focused performance of our central research question. However, the solutions designed by the CoD constitute interventions to support the inclusion-focused behavior of social workers. The second analysis contained a comprehensive description of the collaborative process of designing solutions and what conditions facilitated inclusion-focused social work utilizing the designed solutions; this was sent to the participants for reading and discussion in a physical meeting. The purpose of this approach was to supplement, refine and verify the analysis. A third analysis comprised the prototyping and testing of the designed solution. Each round of prototype testing yielded data that were evaluated with the CoD participants in order to make adjustments for the next round of testing.

## 3. Results

Using the stages of Design Thinking and the Double Diamond model, we discuss what has been learned in this project.

### 3.1. Discover and Empathize

Empathizing and discovery helps gain insight into the issue and articulate the questions that are central to the study. For obtaining approval and internal funding from the university, the researchers had to formulate a question prior to having it carefully discussed with social workers and people with intellectual disabilities. Hence, we deliberately formulated a broad research question that offered scope for further specification in collaboration with the social work practice, i.e., the management of service providers, social workers and people with intellectual disabilities. Although the general goal of the project (how can social workers working with individuals with intellectual disabilities promote social inclusion of people with a mild intellectual disability?) was formulated in advance, after the project started the CoD participants in Amsterdam and Wageningen had the opportunity to redetermine the research question. This revolved around questions like: What is the question? Whose question is it? How can we interpret the central question? Can we adapt the question to our own perspectives? Ultimately, the central question remained unchanged as participants felt that it had sufficient scope and that it fitted in with their own experiences. Refining the central research question to the context of social work and people



with intellectual disabilities occurred through self-enquiry by the social workers and was discussed with people with intellectual disabilities. In the CoD Amsterdam, this led to questions that were predominantly focused on record keeping and transferring information about the service user: Why is the record keeping and transfer we are carrying out good? What am I reporting and why? Since we are thinking about the form of record keeping and the transfer, how can it be improved? How can we enhance the service users' control over their records? Some life experts with intellectual disability nuanced this concern, saying: "Sometimes a service user does not want to think about his records and transfer. He likes it the way it is. Let him (social worker) do it." (quote from participant CoD meetings Amsterdam).

In this empathize and discovery stage, experiences were shared and assessed as practices and pathways to or from social inclusion (Simplican et al. 2015). In addition, conceptualizations of inclusion, exclusion, stigma, discrimination and equality were explored. This led participants to comment that they found themselves "to be a kind of destigmatizer when (they) consult with a private or government organization on behalf of or with a client." (quote from participant CoD meetings Amsterdam). To support the exploration, we deployed a mix of activities and tools:

- Practice assessment: having social workers assess their practices pertaining to service user documentation and records. The self-assessment focuses on whether their practice is inclusive or not.
- Ranking definitions regarding inclusion and based on these rankings conducting a discussion.
- Musical chairs: playing musical chairs so that participants experience and relive social inclusion and social exclusion.
- Paper ball shower: a shower of paper balls that ensures active and interactive discussion with equal input from all participants. Participants write down statements, questions, answers, words or make a drawing on a blank piece of paper, then crumple the piece of paper into a ball and throw it randomly in the air all at once.
- Empathy mapping with the aim of empathizing with those who deal with service user documentation and records.
- Pitch and sketch: individual pitches or sketches by the participants using one or more objects that symbolize their message. The purpose was to draw up an interim assessment of what the participants had practiced in promoting inclusion.

### 3.2. Define

Using the aforementioned activities and tools, we converged to a point where we formulated the collective concern. This was done by clustering and scoring discussed issues. In addition, the CoD defined the design criteria of the intended solution. These criteria were reconsidered several times. In the CoD Amsterdam the concern was formulated in a design proposition (Denyer et al. 2008): if you believe that service users should have control over their records, then reverse the act of who records and transfers information in the records to others. This was captured in the title "Reverse Records". In the CoD Wageningen, the concern was molded into the design proposition: If you want the football workers—people with intellectual disabilities in sheltered employment at The Football Workshop—to move on to regular workplaces where the football workers feel recognized and valued, then focus on a sustainable cooperation with profit and non-profit organizations so that mutual recognition and trust can grow. For that end have the football workers organize football matches against football teams from profit and non-profit organizations including all preparations and evaluation activities. This was captured in the title "Towards Sustainable Reciprocity".

### 3.3. Develop: Ideate, Prototype and Test

In this stage, the focus was on finding, shaping, reshaping and testing possible solutions. Different techniques were utilized in both CoDs such as: the one second brainstorm,

negative brainstorming, role play, organizing a “Goodies Exhibition” and collectively creating a timeline. Additionally, between the CoD meetings the participants collected examples of products that inspired them in the ideation. All these activities and brainstorm techniques were deployed to enhance creative thinking among participants and resulted in:

- Active and continuous engagement of all participants.
- Input from all participants.
- A vast array of ideas ranging from predictable and morally permissible to hilariously ineffective ideas (one second brainstorm and negative brainstorming). The understanding of interactions between social workers and service users and how this relates to feeling ignored or feeling excluded.

The development of the possible solutions was proceeded by an iterative process. By asking “how the Reversed Record Keeping complied with the European Union General Data Protection Regulation (EU GDPR),” life experts with intellectual disability notified us that we must be alert to privacy concerns (quote from participants CoD Amsterdam and Wageningen). Terminology was adjusted repeatedly until all involved could agree on the words used. The term “client” was rejected by social workers and most notably by people with intellectual disabilities. The following quotes came from participants of the CoD Amsterdam and Wageningen respectively: “We favor the expression Amsterdammer or service user” and “we address each other as football workers. We are all football workers”.

### 3.4. *Delivery: Testing, Adjusting and Implementing*

Through the inclusive process, both CoDs delivered tangible results.

The CoD Amsterdam delivered the Reversed Record Keeping Principles comprising:

1. The service user reports, not the social worker.
2. The service user decides what should be in the records. This principle is supplemented with allowing differences of opinion between the social worker and the service user and providing room for that in the records.
3. The social worker verifies with the service user whether what has been recorded is correct.
4. The content in the record is expressed in accessible language.
5. The social worker is evaluated, not solely the service user.

The first three principles are formulated in order from “the action is entirely performed by the service user” to “the action is performed by the social worker”, yet maintaining control with the service user as much as possible. The fourth is a basic principle and applies to every other principle. The fifth emphasizes the power relationship between the social worker and the service user. Strictly, service users ought to have personal plans and goals that must be periodically evaluated by the service user and the social worker. This principle seeks to reverse the situation, and thus equalize the power relation, by stating that social workers also have their learning goals to further professionalize. This evaluation is carried out in conjunction with the service user: “You evaluate my learning goals together with me, I evaluate your learning goals together with you.” These five principles were designed graphically into a poster.

The testing and fine-tuning of the Principles of Reversed Record Keeping yielded additional results. First, the service users stated greater involvement and control in what goes into their records. Second, service users reported more involvement in how content is added to their records; this was facilitated by applying various forms of communication such as drawing, photography, vlogging and audio recording. Third, the CoD participants gained three insights into the usability of Reversed Recording; it appears suitable in long-term professional relationships and for recording life events. The Principles of Reversed Records require intensive attention for and involvement with the service user and fits best with episodes in life that are of greater significance for a person. The principles seem less suitable for daily reporting as the assumption among CoD participants was that daily reporting should be objective, concise and specific.

The CoD Wageningen delivered a decision chart “Towards Sustainable Reciprocity”. It serves as a tool allowing the football workers—people with mild intellectual disabilities—to co-direct the organization of the football matches and surrounding activities and to assess which organizations offer good opportunities for sustainable reciprocal cooperation.

The decision chart complies with criteria set by the CoD participants. Criteria were:

- Comprehensibility that refers to language structure and design; language includes wording that people with intellectual disabilities recognize, unambiguous words and phrasing such as easy-to-read phrases. Structure holds the routing in the decision chart that should make sense in that it fits in with the way of thinking of the social workers at The Football Workshop and the football workers. Design revolves around layout, color, contrast, fonts, font size and visualizations. Are these appropriate for reading and understanding the decision chart?
- Applicability of the decision chart. Applicability was defined as providing insight and supporting decision making. Providing insight was achieved as the chart helps the social worker and the football workers gain insight into the underlying motives of the organizations and their visiting football team. Providing insight also includes self-reflection, since the chart also supports the social worker and the football workers gaining insight into their own underlying motives: Why do we play against teams from profit and non-profit organizations? What do we invest in the relationship between The Football Workshop and the visiting teams? Why do we invest in this relationship? With the insights, decision making is supported in order to determine which organizations are worth building a long-term reciprocal relationship with.

#### 4. Discussion

In all stages of the project, social workers and people with intellectual disability played a crucial role. As a matter of fact, we would assert that they were the lifeblood of the research project. When the blood is thick or flows slowly, the project is at risk of losing support, credibility and emancipatory impact. Challenges that came across in keeping the project vital required continuous alignment with the participants and are briefly discussed below in terms of ownership, power (im)balance, implementation and enhancing emancipatory practice through merging action research and social design research as the vehicles that ride the inclusive road.

##### 4.1. Collective Ownership: Establishing a Collective Concern

Since inclusion constitutes a comprehensive notion, in the discovery stage the biggest challenge was to explore inclusion and find agreement on its meanings. The research question, with inclusion as its central concept, was kept fairly open ended in order to give each participant the freedom to give meaning to inclusion from their own perspective. For all those involved, this required careful listening, patience, mutual trust and recognition and power sharing. For the researcher and facilitator, the challenge was to avert abstractions (use of words), too high paced discussions and to ensure that the meetings fit in with the culture of those involved; the latter holds taking into account the organizational culture, wishes of the participants concerning the design of the meetings and preferred learning styles.

Establishing the collective concern is a challenge in itself. With a view to ownership and thus a long-term commitment, it is crucial that every participant fully supports it. For that purpose, we additionally invited the participants to draw up a personal goal that is in line with the collective concern. In sharing knowledge—experience based, professional, scientific—emphasis was put on experiences from people with intellectual disability and social workers partaking in the CoD. In doing so, we attempted to accommodate and safeguard epistemic justice (Byskov 2021; Geuskens 2018; Schippers 2021).

##### 4.2. Power (im)Balance: Being in Control

Power dynamics are omnipresent throughout each action research, social design research and inclusive research project (McDonald 2021; Nind 2014; Stoudt 2007). With

respect to establishing a collective concern, setting personal goals, ideation and devising the outlines and content of the intended solutions, ownership was maintained with the participants. In the design stage, the challenge centered on who was in the lead concerning the production of the designed solution. Basically, the researchers wanted to keep these steps controlled and carried out by the participants and their network. However, the participants appeared to lack the digital skills—proficiency in Adobe Illustrator and Adobe InDesign—required for graphic design and materialization. This prompted a situation where the researchers, with proficiency in design software, complemented the participants' capacities in the design process. Although in consultation and with the consent of the participants—they even indicated they were happy that the researcher took on this task—the researchers experienced this as a breach in democratic validity since the participants relied too much upon the researchers' skills.

#### *4.3. Implementation of the Designed Solution*

With regard to delivery, our challenge was to get the intended solution implemented. In testing the intended solution as a CoD, we discovered weaknesses and threats (external factors) that hampered implementation. (Verhagen and Haarsma-den Dekker 2019) discern three dimensions of implementation: physical, mental and structural. Physical implementation concerns creating, developing and testing the design and winning support, for instance among service users and staff members. Mental implementation refers to informing, accepting and incorporating new ideas and new design. Structural implementation revolves around learning to utilize the design and letting it fit into the social work practice. Physical and mental implementation was accomplished. In particular, the participants disseminated the intended solution in their surrounding professional network; physical implementation and mental implementation effectuated. Structural implementation, however, was not achieved, for it demands harder nuts to be cracked. Structural implementation may have the consequence that a fundamental change in macro practices and macrosystems (for instance the Electronic Health Record systems) is required such as regulations that prescribe rules for keeping records. This moves beyond mere social change as it also demands political debate and amendments in national legislation. Furthermore, it presupposes a wider scope of the project, which, although we as a CoD cherished, was beyond our scope and possibilities.

#### *4.4. Merging the Inclusive Approach with Action Research and Social Design Research*

Merging action and social design research has led to insights into how to achieve a balanced approach to inclusive research. First, the application of method configuration allows the researcher to accommodate and match the needs and capacities of participants, both social workers and people with intellectual disabilities. As described in this article, we have demonstrated a multitude of methods and resources that have been deployed. Action and reflection processes—and the support of epistemic justice—in inclusive research with people with intellectual disabilities benefit greatly from the employment of a variety of creative and active activities such as drawing, photography and vlogging and kinesthetic activities such as walking, football exercises, musical chairs and so on. However, this is not exclusive to people with intellectual disabilities and social workers and the palette of activities should not be used arbitrarily. It foremost requires careful observation and a feeling for group composition, group culture and group dynamics.

Second, consistent employment of visualizations as an accessible form of communication contributes to understanding the subject matter and the project's progress and facilitates giving voice to each participant. Visual communication is in keeping with (social) design research. Third, ensuring the balance is part of all the research stages where the voices of people with intellectual disabilities invariably come to the fore, from the discovery phase—mutually empathizing with the social worker and the person with intellectual disability who receives services—up to the delivery phase, which includes testing and adjusting the designed solution and implementation. Fourth, maintaining balance lies

in closely monitoring the multiple objectives of action and social design research project, namely, to change a social practice, to collectively design an answer and to yield new or validate extant knowledge. Keeping these objectives continuously in mind needs to be a responsibility for both the researchers and the participants, since the project is a shared endeavor. Fifth, the CoD is a place that accommodates both research approaches. Moreover, the CoD appears to be an exquisite place, where the voices of social workers and people with intellectual disabilities are heard and, in fact, predominate.

## 5. Conclusions

The aim of our research was to bring about changes that contribute to a more inclusive social work practice. However, this article was dedicated to the methodology and what we can learn from executing inclusive action and social design research with people with intellectual disability and social workers in order to advance inclusive social work practice.

In the project, types of equal collaboration were explored in order to redress power imbalances between social workers and service users. We outlined the amalgamation of an inclusive approach with action research and social design research, which seems promising in involving people with an intellectual disability in a meaningful and empowering way.

We conclude that inclusive research can and should not be standardized, since it concerns a particularly emergent and iterative process. It requires flexibility and creativity in finding ways to inclusively collaborate with social workers and people with intellectual disabilities. The involvement of service users in all design thinking phases is possible. The performance of activities and the division of tasks can differ per phase.

Working in partnership with social workers and people with intellectual disabilities requires sensitivity to sharing power and the utilization of diverse communication modalities. A researcher should not eschew losing control over the process and allow the design process to generate unexpected or initially unintended outcomes. Furthermore, inclusive cooperation demands a safe and welcoming environment that offers space to think freely and speak up; for that, substantial attention is needed for group dynamics and learning strategies that encourage co-production.

The beauty and the great value of inclusive action and social design research is the cooperative quest you embark on that generates myriads of collective and individual returns along the way: visible, palpable, tangible, measurable and immeasurable. It all counts.

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## Article

# Inclusive Research in Health, Rehabilitation and Assistive Technology: Beyond the Binary of the ‘Researcher’ and the ‘Researched’

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**Abstract:** The principle of ‘working with, not on’ people with disabilities is widely espoused within inclusive research, yet historically such opportunities have not been fully realized. This paper speaks from the perspective of users of health, rehabilitation, assistive technology services, and the academics with whom they collaborate. We draw on Australia’s Disability Inclusive Research Principles to reflect on the practice of inclusive research across the areas of assistive technology policy, digital information, and health access, as well as the co-design of allied health resources. We consider and provide examples of how power and knowledge play out in health and rehabilitation, the developing discourse around consumer co-design and co-production, and the challenges of enacting inclusive research. This paper is about shared power in the mechanisms of research production and our journeys towards it. Engaging in inclusive research has enabled us to assume roles beyond the binary of the ‘researcher’ and the ‘researched’. We conclude by proposing an adaptation of the ladder of participation for inclusive research.

**Keywords:** inclusion; research methods; health; rehabilitation; assistive technology; consumer-led

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## 1. Introduction

To understand ‘what is’ (ontology), strategies and methods are used to uncover sources of knowledge (this is ‘how we know’, or epistemology). Different fields of research tackle this in different ways. This paper considers knowledge from the perspective of academic researchers working in the area of health, rehabilitation, and information, communication, and assistive technologies, where traditionally the evidence has been largely based on medical and socio-technical approaches. Challenges to the mainstream scientific world view come from the disability academy and from indigenous ways of knowing. These counter views suggest that professionalism may be oppressive, that scientific knowledge is partial, and that lived experience is often unheard (Friere 1972). Contrasting perspectives include social, critical–realist, and other models of disability and culturally sound ways of knowing (Friere 1972; Thomas 2007; Corker and Shakespeare 2002).

On a practical level today, this translates into a range of guidance to bridge these different approaches and inform practice in health and disability research. For example, frameworks such as the World Health Organization International Classification of Functioning, Disability, and Health (WHO ICF) (WHO 2001), combine medical and social views into a biopsychosocial model. Following, as a signatory to the United Nations Convention on the Rights of Persons with Disability (Stein et al. 2009; United Nations 2006), Australia’s health, rehabilitation, and disability sectors are moving to enshrine consumer centeredness in service design and delivery (ACSQHC 2012; Department of Health 2018). Parallel fields,



such as design and social science, have engaged over decades in co-design (Arnstein 1969; Jasanoff 2004; NCOSS 2022) as a paradigm and method to include multiple voices and share power. Co-design tools (People with Disabilities Western Australia 2020) and projects (Bould and Callaway 2021; Layton et al. 2021) are emerging for disability in Australia.

From the perspective of health and rehabilitation, but turning to research (rather than practice), evidence-based practice principles explicitly call for a triumvirate of best quality evidence, professional expertise, and consumer and community knowledge (Sackett et al. 2000). The consumer aspect, however, remains under-realized (Hill 2011) and may be difficult to enact in some organizational settings (Lofgren et al. 2011). For example, challenges have been noted with enacting co-design/consumer involvement in health research, including limited or tokenistic roles, limited time allocation for authentic engagement, and difficulty acquiring tacit research skills and knowledge (Slattery et al. 2020).

The field of intellectual disability research has a relatively long engagement with inclusive research principles (Johnson and Walmsley 2010; O'Brien et al. 2014; Riches et al. 2020), including a consensus statement on how to conduct inclusive health research with the intellectual disability community (Frankena et al. 2019). Academics propose potential models (Bigby et al. 2014) and principles (Disability Inclusive Research Collaboration 2012) for inclusive research. Arguably, the inclusive research paradigm for intellectual disability is further developed than inclusive research in rehabilitation and health. Indeed, as intellectual disability research is largely published in separate journals and not in journals on rehabilitation research and practice, we suggest that health and rehabilitation researchers who would benefit from epistemologies on 'working with the experts', are not hearing about them.

## 2. How Does This Influence Our Knowing and Doing?

Speaking as academics and practitioners working in health, disability, and academic structures (Authors LC, EB and LC), evidence-based practice principles enable us to include consumers' perspectives in our methods. However, often institutional and funder requirements—whilst calling for consumer representation—still require the demonstration and evaluation of research track records, performance metrics, and evidence of highly qualified team members whose research methods are seen as scientific. As our examples will show, 'scientific method' may unwittingly skew views of truth.

Speaking as consumers of rehabilitation, health, and assistive technology interventions, and as participants in research and lived experience experts on these topics (Authors RB and JB), we have some rights in relation to what our services should look like and some roles in how to design them. However, we find legitimate research roles are limited to being researched, being consulted, joining project advisory groups, or 'being examples'. The continuum of community and consumer engagement in health, rehabilitation, and assistive technology research has been well-documented. Within this, recognition that if we are to move beyond such limited roles of 'being researched and consulted' to true co-researcher roles and research leadership by people with lived experience expertise, the benefits will be significant. They also come with the requirement for more time and funding commitment for authentic participation (Manafa et al. 2018).

This paper aims to represent the varied perspectives of users of health, rehabilitation, and assistive technology services and the academics with whom they collaborate to: (1) reflect on the practice of inclusive research across health, rehabilitation, and assistive technology, using Australia's Disability Inclusive Research Principles; (2) provide examples to consider how shared power and knowledge play out in health and rehabilitation, and the developing discourse around consumer co-design and co-production; and (3) outline some of the challenges of enacting inclusive research.

### 3. What Do Disability Inclusive Research Principles Look Like in the Fields of Health and Rehabilitation?

We have selected a set of Inclusive Research Principles (DIRP) (Australian Disability Research Agenda Collaboration 2018) to guide our thinking about inclusive research. These principles were developed by the Disability Inclusive Research Collaboration (DIRCC), a group of organizations for people with disability, universities, and research centers in Australia that came together in 2014 at the University of Sydney for the Research rights: Disability—Inclusion—and Change Conference. The set of principles were developed to guide the organizing committee in developing the conference agenda, and were also presented in opening addresses (DIRCC 2012). We have reflected upon and developed plain language explanations of each of these principles (see Table 1 below).

**Table 1.** Disability Inclusive Research Principles with Plain Language Explanations.

Disability Inclusive Research Principles (Johnson and Walmsley 2010)	Plain Language Explanations Developed by the Authors of This Paper
Research that is informed by and/or led by people with disability	<p>Research that is important to, and/or led by, people with disability</p> <ul style="list-style-type: none"> <li>- research looks at issues that are important to people with disability</li> <li>- research uses the lived experience of people with disability</li> <li>- people with disability are part of the research team</li> <li>- the leader of the research project is one person or a small group of people, Some or all of these people have a disability.</li> </ul>
Ownership	<p>Identifying who the research belongs to</p> <ul style="list-style-type: none"> <li>- everyone in the team needs to know what they are doing on the project</li> <li>- people with disability and the organization where they work should be included in every stage of the research process.</li> </ul>
Inclusive and participatory	<p>Research is inclusive and people with disability are part of the research team</p> <ul style="list-style-type: none"> <li>- researchers with and without disability work together</li> <li>- inclusive research begins at the start of the project</li> <li>- the team sets out the focus and the goals</li> <li>- everyone in the team can ask questions</li> <li>- everyone in the team is listened to and respected.</li> </ul>
Co-presenting	<p>Sharing of research activities and findings includes people with disability as co-presenters</p> <ul style="list-style-type: none"> <li>- people with and without disability talk about the research findings with other people.</li> </ul>
Materials that are accessible	<p>Information is accessible</p> <ul style="list-style-type: none"> <li>- all information about the research project is easy to read and easy to understand</li> <li>- pictures are used with words to explain things</li> <li>- captions and transcripts are used for videos.</li> </ul>
A range of types of activities	<p>Research activities are flexible</p> <ul style="list-style-type: none"> <li>- information and activities should be accessible to all participants</li> <li>- everyone should be able to have a say.</li> </ul>
Research that transfers through to real life	<p>Research should support people to have a better life</p> <ul style="list-style-type: none"> <li>- everyone must benefit from working on a project</li> <li>- it is important to check if the research is going well</li> <li>- inclusive research should help people with disability and disability organizations.</li> </ul>
Re-defining what research is	<p>Change what research is</p> <ul style="list-style-type: none"> <li>- think of different ways of doing research</li> <li>- there is a need to ask people with disability what would make inclusive research better.</li> </ul>
“The right people asking the right questions and getting the right answers”	<p>Think about the questions we should ask and who should be invited to answer these questions</p> <ul style="list-style-type: none"> <li>- the research questions should be important to people with disability</li> <li>- there is a need to think about who should be invited to take part in the research project (as research participants)</li> <li>- ensure all participants can have a say by making information accessible.</li> </ul>
Consent	<p>Consent</p> <ul style="list-style-type: none"> <li>- The research needs to be done in the right way</li> <li>- The research project should be reviewed by an ethics board.</li> <li>- The ethics board are separate from the research team</li> <li>- People with disability are asked if they want to take part in the research and it is their choice</li> <li>- They can change their mind and stop participation at any time.</li> </ul>

We will now present three research journeys from health and rehabilitation settings that we have led. Our reflections on the inclusive research principles are indicated in bold font:

**Example 1.** *Assistive technology: research that is directed by assistive technology users themselves.*

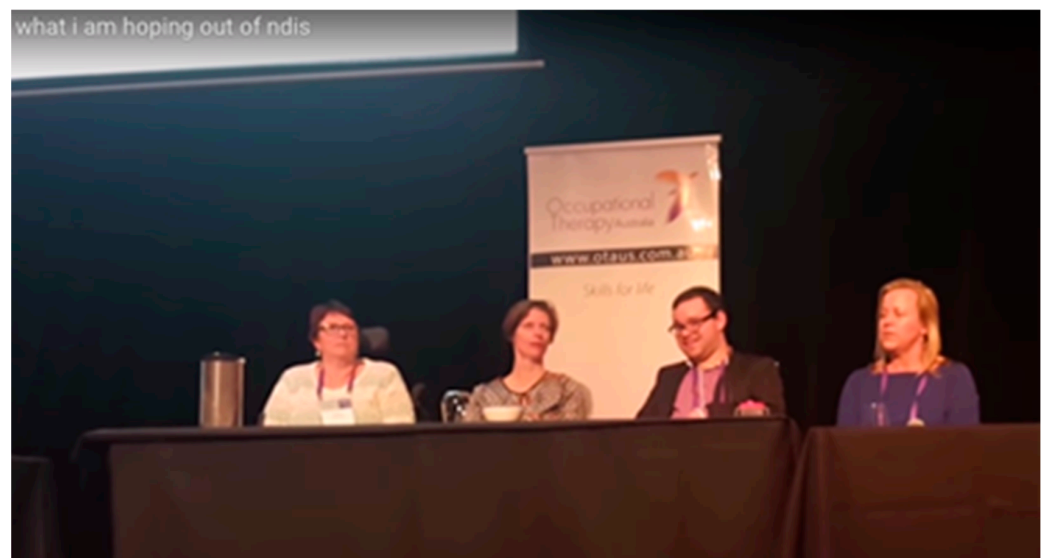
In the State of Victoria, Australia, an alliance of people living with disability, assistive technology practitioners, advocates, and academics (the ‘Aids and Equipment Action Alliance’) was formed in response to perceived policy failures in public provision of AT. This multi-stakeholder alliance **led a research endeavor** by commissioning the philanthropically funded project *The Equipping Inclusion Studies* (Layton et al. 2010). More than 50% of the alliance steering group for this research were people with lived experiences of disability. We ensured the **right people asked the right questions** by turning the purpose and mission of the Alliance (to provide evidence to influence government policy) into the research questions. We ensured the **research design** was participatory and inclusive through use of methods which sought the views of Victorian adults with a disability about AT needs and outcomes. Authors NL and RB were engaged in this research, and the experience of undertaking commissioned research and ‘working for’ people with disabilities profoundly shaped the research process (Layton et al. 2017). This happened in several ways. In terms of **consent**, standard ethics processes assume anonymity is required for people with disability, however the alliance took issue with this perceived conflation of disability and vulnerability, and sought ethics modification to enable people to be named and ‘own their own data’ (Layton and Wilson 2009). In terms of **inclusive and participatory approaches**, we wanted to use methods which ensure voices of people with disability are validated as data: the alliance felt this was important. It seemed self-evident that the research design must include everyone, and when it was discovered that fully accessible online survey methods did not exist, we created one (Gottlieb et al. 2010). **Co-presenting** is essential: once the research was complete the roles of co-authorship, disseminator of findings, and knowledge translator, were actively taken on by alliance members alongside and beyond the academic researchers (Layton et al. 2012; Layton et al. 2014), and continues to date with a set of personal outcome tools under development by a consortia of AT users and research partners (Buchanan and Layton 2019; Layton and Callaway 2020). No presentation occurs without personal stories to contextualize the content, and sometimes it is necessary to redefine what research is. When we identified an inherent disability bias in standardized data collection instruments for quality of life, steps were taken to address this with instrument authors to both address the impact of this bias and to revise the tool (Layton and Wilson 2010).

**Example 2.** *Moving beyond the binary of ‘therapist and the client’, and the ‘researcher and the researched’*

In Australia, there are a range of options people with disabilities may consider to meet their goals for community living across their lifespan, whilst addressing their disability-related support needs (Callaway et al. 2020). One of these is a coordinated approach to the provision of both highly-accessible housing and support, called Specialist Disability Accommodation (SDA). Authors JB and LC first met when a new approach to SDA provision had been developed and located on the border of a large University campus in the State of Victoria. This accommodation included a new collaborative model of allied health student fieldwork education through which tenants could work with students on their nominated personal goals. JB accepted an offer of tenancy at this SDA in 2015. At that time, LC was designing the model, supervising students delivering fieldwork hours, and establishing a framework for multi-stakeholder research evaluation to ensure research was **informed by people with disability** and other key stakeholders. From that time, JB and LC developed a collegiate and collaborative relationship, co-designing student education opportunities, and the evaluation framework. As JB notes: ‘I think if people with disabilities want a brighter

future, we should want to train others—I’ve personally learnt five times more than I give through this process’. Now into its seventh year, and expanded across regions of Victoria as well as into Tasmania, we draw on occupational therapy and lived experience expertise equally, and with mutual benefit, to inform both education and research design, translation and impact. The work is built on shared trust, and timely identification when things will or will not work, or have or have not worked, enabling honest and open conversations about this. This includes discussion about projects, and when JB feels he would or would not add value in contribution to research projects or student education activities.

This approach has aided **redefining what research is**, with both process and outcome evaluation built into each placement block JB co-designs. Moving beyond this first phase of collaborative work, and the binary of ‘therapist and the client’ and the ‘researcher and the researched’, **ownership** has become central to our collaborative model of both research and education practice. JB draws on his lived experience expertise, and LC on her allied health research and practice knowledge, in combined presentations of these varied perspectives (see Figure 1). JB’s lived experience expertise is drawn upon using a co-researcher approach, with human research ethics committee approvals in place and **co-presenting** of research evaluation findings (Callaway et al. 2017a, 2021).



**Figure 1.** Co-presenting [left to right] colleague LF (Acknowledging our colleague L.F.), and authors NL, JB, and LC at Occupational Therapy Australia—Victoria conference panel. Source: Personal photo of author NL.

**The range of types of research activities undertaken** has been expanded over the last seven years. JB has now delivered a number of paid co-researcher roles (National Disability Research Partnership 2021) and joint supervision of student project work, with both JB and LC holding roles on the new National Disability Research Partnership Community of Practice ([www.ndrp.org.au](http://www.ndrp.org.au) (accessed on 12 January 2022)). For shared knowledge translation, activities have included joint conference presentations (Callaway et al. 2017a, 2021), invited guest lecture and/or speaker roles at universities, disabled person organization events or professional forums, and joint authorship in the media (Callaway et al. 2017a). Recognition and nomination for awards relevant to JB’s individual performance have also been successful (see Figure 2).



**Figure 2.** National Year of Digital Inclusion Award Recipients, including JB (pictured at front, seated in a powered wheelchair). Source: <https://www.godigi.org.au/blog/congratulations-our-national-year-digital-inclusion-award-recipients> (accessed on 12 January 2022).

Throughout these range of activities, consideration of **materials (and methods) that are accessible** has been important. Strategies include requesting questions for JB prior to the event so he can use his preferred Augmentative and Alternative Communication (AAC) device to prepare responses; utilizing online forum text box chats for two-way communication between JB and LV (via direct message), or ourselves and the audience during live presentations; and scheduling JB as the first speaker during presentations so that he can then respond using his preferred AAC whilst others are presenting. Our shared aim is that the **research we deliver transfers through to real life**, linking to both practice and policy (Callaway et al. 2017a, 2017b).

### **Example 3.** *Co-design of allied health resources.*

In 2020, the ‘My Allied Health Space’ team which includes authors NL, EB, JB and LC partnered with the Victorian Government Department of Health to develop digital resources with two overarching goals: (1) ensure people with disability and their supporters have access to information and resources to guide selection and evaluation of disability workforce over time; and (2) ensure health professionals can assess and grow their own work capability to work with people with disability.

Often website design does not offer digital or information access for some people, including those with disability. However, the Council of Australian Governments jointly signed a 10-year National Disability Strategy in 2010 which espouses the need for inclusive and accessible communities, including digital information and communication technologies. Emphasis in this project was on being **inclusive** and **accessible**, so the clarity of the message being communicated and the functionality of the information matched the user’s requirements.

This project used consumer co-design principles with a cross-institutional, interdisciplinary team of academic researchers, people with disability and the health professionals working with them. To ensure **the right people asked the right questions**, regular team meetings were held to plan, explore, develop, and deliver both resources and checklists for people with disabilities and their families and friends, and training content for allied health professionals.

**Inclusive and participatory approaches** were utilized to ensure outputs **transferred through to real-life**. People with disabilities and health professionals worked with EB

to lead the production of video training content. Information that was not accessible was identified. For example, the term ‘Aboriginal self-determination’ was not familiar to one person with disability. They said: *“I’ve never actually had to think of it as Aboriginal self-determination. I consulted with some Elders in my community and we decided to put it as an Aboriginal perspective the topic should be ‘being supportive of Aboriginal sovereignty as an allied health worker’”*. Their video content aligns with many of the Disability Inclusive Principles, when asked what was most important to them when working with allied health professionals:

*... being listened to, to be understood, and have a right to interact on our terms, and have the outcomes we choose in a timeframe we choose. We need to sit and talk as equals respectfully. We don’t need to be talked down to. We also need to feel relaxed, and know it’s okay for us to speak up. After generations of control of our people, and being kept away from education and its benefits, we still feel the effects ... We don’t expect much, but what we do expect is respect, dignity, understanding, and choice. You need to talk to us mobs in the terms we understand. We don’t understand everything you are talking about, so talk to us in our words, don’t use your jargon, bring it down, right down, to an equal level where we get it, we understand and we feel comfortable.*

An advisory committee was also formed for the duration of the design process. This committee included people with disability, Victorian government representatives and allied health and disabled persons’ organization representatives. The project also received approval from Monash University Human Research Ethics Committee, and **consent** was received from 30 people with disability, 150 health professionals and 54 allied health educators who contributed to co-design workshops over a period of eight months to inform iterative design of the digital resources. Feedback from each workshop was incorporated into subsequent design iterations until consensus on design was gained via informants across the two stakeholder groups.

The features of My Allied Health Space ([www.myalliedhealthspace.org](http://www.myalliedhealthspace.org) (accessed on 12 January 2022)) offer **a range of types of activities** which include: (1) dual website and information sheet view options (standard or Easy Read view) so the user can choose their preferred or the most accessible digital information style; (2) multiple mixed information resources (captioned video, image and written content) so that the user has choice of a range of information resources and tools, offered in varied formats; (3) **AAA-accessibility** to respond to the circumstances of a range of people who may use varied and alternative methods for digital access (e.g., screen reader; voice control for direct access; eye gaze or switch control of computer systems); and (4) a comprehensive, interactive learning management system for allied health professionals broken into multiple modules for self-paced learning. These approaches have led to a user-centered design being delivered, with **ownership** shared across all team members. All have been listed as contributors on the website, along with the logo of the organizations in which they work.

The narratives above have summarized a range of strategies to enact and deliver disability inclusive research.

#### **What may be the challenges of enacting inclusive research?**

Checklists and outputs are unlikely to ensure the principles of inclusion are met, and indeed we must ensure that signaling a few markers of inclusion will not pass muster. We work in the health and rehabilitation space, and conducting inclusive research within biomedical paradigms brought us face to face with a range of boundary issues/pragmatic constraints. We describe two of these here, related to **co-presenting**; and to **redefining what research is**, where we observe we were unable to fully realize inclusive research principles.

The lived experience experts of My Allied Health Space were listed as co-authors on one abstract (Callaway et al. 2021a) but not on another (Callaway et al. 2021b) with both papers presented by only one listed author. This is due to two factors. Firstly, presenters at conferences are usually required to register to attend, and registrations are costly and most often are out of pocket expenses of the presenter(s). Secondly, the strict time limit

of presentations, eight minutes, and 15 min respectively, make co-presenting by multiple speakers problematic (even with pre-recording presentations, which was the case for these conferences occurring during the height of the COVID-19 pandemic in Victoria). For another project, authors EB and LC included two people with disability as co-presenters for a conference, and were subsequently sent instructions as to the format of the recording, which included uploading two separate files, a PowerPoint, and a video of the presentation. It was not possible for all four co-presenters to be in the same room, as one presenter was in hospital. This co-presenter sent an audio file for their part of the presentation. Strategies were required to ensure inclusion of another co-presenter. They needed to record in bitesize segments, and were more comfortable with audio than a video recording. For consistency EB also recorded audio, so there was no video of any of the presenters. The audio files were edited together to give the impression that we had all presented together, and to ensure the presentation was within the time limit, short or long pauses were cut from the recording, and the speed of some audio clips were slightly adjusted. After uploaded the two files we received the following reply:

*Thanks for your presentation. It is excellent. I do however, need a separate video file and ppt [PowerPoint] file for consistency. All other presenters have sent the two separate files. Sorry for the inconvenience, but can you please send the two files separately, as per the instructions.*

The strategies we used for inclusion of all speakers were explained to the conference organizers, and they were apologetic, and they said we did not need to redo a videoed version of the presentation. This flexibility is needed for all conferences to ensure inclusion of people with disabilities.

This principle is echoed by RB, a disabled woman<sup>1</sup> with lived experience of being bedridden and homebound ([www.notdoneliving.net/just-invisible.html](http://www.notdoneliving.net/just-invisible.html) (accessed on 12 January 2022)). RB states,

*If you were talking to people about making a conference accessible, people will talk about interpreters, ramps, things like that. Or a deafblind person who needs tactile interpreting. Or a person with intellectual disability who needs cognitive accessibility. But I need virtual accessibility . . . and to drop me . . . just because I am the only one talking about it, its terrible.*

The exclusion of people who, in research terms, may be an ‘n of 1’ serves to further marginalize the person who is most marginalized in the first place’.

This point brings us to fundamental questions about how to enact the principle of ‘**redefining what research is**’ uncovered an epistemological tensions (Hathcoat et al. 2019). As RB describes her experiences as a research ‘outlier’:

*When you come to me with a questionnaire, and it says to me, is my answer a or b, and I say well actually my answer is c,d,e,f and sometimes z, then I don’t want the researcher to say well sorry that’s impossible, I want them to say ‘hey wow—you are the person with the disability’ . . . my lived experience is real, I want to be believed as a person with disability and if what I say doesn’t fit with your paradigm, that means your paradigm is wrong. If what I say is something that your theory says is impossible, that doesn’t mean that my experience hasn’t happened, it means your theory needs to be revised, and that what collaborative research is about—that my experience is just as important as your theory or your paradigm.*

As a researcher trained in psychology and health systems research, EB reflects upon RB words and highlights some potential areas in need of change.

*When learning about how to do good research, you are told about all the steps you need to take to ensure rigor in the planning, execution and reporting. You learn about the pros and cons of each methodology. For surveys, the advantages are that they enable you to obtain a large amount of data from a representative sample, so that the results are generalizable to a specific population. One of the disadvantages of surveys being that*

*the data is unlikely to contain the same level of depth as interviews or focus groups. You learn how to analyze data, and in the case of closed-ended questions, where respondents select 'other', about techniques you can use to interrogate those responses to identify themes, or the most common responses. You learn that it is not a requirement to provide every possible breakdown of the data, rather you need to present the highlights, or those findings that are statistical and/or have practical significance. So, consequently, if only one participant answers 'z', their response gets left out of the findings. The same is true in research using interviews or focus groups as the methodology. Thematic analysis of the data similarly requires the researcher(s) to examine the data to identify common themes that come up repeatedly. However, there are instances where a response is a one-off, there is no theme, and whilst it is not included in the findings I can see how this could lead participants such as RB feeling that their voice had not been heard, or worse still completely ignored when reading the findings.*

*RB also mentioned the need for theories to sometimes be revised, which can often be easier said than done, as people (i.e., reviewers, editors) can be much more accepting of 'confirming' evidence. For example, ... a review in 2005 found significant results are more likely to be published (Dubben and Beck-Bornholdt 2005). The source of this problem is unknown, is it failure of the researcher(s) to write up the study, failure to submit for review, or failure for the paper to be accepted by a journal. Consequences of leaving non-significant findings unreported, apart from an unproductive expenditure of time and funding, are the potential to impede progress, prevent the creation of new theories or the revision of existing theories. Ferguson and Heene (2012) reported that publication bias can lead researchers to conduct studies and analyze results in ways that minimizes the danger of non-significant results. This too, is something I have encountered in the very early stages of my research career. I recall running an experiment and analyzing the data and the results being insignificant. However, rather than our data and findings offering the potential to revise an existing theory, I was told that our non-significant findings were due to having some outliers in the sample. I was subsequently asked to re-advertise and repeat the study with some 'replacement' participants, and re-run the analysis. In such a pursuit to obtain statistically significant findings that support an existing theory, it seemed like we were potentially removing important information about the variability we had encountered, and overestimating the true effect of the existing theory.*

These examples and directions are drawn together in the discussion, with a proposed way forward.

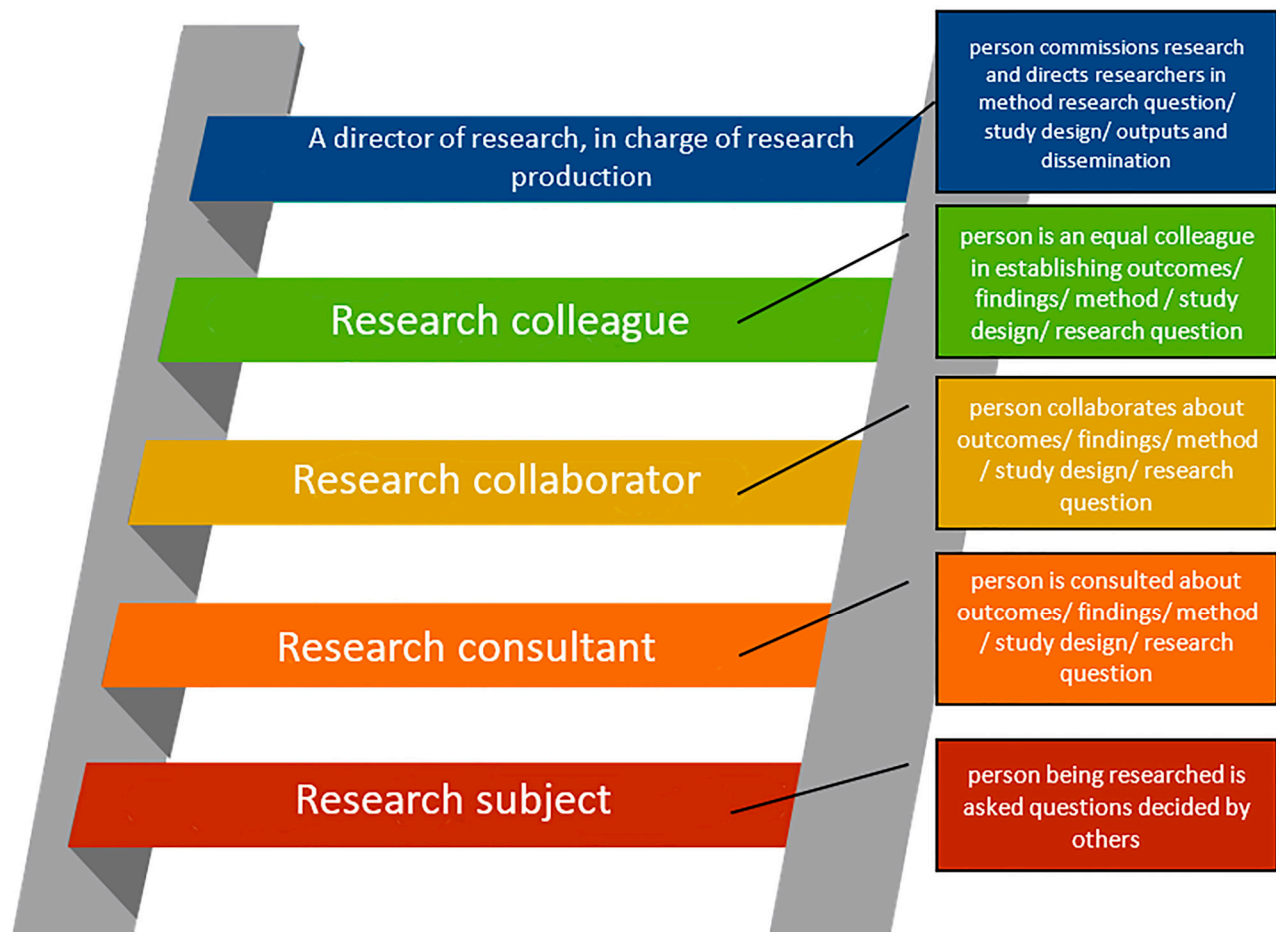
#### 4. Discussion

We agree with the question posed by Milner and colleagues that 'academic researchers might want to check how far inclusive methods had travelled down a road intended to change the power relationships that underwrite knowledge production' (Milner et al. 2020, p. 127). These examples of inclusive research in health, rehabilitation, and assistive technology can be described as partial. Despite our best efforts, there are many factors which limit the full realization of co-produced and inclusive work. Based on the above learnings we suggest a progressive model is needed, but must go hand in hand with research governance and practice that builds, rather than inadvertently blocks, inclusion for all.

Arnstein's (1969) ladder of citizen participation provides a useful approach (Callaway et al. 2020). Originally it presented a hierarchy of citizen participation from non-participation through to tokenism and ending with the ideal of citizen control. In the last decade, however, the ladder concept has been applied to consumer participation, broadly moving through rungs of 'doing to' (coercing, educating); 'doing for' (informing, consulting, engaging); 'doing with' (co-designing, co-producing) and arriving at 'doing for themselves' (co-delivery, co-ownership) (New Economics Foundation 2012; People with Disabilities Western Australia 2020).



We draw on this co-design and co-production thinking to propose a revised ladder of participation suitable for inclusive research (see Figure 3). Our proposed classification of research roles recognizes that all researchers may hold roles as a research subject; a research consultant; a research collaborator; a research colleague or a director of research who contributes to or is in charge of the mechanisms of research production.



**Figure 3.** Ladder of research inclusion.

Such a ladder will, at a minimum, alert those involved with research as to its potential emancipatory opportunities and enable claims of ‘inclusive and co-designed’ research to be interrogated. To accept the premise that people with lived experience can, and should, engage across all aspects of research production will require a changed ontological positioning on the part of academic researchers and lived experience experts like us who have been acculturated into roles predetermined by ‘the academy’.

To enact the ladder and deliver on inclusion will require a range of conversations and strategies. A shift towards intersectionality (Gressgård 2008) is a key epistemological tool. Discourse amongst intellectual disability thinkers (Jones et al. 2020; O’Brien 2020) explores whether participants in research will assume differentiated roles based on what they bring, or whether group collaboration will play out, knowing the right people are in the room and each will do according to their capability. Strategies such as engaging in a strengths-based dialogue about what each person brings to the research endeavor may serve to bring rehabilitation researchers on this journey. And attention to the ways in which this inclusive view might be adopted by stakeholders holding power in research environments, for example research funders and ethics boards, would be a further step on the road toward inclusion (Gaventa 2006).

## 5. Conclusions

In our introduction, we asked how our knowing and doing is influenced, and we framed our answer from the position of practitioner and consumer researchers. But really, our knowledge, our skills, and our position on the trajectory of learning how to do research are all intersecting qualities. These are poorly articulated by the binary of ‘researcher’, and person with disability or the ‘researched’. We know that our knowledge is likely to be partial as our positioning which, by definition, does not encompass the positions of all others. Exploring the practice of inclusive research across the areas of assistive technology policy; digital health access; and the co-design of housing and support, demonstrates a lag in the inclusive credentials of thinking about inclusion in rehabilitation research. Explicit strategies, such as the ladder of inclusive research participation, may enable the implicit role (and power) entrenchment in health and medical research to be illuminated, discussed and redressed.

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## Note

<sup>1</sup> R.B. chooses to describe herself with these words.

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## Article

# Reflecting on the Value of Community Researchers in Criminal Justice Research Projects

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**Abstract:** While the importance of community researchers has long been acknowledged in disability studies, inclusive research practices such as these are less common in research about another marginalised group: people who are in prison or have spent time in prison. Over the past decade in Australia, the number and rate of people imprisoned has risen rapidly, and recidivism rates remain high, indicating a need for improved services. In this article, we draw on methodological reflections from two case studies on research with marginalised communities, one in disability studies and one in post-prison research. We apply insights from disability research to argue the importance of incorporating community researchers in qualitative research projects seeking to explore the experiences of people involved with the criminal justice system, such as people who have been released from prison.

**Keywords:** disability; inclusive research; community researchers; prisoners; former prisoners; criminal justice system

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## 1. Introduction

Over the past decade in Australia, the number and rate of people imprisoned has risen rapidly, and by 2019 the Australian prison population was at its highest-ever recorded level (ABS 2019). A majority of people in Australian prisons have been incarcerated before, with prison and unstable housing or homelessness representing a 'revolving door' for many individuals (Baldry et al. 2018; COAG 2016; Schetzer and StreetCare 2013). People who have spent time in prison are disproportionately likely to face a range of challenges and intersections between oppressive social structures such as mental and physical ill health, disability, substance abuse, socioeconomic disadvantage, racism, and stigma of criminal history (AIHW 2019; Western 2018; Johns 2017; Young et al. 2017).

Community researchers (also known as peer researchers or participant researchers) are members of the community or group being researched. It is increasingly acknowledged that community researchers are important when exploring research issues that impact marginalised (sometimes termed 'vulnerable') populations, such as people with disability.<sup>1</sup> Community researchers are beneficial for academic research teams because they have unique knowledge of the problems to be investigated by virtue of their lived experience, can increase the real-world impact of projects by making sure the concerns and interests of the marginalised groups are central to the research, and have the methodological potential to help academic researchers access (and anticipate participation barriers for) 'hard to reach' populations. For the community researchers, involvement in research can be empowering, allow their voices to be heard regarding issues that concern their communities, build self-advocacy, and provide training, skills, and new job opportunities (Edwards and Alexander 2011; Strnadová et al. 2020; Warr et al. 2011).

This article draws from two case studies to argue the importance of an underutilised resource in criminal justice research: incorporating community researchers in qualitative research projects seeking to explore the experiences of people involved with the criminal justice system (here focusing particularly on people who have been released from prison). We firstly review relevant literature on people with disability in prisons and their experiences post-release. We show how characteristics associated with marginalisation intersect within this population. We then consider the benefits and challenges associated with conducting qualitative research about people's experiences after their release from prison. The article then moves to the first case study, a qualitative research project which investigated gendered barriers to women's participation in individualised disability funding schemes. This project employed a community researcher, and we provide a reflection from both the academic and community researchers on how they worked together and what each brought to the project. The second case is a qualitative research project that investigated the experiences of people following their release from the only adult prison in the Australian Capital Territory (the ACT). This project did not employ a community researcher and we provide a reflection from the academic researcher regarding the challenges associated with recruiting participants and developing trust and rapport with participants.

Drawing from these case studies, we argue that when conducting qualitative research about the experiences of people exiting prison, academic researchers should strongly consider an inclusive research design, specifically the engagement of community researchers. Whilst the importance of community researchers has been acknowledged in the disability literature for several decades as part of the movement towards 'inclusive research' or 'participatory research' (Bigby et al. 2014; Nind and Vinha 2014; Vaughan et al. 2019), these practices are far less developed and employed in research about people who are currently in prison or have spent time in prison (Awenat et al. 2018; Haarmans et al. 2020; Watson and van der Meulen 2019). This is particularly true in Australia (Doyle et al. 2021a; Lewis and Ditloff 2021). We argue that employing community researchers in this space is important as people in prison, or who have spent time in prison, are likely to experience a complex intersection of marginalising social structures such as race, mental ill health, and socioeconomic disadvantage. Insights about inclusive disability research are also likely to apply to criminal justice research, as there is considerable overlap between the disability and prison populations—up to 30% of the Australian prison population are known to have chronic health conditions that limit their ability to participate in daily tasks, education, or employment (AIHW 2019). We therefore recommend that qualitative academic researchers investigating the experiences of people following their release from prison should ensure they engage with community researchers in their efforts to gain a holistic understanding of the post-release experience. By gaining this understanding, academic researchers will be better placed to provide insights into designing and implementing more appropriate policies and programs for this population, during incarceration and post-release.

## 2. The Experiences of People in Prison

It is widely acknowledged that people in Australian prisons are a disadvantaged group. They commonly have high rates of chronic and infectious disease, alcohol and other drug dependence, and mental illness (AIHW 2019; Butler et al. 2007; Dias et al. 2013). The AIHW conducted a prison census in 2018 and found that around 30% of prison entrants self-reported having a chronic health condition (which the AIHW considered as analogous to disability) that affected their participation in day-to-day activities, education, or employment (AIHW 2019). Internationally, the overrepresentation of people in prison with intellectual disability is of particular concern, with estimates ranging from 2–40% of the prison population, depending on the methodological, diagnostic frameworks and terminology adopted by researchers (Dias et al. 2013; Hellenbach et al. 2017; Hayes et al. 2007; Jones 2007; Young et al. 2017).

Upon release from prison, people face a range of challenges. These includes systemic barriers that lead to their exclusion from basic needs such as secure and stable housing

(especially housing that is suited to disability access requirements, such as proximity to public transport and social services) and employment (including support to transfer skills gained in prison) (Doyle et al. 2020, 2021b; Baldry et al. 2018; Johns 2017; Schetzer and StreetCare 2013). As well as structural exclusion, people can face underlying identity-based and confidence issues in their efforts to obtain and maintain employment (Cherney and Fitzgerald 2016; Doyle et al. 2021b; Johns 2017). This points to the importance of post-release support and the need for a continuum of care to extend beyond the prison and into the community (Baldry et al. 2018; Cherney and Fitzgerald 2016; Johns 2017; Schetzer and StreetCare 2013). The post-release challenges are further compounded for people with disability, as they often have complex physical health, mental health, and substance use treatment needs (Bhandari et al. 2015; Dias et al. 2013; Heslop et al. 2014; Young et al. 2017). Scott and Haverkamp (2014) argue that increased support is needed in the community for people with intellectual disability upon release from prison.

### 3. Research Methods for Investigating the Experiences of Marginalised Populations

There is a long-established tradition of qualitative research with people with disability (Barnes 1992; O'Day and Killeen 2002). Following the social model of disability—in which impairments are seen as disabling for individuals due to socially imposed barriers such as inadequate transportation, unsuitable infrastructure, and discriminatory attitudes—Berger and Lorenz (2016) argue that qualitative methods are best suited for exploring the social experiences of people with disabilities in ableist societies. They are important for establishing how the impairment itself, societal attitudes, and public programs combine to shape an individual's experiences (O'Day and Killeen 2002). In disability research, qualitative methods are tied strongly to an interpretive approach to knowledge production, in which academic researchers acknowledge their positionality and the impossibility of achieving objectivity, and aim to get to know the social world being studied first-hand. Academic researchers in this tradition try to understand and depict the social world as it exists for those being investigated (Barnes 1992).

The importance of community researchers has been acknowledged in the disability studies field since the 1990s, forming part of the movement towards 'inclusive research' or 'participatory research' (Bigby et al. 2014; Nind and Vinha 2014; Ward and Simons 1998). Community researchers have also been employed with many other marginalised populations, such as drug users, residents of socioeconomically disadvantaged neighbourhoods, and sex workers (Warr et al. 2011). In Australia, Aboriginal and Torres Strait Islander community researchers have been employed to assist academic researchers with ensuring research projects are community-led (Bell et al. 2021).

Community researchers have unique knowledge of the problems to be investigated by virtue of their lived experience. They can draw on their networks to increase the research team's access to participants in the disability community, and can plan and design research in ways that improve the potential of the research to uncover useful information (for example, by anticipating barriers to participation) (Strnadová et al. 2020). When conducting interviews, community researchers may be able to more easily build rapport through shared experiences (Warr et al. 2017)—although as Barnes (1992) notes, disability experiences and impairments are varied and having an impairment will not automatically lead to a good understanding of disability. For the community researchers, involvement in research can be empowering, allow their voices to be heard regarding issues that concern their communities, build self-advocacy, and provide training, skills, and new job opportunities (Strnadová et al. 2020; Warr et al. 2011). Benefits for academic researchers without disability include personal growth and the development of new skills, such as greater understanding of the disability community and the challenges facing it and better ways of putting knowledge into action, as well as the potential to achieve greater real-world impact for their research (Strnadová et al. 2020).

Whilst the importance of community researchers has long been acknowledged in disability studies, the employment of community researchers and other inclusive research



or participatory research practices is comparatively underdeveloped in projects investigating the experiences of people serving time in prison and upon release (see Abbott et al. 2018; Awenat et al. 2018; Crabtree et al. 2016; Doyle et al. 2021a; Haarmans et al. 2020; Lewis and Ditloff 2021; Sullivan et al. 2008). The limited literature available on service user involvement in prison and post-prison research sometimes conflates service users as *participants* contributing data, with service users as research *co-collaborators* guiding and influencing the study as a whole (Awenat et al. 2018). However, a convict criminology movement has been developing, particularly in the United States and United Kingdom (UK). Convict criminology generally refers to research by people in prison (or who have spent time in prison) who have combined their prison experience with a higher degree in criminology (Earle 2018; Ross et al. 2016).

One study that did reflect on how access barriers to current prisoners altered the scope of their research is Watson and van der Meulen (2019). They concluded that it would have been advantageous to include people who have spent time in prison in their research design, data collection, and analysis as it could have improved not only the quality of the research but also contributed to supporting the skill development and personal capacity of this population. A UK study by Awenat et al. (2018) involved former offenders with lived experience of suicidal thoughts or behaviour during incarceration as part of the research team. They found that participants felt accepted and valued by the research team and argued that the involvement of this population was highly influential to participants' sustained engagement in the study. More recently, Haarmans et al. (2020) shared their experiences of organizing a participatory action research project in a UK prison. They noted that despite the challenges associated with involving people in prison as part of the research team, their active involvement in research can lead to new knowledge and personal transformation.

In Australia in the last few years, there have been few qualitative projects investigating the reintegration experiences of people following their release from prison (Baldry et al. 2018; Carlton and Segrave 2016; Cherney and Fitzgerald 2016; Doyle et al. 2020, 2021b; Griffiths et al. 2017; Johns 2017; Schetzer and StreetCare 2013). The academic researchers conducting these studies all noted the challenges associated with conducting this type of research, such as recruiting participants and obtaining and maintaining trust and rapport (Doyle et al. 2020; Baldry et al. 2018; Johns 2017; Carlton and Segrave 2016; Cherney and Fitzgerald 2016). These studies did not employ community researchers; the research was either conducted by academic researchers or in collaboration with service providers that work with people upon release from prison. For example, in Schetzer and StreetCare's (2013) study on the experiences of people recently released from prison into homelessness and housing crisis, interviews were conducted by members of StreetCare with support from the Homeless Persons' Legal Service. StreetCare does employ people with lived experiences of homelessness, but not prison (StreetCare 2020).

We now move to two case studies of qualitative research projects. The first, which employed a community researcher, investigated gendered barriers to women's participation in individualised disability funding schemes. The second investigated the experiences of people following their release from the adult prison in the ACT. This project did not employ a community researcher. The purpose of these narratives is not to provide the results of these studies, but rather to show the important role of community researchers in research about marginalised populations, and to highlight the need for community researchers to be employed in the criminal justice sector. The reflections focus on research design, participant recruitment, building trust and rapport with participants, and how community researchers can strengthen these aspects.

#### **4. Case Study 1: Gendered Barriers to Accessing Individualised Disability Funding Schemes**

Australia's National Disability Insurance Scheme (NDIS) is a major policy reform based on an international trend towards personalisation in social care. It aims to increase choice

and control over services and supports for people under 65 years of age with permanent and severe disability, thereby boosting citizen empowerment and improving health and social outcomes (Malbon et al. 2019). However, women and girls are underrepresented in the NDIS; they make up about half the disability population overall, but the female participation rate has been approximately 37% since the inception of the scheme (NDIS 2021). Marginalisation of women with disability is a major concern in Australia and internationally (Sakellariou and Rotarou 2017; Smith 2008; UN Secretary-General 2017).

The NDIS has attributed the low female participation rate to the fact that males (particularly young males) are more heavily represented in the types of disabilities primarily funded by the scheme (NDIS 2019). However, it is increasingly recognised that disabilities such as autism can be underdiagnosed in women (Zener 2019), and several disabilities or chronic health conditions more common in women have been given insufficient attention from the disability support and medical systems (Mirin 2021; Briones-Vozmediano et al. 2018; Samulowitz et al. 2018). Other relevant issues in the exclusion or underservicing of women with disability may include complications related to caring responsibilities (particularly mothering) (Malacrida 2012), and gender socialisation to undervalue their own needs and requirements in situations where negotiation is required (Amanatullah and Tinsley 2013). The latter may lead to women being less effective self-advocates than men in schemes such as the NDIS, that put an unprecedented emphasis on individuals to navigate care systems and advocate for their own needs and rights (Yates et al. 2021). However, at the time this project was conducted there had been little research investigating women's outcomes in relation to individualised disability funding schemes, and none at all focusing on women's experiences with the NDIS.

This project was an exploratory interview-based study, funded with a seed grant from the Disability Innovation Institute, UNSW. Two of the present authors (Sophie Yates and Jen Hargrave) were part of a research team partnering with two disability organisations (Women with Disabilities Victoria and Women with Disabilities ACT) to investigate women's experiences accessing and navigating disability support in Australia, particularly the NDIS. As there had been no previously published research into gender inequality in the NDIS, the study sought to establish themes and directions for future research in the area. Inclusion criteria were women with disability over the age of 18, located in the state of Victoria or the ACT, who had applied or considered applying for the NDIS.

Women were recruited for the study through the contact lists of the two partner organisations. Jen Hargrave (third author), who also worked for Women with Disabilities Victoria, acted as a peer or community researcher, and organised and led most of the interviews, which were jointly conducted with Sophie Yates (second author), in her role as Principal Investigator. The interviews were originally planned as face-to-face encounters but were required to move online due to COVID-19 restrictions. Data were collected using two methods: semi-structured interviews using questions co-designed by the research team and partner organisations, and a visual mapping exercise known as System Effects. This exercise allowed participants to identify barriers to accessing disability support, the factors they saw as influencing those barriers, and any connections between barriers. Participants were compensated for their time with an AUD 100 online Mastercard, which the partner organisations considered to be an appropriate amount for interviews of approximately one hour. They were assured their contributions would be anonymous, and many chose their own pseudonyms for use in publications.

#### 4.1. Research Design

Sophie: My background is in public administration and gender research, so I was new to the disability field when we started planning this project. Having internalised the doctrine of 'nothing about us without us' from other social justice research, I knew that co-design (where research is designed by both academics and partners from the target group) and the employment of a peer researcher would be crucial to the success of the project—both for my own comfort levels as someone unfamiliar with the field, and

for designing and implementing a project most likely to uncover valuable insights for addressing gender inequality in the disability support system. I was lucky that I already had Jen in my networks and was able to approach her to secure her involvement and that of her organisation before we applied for the grant.

Jen: I grew up with a disability and with a mum with a disability, which put me in the position to learn firsthand about barriers to disability supports for myself and for my mum—many of which we didn't conceptually identify at the time.

I am not an academic, but I came to this community researcher role with a little formal research experience which was also helpful to understand common research processes and constraints. Without these prior experiences I may not have had the confidence, the trust in myself to step into the role. Working beside an experienced researcher was a critical enabler to the project. Sophie did all the establishment and management of the project. She got me on board fairly early in the process, prior to the ethics application, seeking my involvement and input. She was open to my questions and recommendations. In a short time, I knew I could trust her to genuinely try to understand my perspectives and implement changes appropriately.

Sophie: Jen had input into the grant application and—crucially—the ethics application and interview schedule. She explained which language was most appropriate to use and why, and challenged me about the inclusion of women with intellectual disability in our project. I had thought that it would be too difficult to obtain ethics approval for this cohort, but Jen pointed out that she had never before excluded particular disability types from interview recruitment, and was not comfortable doing so now. This made me confront my own biases—I realised she was right, and we reworked the ethics application to make our processes appropriate for women with intellectual disability (for example, developing easy read and guardian consent forms). Obtaining ethics approval was not actually as difficult as I had anticipated, which made me think about the ways that researchers' apprehension about ethics procedures may lead to the exclusion of certain participant groups. Without Jen's input, we would not have obtained insights from this important group of NDIS participants. I also found the input of partner organisation, Women with Disabilities ACT, very useful, as one of their staff members suggested the inclusion of a question that provided useful insights into how the NDIS communicated with participants.

#### 4.2. Recruitment, Trust and Rapport

Jen: Trust around recruitment was something Sophie and I discussed. I pointed out that recruiting through community organisations is quite an ask and she was curious why. I work for a community organisation, Women with Disabilities Victoria. I explained that it can take quite a bit of time to recruit, that recruiting for a researcher can be like setting up participants on a blind date, and that if the participant does not have a good experience of the research, they may raise this with the organisation they trust rather than with the academic directly, and even seek follow up support from the organisation. Perhaps this is an argument for building trusted community members and community workers into projects to support recruitment in a deliberate and resourced way.

It is not new to say, but my personal experience was something that could establish trust with interviewees, and some even referred to it, e.g., 'I feel better knowing that (I am talking to someone who will understand my experiences).' This is not to say that as a disabled individual I can create an instant connection to every other identity or experience, but to say that it is conducive. My own experiences as a research participant, a service recipient, and as a disabled community member do give me some insight into how we can wait for someone to show they can be trusted. Sometimes, if not often, trust might not come in a one-off interview. While participants were quite open about their experiences of being a woman accessing disability supports in Australia, speaking with them over a series of interviews could have allowed them to share more of the really difficult stuff.

Something I noticed setting up and co-facilitating interviews was how my different professional experiences informed my work. For example, previous roles included phone

counselling in a feminist service (which gave me a strengths-based approach with interviewees), creating Reasonable Adjustments for tertiary students with disabilities (which gave me confidence in organising disability-access supports for interviews), and systemic advocacy on gender and disability (which orientated me to the diversity and the patterns of women's individual experiences of ableism and sexism).

A prominent background experience on my mind was my experience using research in systemic advocacy, and that potential power of research was a constant personal motivator. It is perhaps reckless to admit to this, as it is precisely this point that is held as a criticism of community researchers—that they are motivated by advocacy and bias; it is not an easy criticism to counter to people who cannot understand how informing lived experience is.

*Sophie:* When it came to recruitment and rapport-building, Jen's involvement was invaluable. Drawing on her professional experience and lived experience as a woman with disability and an NDIS client, she was able to build rapport with participants during the recruitment and set-up process, which often involved several phone calls to explain what the project was about and how the interview would be conducted. She was sensitive to accessibility requirements, which enabled the inclusion of a wider variety of participants and helped them feel they were talking with a research team genuinely interested in their needs and experiences. I learned from her about appropriate language to use and the importance of avoiding deficit-related constructions of disability. Lastly, her professional advocacy experience and lived experience as an NDIS client led her to ask astute follow-up and probing questions that would not have occurred to me, while my gender research background enabled me to zero in on some issues that might be relevant to gender. I think we would both agree that our skills complemented each other well.

I was glad that we had built financial compensation into our research design. I didn't get the sense that it helped much with recruitment—in fact, many participants seemed surprised when I reminded them that I would send them a voucher after the interview. I got a bigger sense that people valued having their stories heard and hoped telling us about their experiences would help drive change. Some also just appreciated having a chat after being stuck inside for months due to COVID-19! However, it became clear that while some participants were financially stable, a number of them would actively benefit from an AUD 100 Mastercard to help with household expenses, so I felt pleased that we could show our gratitude for their participation with this material compensation.

We did have a few issues with recruitment in that we originally planned to interview 15 women from Victoria (one of Australia's most populous states) and 15 from the ACT (which is a much smaller jurisdiction). However, despite trying for months, we could not find enough participants from the ACT who fit our recruitment criteria. Several people agreed to be interviewed but later changed their minds or stopped responding to emails, so we decided to make up the numbers with Victorian participants. Thus, despite the involvement of a community researcher and recruitment assistance from a local community organisation, there can still be challenges with finding enough research participants from small and potentially 'over-researched' groups.

We now move to the second case study, where inclusive research practices such as community researchers were not employed.

## **5. Case Study 2: The Experiences of People following Release from the Canberra Prison**

The ACT opened its first adult prison in 2009. The prison is the first (and only) one in Australia designed and built to operate as a 'human rights' prison (ICS 2019). It was expected to house 270 prisoners (known as detainees in the ACT); however, in recent years, the population has reached over 350 (ABS 2021). The prison houses male and female detainees at all classification levels (minimum, medium, maximum), sentenced and unsentenced (remand). Similar to other Australian jurisdictions, Aboriginal and Torres Strait Islander people are over-represented, comprising over a quarter of the prison

population. Recidivism rates in the ACT are even higher than in the rest of the country, with 78% of detainees in the AMC having been incarcerated previously (ABS 2021).

Various support services are available to people exiting the prison in Canberra to assist them in reintegrating into the community (see Bartels and Doyle 2020). One service, the Throughcare Outreach Program, is tailored to each client, commences pre-release, and offers short term support, with the assistance of local service providers (CatholicCare n.d.; Griffiths et al. 2017). There has been limited qualitative research investigating the experiences of people following their release from the prison. One recent study, the 2017 *Evaluation of the Extended Throughcare Pilot Program*, employed qualitative and quantitative methods to investigate clients' experiences with Throughcare and suggested areas of improvement (Griffiths et al. 2017). Overall findings were positive, however, challenges included confusion by clients about the Throughcare program, insufficient stable and suitable housing in the ACT, and insufficient engagement with employment services.

The purpose of the qualitative pilot project reported here was to gain an insight into the challenges people face following their release from the prison. Interviews were conducted throughout 2019. There were two conditions that participants needed to fulfil to qualify for the study: they needed to have spent at least one month in the Canberra prison and have been released in the last six months. Previous studies have shown even a short period of incarceration can have an adverse effect on reintegration into the community (Australian Law Reform Commission 2017). People serving shorter sentences are more often those who have committed multiple less serious offences and tend to cycle in and out of the justice system (Baldry et al. 2018; Borzycki 2005; Dowse et al. 2009). It was initially intended that follow up interviews would be conducted with participants around two months after the initial interview, but due to recruitment difficulties, further discussed below, each participant was only interviewed once. Most interviews lasted for around 60 min.

### 5.1. Research Design

Following approval from the UNSW Human Research Ethics Committee, permission from ACT Corrective Services, and support from a range of service providers in the ACT, a flyer with information on the project was placed in the offices of government and non-government organisations that provide support to people upon release from the prison. These service providers also provided some guidance during the design stage, such as the wording on the flyer and where the flyer should be placed in their offices. The flyer had the contact details (phone number and email) of the academic researchers and details of the financial compensation for participation. Participants were paid in AUD 20 Essentials cards, with the intention that they would receive AUD 30 for a second interview and AUD 40 for a third interview.

### 5.2. Recruitment, Trust and Rapport

Caroline Doyle (first author): At the time of the interviews, I was the President of Prisoners Aid ACT, a non-government organisation that provides assistance to current and former detainees and their families in the ACT. I have been involved with this organisation for the past seven years and therefore had some understanding of the challenges people can face whilst incarcerated and post-release.

I found that the majority of participants saw the flyer in the reception area of a service provider and called the listed phone number. During the initial phone contact, I spent time developing rapport with participants. For example, I would explain my involvement with Prisoners Aid ACT, my motivation for the research project, and ask them how they were adjusting to life following their release. We would agree on a time to meet and at the beginning of the interview, I made sure that I continued to develop this rapport with participants. I found that participants felt comfortable in knowing my experience with Prisoners Aid and that I wasn't just 'another researcher', but rather someone who had some knowledge and understanding of the day-to-day challenges they were facing.

Some participants did ask during the initial phone contact ‘but, is this really going to change anything?’ I found that participants appeared to be motivated by two factors. The first was the monetary payment, with some specifically referring to the fact that they were ‘really struggling at the moment’ and needed it to buy food or baby clothes. However, others mentioned that they were not interested in the monetary payment, but rather wanted to see changes for future people in the same position and that this was the first time someone had asked about their experiences. Whilst they were interested in seeing change, they were very sceptical about any change happening.

In terms of establishing trust with participants, I explained to them, in simple language, the information on the consent form—‘the admin part’ as I called it. I especially focused on how anything they told me would not be shared with ACT Corrective Services or any other government agencies. I also reminded them that anything they said during the interview would not affect any services they would receive from Prisoners Aid or other service providers. I found this was an important reminder as one participant explained to me how they had told confidential information to a service provider and then this information was used against them. One challenge with completing the consent form was that some participants did not yet know their mobile phone number or email address as they had been recently released and had forgotten their passwords, and only knew their prison email address information. Many also did not know what their permanent address would be, or even have stable accommodation.

In interviewing participants, I had to ensure that I was aware of my positionality. For example, given the interviews were conducted face-to-face, I thought about the clothing I needed to wear. I considered it was appropriate to wear clothing that wasn’t too formal. I also used language that I considered appropriate, such as ‘COs’ and ‘screws’ when referring to custodial officers or a ‘shot of ice’ when referring to taking crystal methamphetamine. But I did find during interviews when I asked participants to discuss their post-release experiences, they said things like “I’m only giving you pretty much the basics but, you wouldn’t know unless you’ve been in there”. For some, they saw me as just ‘another’ person who wouldn’t have any idea as to what it would be like to walk in their shoes.

Several participants spoke about their feelings of embarrassment when explaining their prison episode(s) to potential employers or landlords. They would tell me about how going to prison was their own fault and that they can’t rely on anyone. I had to be very careful to show participants empathy and that I wasn’t judging them for their past. I was prepared with the contact details of service providers that assist people post-release in the ACT.

Whilst it was initially proposed that participants could tell other people who fit the inclusion criteria about the research project, this proved to be difficult for two reasons. Some reported that they did not want to socialise with other former detainees, and some participants said that their peer group was still inside the prison. Another challenge related to the difficulty of arranging interviews with participants in ‘the future’. Most participants requested to meet within the next 24 to 48 h, as they were not sure of their future plans, such as a potential job interview, a court date and time, or a housing inspection. Furthermore, on two occasions I made arrangements to meet participants, but they did not turn up at the pre-arranged time and did not answer follow-up phone calls/messages. The target had been to interview 20 participants but given these challenges only 11 participants were interviewed.

After each interview, I learnt more about the experiences and challenges people can face following their release from prison. I also gained more understanding about the lack of confidence people can have following a custodial sentence. I feel that if I had had a community researcher (such as someone who has served time in prison) working with me during the research design stage, the recruitment process, and interviews, then I would have been in a better position to not only access participants and help them feel comfortable sharing their experiences, but also to ensure that the concerns of people who had spent time

in the prison were central to the project. I also feel that involving a community researcher could have offered an opportunity for someone from that community to gain research experience, build skills, and increase their sense of self-efficacy. These are all very important for people who have spent time in prison: as I consistently found through my interviews, many former detainees have very low self-confidence.

## 6. Discussion

The two marginalised communities explored in this paper share some commonalities. Disability is common among the prison population, with the AIHW (2019) finding that around 30% of prison entrants self-reported having a disability that affected their participation in day-to-day activities, education, or employment. Generally speaking, both people who have spent time in prison and women with disabilities have experienced disadvantage and may have distrust of institutions as a result of their experiences. Both groups have experienced barriers to their full participation in society, with people released from prison often feeling like they are not welcomed in the community. These issues, combined with the more practical barriers discussed, can make it difficult for academic researchers to access these communities and learn more about their experiences.

Comparing our experiences conducting research with marginalised communities helps to demonstrate the importance of involving people from those communities in the research process. While Caroline had knowledge of the problems facing people who have spent time in prison (both from her research experience and involvement in an organization that assists people in prison and their families), her lack of lived experience was noted by participants. She was sometimes seen as one more person who didn't understand their story, which made it more difficult for them to explain their experiences. She also experienced challenges with recruitment, not having networks that could easily reach people who had spent time in prison or the trust to support them to feel their stories would be heard and would make a difference. Conversely, Jen's status as a member of the disability community—particularly as someone who had worked in disability advocacy—meant she provided the research team with better access to community members than they would otherwise have had. She was also able to improve the research experience for participants, designing procedures that increased accessibility and using her own lived experiences and passion for helping her community to build rapport with participants. As highlighted in the literature, working in partnership with an academic researcher enabled Jen to feel like she was developing her research skills and formally contributing to the knowledge base to inform advocacy for women with disabilities, which was important to her on a personal level.

We have no counterfactual to inform what Caroline's experiences would have been like if she had partnered with a community researcher; however, we feel that some of the challenges we have discussed here would have been ameliorated by incorporating this kind of inclusive research technique. Of course, inclusive research with people who are or have been in prison does bring its own set of challenges. Some of these are similar to those identified in disability research, namely building in the time necessary for dialogue, training and explanation of concepts and vocabulary, and enabling community researchers to disagree with the academic researchers through acknowledging and mitigating power differentials (Haarmans et al. 2020). As noted above, many people who have spent time in prison also have disabilities—particularly intellectual disabilities—so that some insights regarding inclusive research in disability contexts will have relevance to criminal justice contexts. Further, Sullivan et al. (2008, p. 18) note that challenges they faced in their prison-based project relating to 'hierarchical power structures, the relative powerlessness of participants, and their general lack of research experience' are common in most participatory research contexts. Other challenges will be more unique to prison and post-prison research, such as prison regime routines (e.g., correspondence restrictions) and disruptions (e.g., prisoner transfer); the need to obtain buy-in from prison managers and other authority figures; and disruption stemming from housing, addiction, and other difficulties people often face upon

release from prison (Abbott et al. 2018; Crabtree et al. 2016; Piché et al. 2014; Sullivan et al. 2008).

This article contributes to the methodological, disability, and criminal justice literature by highlighting the value (and potential value) of community researchers in both fields. Through analysing reflections on using a community researcher in a disability research project, we argue that academic researchers will gain a deeper and more holistic understanding of the post-release experience through engaging community researchers in the criminal justice space, such as in projects seeking to understand the experiences of people who have spent time in prison. This will also provide opportunities for people with prison experience to gain skills and increase their sense of self-efficacy. As Hill et al. (2015) note, research practices that help prisoners (or former prisoners) regain a sense of autonomy and personhood are especially appropriate, given the institutional restrictions and constrained choices that people face inside prison. In employing these methods, scholars of criminal justice could build on findings from previous studies which acknowledged the importance of employing people with prison experience in mentoring others exiting prison (Graffam et al. 2019; Seppings 2015; Weaver and Lightowler 2012).

Ultimately, we argue that incorporating inclusive research methods such as community researchers into criminal justice system research will provide policymakers with useful insights to design better policies and programs for people currently in prison and upon release, and ensure they are provided with the most appropriate support to assist in their (re)integration into the community.

## 7. Conclusions

By acknowledging incarcerated and formerly incarcerated people in Australia as a disadvantaged group across a range of social, economic, and health outcomes, and by advocating for more inclusive methods in research with this population, we have sought in this article to bring the sensibilities of disability scholarship into conversation with the criminal justice arena. Through the use of community researchers, combined with other inclusive techniques, we urge researchers to attend to process and relationship in addition to the more common criminal justice system goals of outcomes and efficacy. Our case study comparison has provided practical insights into the benefits community researchers could offer academic researchers seeking to understand the experiences of people following their release from prison. While we do acknowledge the challenges of adopting community researchers in this space, the benefits of collaboration for both academic and community researchers, as well as the production of knowledge itself, can be significant. We also argue that support, in the form of financial compensation, training, and counselling (if required), should be provided for these community researchers. We hope that scholars of criminal justice read this article and consider the benefits of adopting community researchers in their future research projects. Doing so may facilitate new ways of thinking about long-standing issues with an ever-escalating prison population.

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## Note

- <sup>1</sup> Here we should note that while the language of vulnerability is still prevalent in research on the criminal justice system, in this article we follow researchers and community activists who critique the use of ‘vulnerable’ as implying personal weakness and obscuring the structural bases of disadvantage (e.g., Lee 2020; Katz et al. 2020; Walker and Fox 2018). We prefer the language of marginalisation, which draws attention to the social processes that actively disadvantage people (Walker and Fox 2018).

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## Article

# Sex Education for Students with an Intellectual Disability: Teachers' Experiences and Perspectives

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**Abstract:** Background: Sex education assists students in the development of a healthy sexual identity and relationships. However, students with an intellectual disability tend to receive less holistic sex education as compared to students without a disability. In this inclusive study, we explored the perspectives of 10 high school teachers through interviews and focus groups on how students with an intellectual disability are informed about sexual relationships and prepared for their future life living with as much autonomy as possible, including living with a partner and becoming parents. Method: The interviews and focus groups were analysed using the inductive content analysis. Results: Data analysis revealed three themes: (a) sex education; (b) self-determination and self-advocacy skills; and (c) teachers' concerns. Conclusions: Several recommendations are discussed. These include incorporating sexuality education-related goals in an Individualised Learning Plan (ILP); teachers adopting a rights-based approach and focusing on students' self-determination, agency, and rights regarding sex education; and providing schools with necessary resources to teach sex education.

**Keywords:** students with intellectual disability; sex education; sexuality and gender identity; sexual abuse

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## 1. Introduction

According to the UN Convention on the Rights of Persons with Disabilities (United Nations 2006), people with a disability, such as adolescent students with an intellectual disability, have a right to a quality education, with the information provided in an understandable and accessible way. They also have a right to have social and sexual experiences that would contribute to life satisfaction and fulfilment (Akbas et al. 2009; United Nations 2006). Moreover, it is increasingly recognised by parents, teachers, and youths themselves that sex education is a core component of comprehensive and high-quality education, as it enables youths to develop knowledge, positive attitudes, and values to make healthy choices about their sexuality and relationships (Swango-Wilson 2011). Ultimately, a comprehensive sex education program is a universal human right for all individuals, including students with intellectual disability, and providing students with intellectual disability an accessible sex education program ensures that their rights are respected (United Nations Educational, Scientific and Cultural Organization 2018).

Despite the rights of students with intellectual disability to receive a comprehensive sex education program, they often do not, unlike students without a disability (Frank and Sandman 2019; King et al. 2018) due to stereotypes associated with people with intellectual disability. The negative stereotypes include seeing people with intellectual disability as eternal children or desexualised<sup>1</sup> beings, incapable of living adult lives and having children (Björnsdóttir et al. 2017). On the other hand, other misconceptions and negative stereotypes include seeing people with intellectual disability as hypersexual beings who have uncontrollable sexualities, and who are a potential “danger” to the community. Parents

of people with intellectual disability have been known to avoid providing information about sex to their children due to the belief that doing so would encourage sexual behaviours (Frank and Sandman 2019) and potentially lead to pregnancies. This contributes to limited opportunities to make choices in their daily lives (Wissink et al. 2015). These prevailing negative stereotypes are barriers to their autonomy and self-determined behaviour in different areas of their lives (Björnsdóttir et al. 2017).

It is especially concerning that sex education provides only limited access to information for these students and is mediated by risk-averse informants (King et al. 2018). Indeed, sex education for students with intellectual disability is typically grounded in a medical and biological view, and does not include issues such as sexual pleasure and intimacy (Turner and Crane 2016; Alexander and Gomez 2017). Furthermore, sex education curricula for this population of students often does not provide information on alternative gender, sexuality, and relationships (Löfgren-Mårtenson 2012).

The pace of instruction and method of delivery are not less important than the content of sex education for students with intellectual disability. Researchers (Corona et al. 2016; McDaniels and Fleming 2016; Finlay et al. 2015) recognised that over-reliance on discussions and verbal explanations of abstract concepts is a considerable barrier in sex education programs for students with intellectual disability. As highlighted by Rowe and Wright (2017), the use of visuals (e.g., videos) considerably aids students with an intellectual disability in sexual knowledge understanding. Visual supports and modelling are evidence-based practices for this population of students (Cannella-Malone et al. 2021; Rowe and Wright 2017; Spriggs et al. 2017). For example, research (Schaafsma et al. 2015) showed that modelling and role-playing are critical in teaching protective behaviours to students with intellectual disability. Yet, a recently published scoping review (Strnadová et al. 2021b) revealed a limited use of evidence-based practices in the delivery of sex education.

The lack of attention to the development of knowledge about sexuality, rights, and relationships in these students has likely increased the risk of harm (e.g., sexual abuse) for this population (Collings et al. 2020). Due to the minimal sex education they receive (Borawska-Charko et al. 2017), students with intellectual disability may not have knowledge of appropriate and inappropriate sexual behaviours, as well as with whom they should be intimate with (Gil-Llario et al. 2020). Sexually abused students and adults with an intellectual disability tend to be passive in their sexual relations and tend to make poor relational decisions. They also can get involved in juvenile/criminal justice systems (Byrne 2018) often due to a lack of knowledge about acceptable behaviour. Furthermore, Gil-Llario et al. (2019) found that people with intellectual disability who self-reported experiencing sexual abuse had a low quality of life and ability to identify potential situations that could lead to sexual abuse. Education and knowledge about sex are important tools for students with intellectual disability to reduce sexual abuse, support positive sexual identity, and develop decision-making abilities (Collings et al. 2020). They are also recognised as self-defence skills in enabling individuals to provide informed consent for sex (Hollomotz 2009). However, it is necessary to avoid the individual model of disability in explaining the increased risk of harm by focusing only on self-defence skills and characteristics of individuals as social factors also play a part (Hollomotz 2009). As such, risk of harm must be understood within an ecological model approach that considers the formation of these self-defence skills as resulting from the interaction between the individual's disability and the systems in the ecological framework. These systems include the individual's microsystem (i.e., immediate social network). The microsystem is in turn embedded within the exosystem (e.g., neighbourhood, employment) and the macrosystem (i.e., society and culture) (Hollomotz 2009). For instance, parents of students with intellectual disability may be more involved in supporting their child's relationship with others as compared to if their child did not have intellectual disability (microsystem). Schools may also provide differentiated sex education programs to students with intellectual disability (exosystem); policies on sex education have been developed specifically for students with intellectual disability (macrosystem) to better accommodate their needs. Hollomotz (2009) importantly

highlights that the high risk of sexual abuse of people with intellectual disability is socially created (p. 109), and that if we are truly committed to reducing the risk of sexual abuse, we need to move beyond “vulnerability” and rather aim to “eliminate conditions that create risk” (p. 110). Indeed, many services delivered to people with intellectual disability over their lifespan do not support self-determination development, with people being told what to do, where to do it, when and with whom. This limited focus on people’s self-determination and self-advocacy development means that services provided for this population “feed into a high experience of sexual abuse” (Gill 2010, p. 204).

### 1.1. Teachers’ Perspectives on Sex Education for Students with Intellectual Disability

Research studies have revealed that teachers’ attitudes and skills related to sex education may prevent them from delivering all topics included in the curriculum (de Reuters et al. 2015; Hanass-Hancock et al. 2018). For example, de Reuters et al. (2015) found that despite acknowledging that sex education was an important topic for students with intellectual disability, teachers lacked confidence in delivering sex education. Furthermore, believing that these students had limited capacity to understand sex education, teachers did not provide details related to the topic. In Frank and Sandman’s study (2019) teachers did not believe that sex programs are beneficial for students with disabilities. This was also one of the findings in a recently published scoping review (Strnadová et al. 2021b). Likewise, Aderemi (2013) and Rohleder et al. (2012) reported that teachers had minimal tools, resources, and skills to deliver an extensive and accessible sex education program for students with disabilities. Chappell et al. (2018) also revealed that teachers in their study experienced difficulties discussing same-sex relationships in school due to cultural barriers, disapproval from other teachers, and students’ uneasiness with the topic. Therefore, to ensure that sex education is implemented as it is intended to, it is crucial to seek teachers’ perspectives regarding sex education for students with an intellectual disability. This can be accomplished in different ways, including qualitative approaches (such as interviews and focus groups), as well as evaluation questionnaires.

### 1.2. Context of the Study

Sex education is included in the New South Wales (NSW) Education Curriculum, as part of the *Personal Development, Health, and Physical Education (PDHPE)*. Specifically, students in Years 7–10 (Stages 4 and 5) are taught this content as part of the *Health, Wellbeing, and Relationships* and *Health, Safe, and Active Lifestyles* strands. It is important to note that students often do not receive the same education for sexuality and relationships. Some schools will deliver lessons on these topics within schools by classroom teachers and others use a range of external providers.

Students with disability, especially students with intellectual disability, often do not receive the same educational opportunities in sex education as their peers without disability. These students will often not attend the same *PDHPE* classes as their peers and will receive lessons using a blend of the *PDHPE* and *Life Skills* curriculum to teach these topics. It is important to note this is usually up to teacher discretion for how these topics are taught to students with disabilities.

In this inclusive research study, we aimed to investigate how high school students with an intellectual disability are informed about sexual relationships and prepared for their future life living with as much autonomy as possible, including living with a partner and becoming parents. The research questions guiding this study were:

- (1) What are teachers’ experiences with and perceptions of sex education for students with an intellectual disability?
- (2) What are the challenges in developing autonomy concerning sex and relationship knowledge and skills in students with an intellectual disability?

## 2. Research Methodology

### 2.1. Research Process

This study was approved and supported by the university [This study was approved and supported by the Human Ethics Committee of the University of New South Wales Sydney]. This article reports on one part of the study, which focused on teachers' perspectives. The recruitment criteria were that participants in this study need to be high school teachers teaching sex education. The authors contacted mainstream schools in New South Wales to recruit the participants. The schools advertised the possible opportunity to take part in this study by personal communication with teachers. When the authors met with potential participants, they introduced the aims of the study to them and explained the participant consent form. Depending on participants' preferences, interviews or focus groups were conducted either by an academic researcher or by a dyad of researchers (one academic researcher and one co-researcher).

### 2.2. Research Design

This was an inclusive research study (Walmsley and Johnson 2003; Walmsley et al. 2018), in which a collaborative approach to inclusive research was used; i.e., a co-researcher with intellectual disability (J.L.) was a member of the research team and co-authored this article. This research study was co-designed by the first and second author, based on their previous joint research with parents who have an intellectual disability (Collings et al. 2020; Strnadová et al. 2019b), Strnadová et al.'s (2019a) research, and the authors' experience in supporting people with intellectual disability over the life span. All of these experiences pointed out insufficient sex education for students with an intellectual disability. The first and second author conducted most of the interviews together. Using her experiences of being a parent, the second author also provided some suggestions to teachers. An example of such an interaction can be seen below:

Maddison: "And some kids will say, even if they're lower level, 'I want to be a mummy!' That kind of thing. The maternal instinct comes out. But I think a mummy to them is having a doll. ( . . . ) They don't really have a realistic view on what parenthood is!"

The second author: "I know when my last daughter went to school, if she wanted to deal with sexuality and being a parent, she was given a doll to take home. Do you do anything like that?"

Maddison: "No, we don't. We've never come across that situation where someone seems to intent on having it, and I know there are dolls like that available where there's time to wake up, and nappy change, and be fed and cry, kind of thing. ( . . . ) But in speaking of that, I'm glad you've actually brought that up, because I do have a student who ( . . . ) wants to be a mother, and I do know she's sexually active. I'm really glad you brought that up, because that's just prompted something that mightn't be a bad idea for her, so thank you! Where do I get it from?"

The interview protocol (available upon contacting the first author) was based on (a) an extensive literature review about sex education for students with an intellectual disability and (b) the second author's experiences as a mother with an intellectual disability, a peer supporter for other people with an intellectual disability, and an employee of an organisation that advocates for people with an intellectual disability.

As highlighted by Strnadová and Walmsley (Strnadová and Walmsley 2018), there needs to be clarity about the process of co-authoring an inclusive research article, otherwise there is a risk of tokenism. In this manuscript, the first two authors (i.e., an academic researcher and a co-researcher with an intellectual disability) wrote the Findings section together, over a series of meeting days. They went through the data analysis, discussed the main arguments, and formulated sentences together, with the academic researcher typing up the text. They also created a list (using bullet point) of topics to be addressed in the

Discussion section and in answering the research questions guiding this study. Then, the first and third author wrote the Introduction, Method, Discussion, and Conclusions sections.

### 2.3. Participants

A total of ten teachers participated in the study. This sample size is considered sufficient in qualitative inquiry as it does not seek to generalise the findings, but to understand, interpret, as well as explain a highly contextualised phenomena (Kamberelis and Dimitriadis 2005). Six teachers were from a mainstream high school and four were from a special school. Seven of them were female and the rest were male. The age of teachers ranged from 26 to 62 years, with an average age of 38.3 years. Their teaching experience ranged from 4 to 45 years, with an average of 14.9 years. Four teachers had a bachelor's degree in Education or Occupational Therapy, four teachers had a master's degree in Special and/or Inclusive Education or in Education, and two teachers had a (graduate) diploma in Special Education. Five teachers had no training or professional development in teaching sex education, four teachers had one-off or some training on this topic, and one teacher was trained in PDHPE. For more details about the participating teachers, please see Table 1. The conducted interviews and a focus group had an average length of 38:27 min (ranging from 19:24 to 54:35 min).

**Table 1.** Teachers' demographics.

Pseudonym	Age	Gender	Teaching Experience	Qualifications	Type of School	Training in Sex Education
Summer	48	Female	25 years	Bachelor's in Education	Mainstream school	Some professional development
Maddison	62	Female	45 years	Diploma in Special Education	Mainstream school	Some professional development; Family Planning NSW training
William	28	Male	6 years	Master's in Education	Mainstream school	No training in sex education
Audrey	37	Female	10 years	Master's in Special Education	Special school	One professional development event ran by school
Hannah	26	Female	4 years	Bachelor's in Occupational Therapy	Special school	One professional development event ran by school
Mila	29	Female	7 years	Bachelor's in Occupational Therapy	Special school	No training in sex education
Jasmine	28	Female	1 year	Bachelor's in Education	Special school	No training in sex education
Willow	28	Female	6 years	Master's in Special and Inclusive Education	Mainstream school	No training in sex education
Jack	52	Male	30 years	Graduate Diploma in Special Education	Mainstream school	No training in sex education
Samuel	45	Male	15 years	Master's in Inclusive Education	Mainstream school	Training in Physical Development, Health, and Physical Education (PHPDE)



## 2.4. Data Analysis

After the interviews and/or focus groups were audio-recorded with the participants' permission and transcribed verbatim, the authors analysed the data using inductive content analysis (Elo and Kyngäs 2008), as there is a lack of knowledge about sex education for female students with an intellectual disability. There have been, however, some studies conducted with a focus on the topic of sex education for women labelled/with intellectual disability (Eastgate et al. 2011; Björnsdóttir et al. 2017).

The first author and the second author conducted open coding, and in the process of abstraction, grouped the categories into themes. All three authors discussed the derived themes, allowing for investigator triangulation and peer checking (Brantlinger et al. 2005). The authors' diverse disciplinary and lived experience backgrounds (as the authors were from the fields of special education and disability studies and one author had lived experiences of being a person with an intellectual disability) allowed for a more in-depth understanding of the data. All disagreements between the authors were resolved, which enhanced the authors' self-questioning and self-reflexivity (Archibald 2016). Pseudonyms are used in this article to protect the privacy of the participants.

## 3. Findings

Three main themes arose from data analysis of teachers' interviews and focus groups: (a) sex education, (b) self-determination and self-advocacy skills, and (c) teachers' concerns.

### 3.1. Sex Education

The sex education theme consisted of two categories: (i) sex education at school—content and resources; and (ii) adjustments and teaching approaches. In terms of what students with an intellectual disability were taught in sex education, the most common topics included (in the order of frequency, from highest to lowest) female and male body parts, personal and internet safety, social media and cyberbullying, masturbation, protective behaviours, safe sex and protection, emotions, boundaries, consent, safe and unsafe behaviours, family planning, hygiene, puberty, menstruation, public and private places, relationships, homosexuality, sexual abuse and assault, saying no, appropriate touching, sexually transmitted diseases (STD), drugs and alcohol, abuse of power, and trusting people. Some teachers find it challenging to teach their students about relationships. Maddison, for example, commented: "The challenge is that they really understand the implications of a relationship. ( . . . ) That comes down to their ability to comprehend such issues." Willow described her approach to teaching students with an intellectual disability about relationships:

When we talk about relationships as well with students, we talk about different positive relationships, and what they look like, and different strategies in term of continuously having those positive strategies in place, and then negative relationships and what they look like, and what to do in those situations. . . . we're looking at how that effects the students' mental health, or if we talk about a relationship that's really negative and you need support besides friends and family, or teachers, what other services are available and who you could go to to seek help for yourself or a friend. ( . . . ) We recently even talked about things like abuse in terms of sexual abuse and what that looks like...

However, one of the teachers mentioned that she does not teach her students with an intellectual disability about domestic violence and similar topics, because it would be "too disturbing" for them. Some teachers also mentioned topics that are not taught about in their schools, which mostly included (i) homosexuality/any identity other than heterosexuality, and (ii) masturbation. This might be both due to the school and parents' preferences. For example, Maddison shared an example of a parental reaction to making masturbation a part of sex education at schools: "Oh, my child doesn't do that! He's not like that!" Well, all children are like that, because we are all human, and we do."

Some teachers also discussed their preferences in regard to delivering sex education in mixed classes as opposed to girls-only groups. There was a considerable diversity in opinions. Maddison, for example, preferred mixed classes:

At the moment, we've been teaching them together. There was a time when we had a boys' group and a girls' group, and I think we've sort of moved on from that, for a couple of reasons. One, because we sort of felt that girls should know what boys are feeling, and boys should know what girls are feeling.

Teachers also discussed the adjustments they make for students with an intellectual disability, and about teaching approaches they use. Many teachers highlighted the importance of using visuals (e.g., videos, YouTube clips, mind maps), role plays, discussions, and content adjustment (e.g., breaking things down, paraphrase). Some highlighted the importance of age-appropriate learning and formative assessments in lieu of formal assessments.

I don't do a lot of formal assessments. I find that with our formal assessments, not only do they tend to increase anxiety in our students, but they tend to just be a test of memory, a lot of the time, and our kids really struggle with their working memory, so I do a lot of what we call "formative assessments", so they're in-class assessment tasks ... ( ... ) I still have to do formal assessments because our students are on the mainstream curriculum, but I do one formal assessment every two terms, instead of doing one or two a term ( ... ) ... most of my teaching is basically discussion-based, doing KWL charts, looking at things like—I do exit slips quite a bit, so I might do three stars and a wish, what are the two things we learned about, what's one thing you'd like to learn about? (Willow)

Four teachers from a special school for students with moderate and severe levels of intellectual disability highlighted the importance of incorporating safe and unsafe words in teachers' vocabulary.

### 3.2. Self-Determination and Self-Advocacy Skills

Self-determination and self-advocacy skills theme consisted of two categories: (i) Individualised Learning Plan (ILP) meetings, and (ii) speaking up. Teachers confirmed that each student has one or two ILP meetings per year. Only three teachers stated that students with an intellectual disability attend their ILP meetings. Furthermore, only two teachers mentioned that parents receive a copy of an ILP. None of them would say that students receive their copy. In terms of sex education, four teachers confirmed that ILP meetings also include sexuality-related issues.

Three teachers highlighted the importance of self-advocacy, autonomy, and speaking up for oneself for students with an intellectual disability. Willow emphasised why teaching self-advocacy needs to be a part of education at school as early as possible:

I try and encourage a lot of autonomy and self-advocacy, because I think when it comes, we need to be able to prepare our kids to talk about what they need, even from Year 7, because once they get to Year 12 they'll have all those skills memorised, so it'll be something that will just be automatic to them, whereas if we try and teach that in the older years, they haven't had as much practice with it, so I find that it won't be as automatic.

Two teachers described how they support their students in learning about their disability, knowing their rights and supports, and talking to others about their disability. One teacher highlighted that some students cannot speak up and protect themselves.

### 3.3. Teachers' Concerns

Experiences with students and parents was a substantial theme, which consisted of the following categories: (i) abuse and violence, (ii) masturbation, (iii) collaboration with parents, (iv) inappropriate behaviours, and (v) students and sexuality.

### 3.3.1. Abuse and Violence

Six teachers had experiences with their students with an intellectual disability being sexually abused, which was often committed by a relative or a family friend. For example, Willow shared:

One was with a dad, so the student was sort of in a relationship with the dad, and I had to—we had to do a child wellbeing referral, and go to FACS [Family and Community Services] and have that investigation underway, so not only did I have to support her but I had to support her friends who had disclosed to me as well. And we'd spoken about, you know, what they can do to support their friend. And then also, I think because the girl didn't understand why we were making such a big deal of it. Didn't understand that there was that abuse of power and that that shouldn't be happening to her.

Seeing her students being sexually abused led Maddison to develop an awareness program:

... two of our students were sexually abused, and both of the notifications the children made to me, so I was involved with DoCS [Department of Community Services, now referred to as FACS], ... and from that, I wanted to find out what can I do to—number one, for counselling for these students, and number two, for resources. I sort of made my own program at the time based on—the Circles program was part of it, but I modified that for the students. ... the most important thing we do is about protective behaviours. Rather than about sex, how to protect yourself. We think that's a priority. The kids can protect themselves.

Teachers from a special school for students with complex needs (i.e., severe intellectual disability and autism) developed their own sex education program. This was due to a lack of resources accessible for students with high support needs:

And I guess it took us about two and a half years. It runs from early learning—so, the four and five-year-olds, all the way to secondary, and it's sort of a skills-based, tiered program, so you start in Early Learning, really basic skills, like identification of who you are, and labelling body parts, and all that sort of stuff, and it builds as you get older, depending on students' skill levels. ... we just sort of split it into three areas, which was Emotions, so that involves not, like, only identifying emotions, but self-regulating, when you're experiencing intense emotions, and My Body, so that's about identification and Rules—touching, not touching, exposing yourself, etcetera. And also menstruation was in My Body as well, so we did preparing girls for their periods, and protective behaviours, which is a program we run called Circles, which is like your circles of people in your life. So, me, my family, my friends, and what different rules, I guess, and how you can interact with your family versus strangers. Trying to teach boundaries, and trying to teach consent, which is really hard to teach.

Diverse demands on teachers working in special schools were evident in their focus on students with high support needs. This was also acknowledged by some of the teachers from mainstream schools. For example, Willow commented:

I worked at an SSP [special school] last year as part of my practicum. I think I would really struggle in unpacking the curriculum for students of that comprehension level, ... ( ... ) ... because I was fairly new to non-verbal modes of communication, it was really difficult to gauge the level of understanding and knowledge. I think I'm a bit more equipped to do that now in terms of understanding different forms of communication, and how you utilise those, but I think that would be my biggest struggle: understanding how to unpack that even further, and making sure the communication stuff is then catered for as well.

One teacher also described how the sexual abuse situation of one of her Year 9 female students challenged her in terms of believing whether what the student was saying is true:

“It was hard because I didn’t know whether she was telling me the truth. Because of her intellectual disability, I didn’t know, whether it was truly what was happening. Then she was describing the act, and things like that, so then it was a duty of care responsibility as a teacher that I had to report it.”

One teacher also questioned school processes when sexual abuse of a student is found. She was convinced that teachers of that student need to be aware of the sexual abuse:

Sometimes confidentiality’s an issue as well. ( . . . ) They say that if you know of a child being sexually abused, you’re not to pass that on to your colleagues. I really disagree with that, to some extent. I certainly don’t think it should be in the weekly bulletin, but I do think that if a child is going to your class and you don’t know the child’s being abused, I think you need to know so you know what to look out for. So I think there needs to be some passing on of information. Not gossip, not staffroom talk, but some professional dialogue . . .

Some teachers also mentioned incidents of domestic violence in families of their students and cyberbullying. Willow suggested:

I have had another kid who had disclosed to me that somebody on Facebook had met up with them. He was about thirty years old, she was thirteen. She went to his house and they’d had sex, and when we spoke about it she said to me—and she came from a different—it was a very, very low socioeconomic—a lot of drug and alcohol abuse within the family as well—so, came from an environment where there wasn’t a lot of supervision and wasn’t a lot of care in terms of where the child was, because when we called the next day and said, “Your child’s not at school, and her friend’s told us she met up with someone.” “Oh, do you think I should call the police?” “Yes!” “I thought I had to wait until at least 48 h.” “No, you don’t!” So, eventually, it got to the point where I had to phone the police myself because the mum still hadn’t by about one o’clock. She was found at about three, but denied to the detectives that anything had happened, and spoke to me about “Well, he loves me, and he cares for me.” I think it was seeking that emotional affection that she wasn’t getting at home. And I referred her to the counsellor. Did disclose what had been said, but obviously, it wasn’t taken further by the police because she kept denying to them, even though they had my statement, and then I just said to her, “I really hope for your sake that you’re right,” because nothing else will work with her. I just said, “I really hope you’re right, but, sweetheart, someone else of this age only wants one thing from someone your age, and really hope I’m wrong”. And two weeks later she came and she was in hysterics and shattered and . . . I think that was a big learning experience for her. Not a very positive one . . .

Another teacher commented on a critical lack of available counselling for students who have been abused:

. . . our special kids, fall through the cracks, which is something that needs to be addressed. ( . . . ) certainly by organisations that do counselling. ( . . . ) Our kids have a massive proportion of kids that are being abused. So when I ring, don’t tell me you’re sorry you can’t help me!

### 3.3.2. Masturbation

Five teachers talked about masturbation being an issue for their students. The most common problems were students masturbating in public places, and students injuring themselves while trying to masturbate.

Many teachers also spoke of parents refusing to allow their child to learn about masturbation is sex education, as demonstrated in the following teacher’s experience: “We’ve had ‘absolutely no’. Speaking to the parents, that this inability to masturbate is becoming actually a huge issue in terms of aggression, in terms of self-regulation, so we’ve

had several conversations over several, several years, maybe four years now, and they're just flat-out refusing."

William admitted that masturbation is a topic he avoids in sex education: "I've never really taught masturbation and that sort of stuff. Unless I've got a kid in my class that's doing it in public, I think that's ... you seem to know what you're doing. I'll leave it to you."

### 3.3.3. Collaboration with Parents

In teachers' experiences, some parents found it difficult to talk about sexuality with their children, which might be also grounded in their religion/culture. Teachers felt that it is important not only to prepare students for sex education but also their parents, who have to give consent on topics that will be covered within sex education at school.

One of the teachers from the special school shared their approach to collaborating with parents: "... make it very friendly, parent-friendly, and that's why we're starting really low in early learning, that they don't even feel it's part of their sexual education. Through primary school I can see, especially for the parents who have kids who develop very quickly, they often see the need for us to address issues very early, but then secondary, it's really an eye-opener, and I can imagine college, too, when things start happening, behaviours changing because of the hormones. Emotional regulation and everything else that happens with their body. So, the parents are definitely going through the stages ... "

### 3.3.4. Inappropriate Behaviours

Two teachers expressed concern that some students with an intellectual disability can be more violent when learning about sex education. One of the teachers shared the dilemma of how to teach sex education curriculum, while not encouraging inappropriate behaviour.

Teachers also shared their experiences with an outcome of students having limited sex education: "And it becomes a real issue for over 18's who are now adults in the community. We've had several incidents of clients grabbing women's breasts on the train, and then getting charges pressed against them. So for us, we can see the backflow of all those issues if they're not dealt with earlier."

### 3.3.5. Students and Sex Education

In terms of students' sexuality, one teacher talked about having her students with an intellectual disability in relationships and how important it is to support them and educate them. William even stated that students with an intellectual disability take sex education more seriously than students without disability: "I've taught the same thing in mainstream before, and like any kid, they're generally pretty reluctant and they laugh for a while, but ... I actually think, to be honest, the kids with intellectual disability tend to take it more seriously than the kids in mainstream ... "

Samuel was concerned that some students cannot always disclose their sexual identity to their parents: "I know ... one child here who may be gay, ( ... ) but ... their parent would be horrified. ( ... ) So the boy is going to go through a hard time."

When it comes to sex education for students with a more severe intellectual disability, teachers found it challenging to teach sex education to non-verbal students. They shared some key rules they have around teaching proper vocabulary to students: "... the core vocabulary is really important: because the language that they learn when they are five is the language that they'll use for their entire life. So if you can just bite the bullet and use language that they're going to need to use for the next fifty years, even from a young age, I think that's better than going, 'Let's call it your "willy" now and then in five years you have to learn a new name.' Four teachers from a special school also talked about practicalities related to puberty, and how female students with an intellectual disability refuse to wear bras, which might draw unwanted attention from others.

#### 4. Discussion

There are some positive, and some problematic findings arising from this study. It is certainly reassuring that students with an intellectual disability learn about sex education at schools. In the second author's personal experience, this was not the case in her schooling years. This study set out to answer two research questions. These are answered below, in light of research literature.

##### *4.1. What Are Teachers' Experiences with and Perceptions of Sex Education for Students with an Intellectual Disability?*

Some participants pointed out topics that are sometimes not covered in sex education, especially (i) sexual and gender identities other than heterosexual identity, and (ii) masturbation. The finding that teachers only cover the topic of heterosexual identity aligns with the literature on sex education of students with an intellectual disability. For instance, Nelson et al. (2020) reported that teachers in their study adopted the heteronormative perspective and assumed that their students with an intellectual disability were heterosexual. In terms of the second often-omitted topic in sex education, it is likely that masturbation was not included as a topic in sex education as it goes against religious beliefs. This is concerning, as students with an intellectual disability have been known to engage in excessive masturbation, and in inappropriate environments, which increases their exposure to physical and verbal violence (Girgin-Büyükbayraktar et al. 2017). This finding is consistent with Strnadová et al.'s (2021a) study with 11 girls with an intellectual disability who also shared that diverse gender identities and masturbation were omitted topics in their sex education at school. While masturbation certainly should not be a taboo in sex education, it equally should not be perceived and presented to students with intellectual disability as "a substitute for sexual intimacy to supposedly reduce behavioural issues" while reinforcing existing misconceptions that people with intellectual disability "should not engage in sexual intercourse" (Gill 2012, p. 487). It is also important to recognise in sex education that while knowledge regarding masturbation is important, it is equally important to acknowledge that some people identify as asexual (Gill 2012).

Another alarming finding was that more than half of the participating teachers experienced their students with an intellectual disability being sexually abused by somebody close to them. This is consistent with the literature about abuse, where it was reported that as compared to students without intellectual disability, those with intellectual disability were more likely to be sexually coerced, abused, and assaulted (Grove et al. 2018). Likewise, Platt et al. (2017) found that women in comparison with men experienced a greater likelihood of being abused by their partners. Research also shows that domestic violence and other forms of gender-based and sexual violence happen to girls and women with intellectual disability twice as likely as to the mainstream population (Feldman et al. 2012). Teachers also discussed the occurrences of domestic violence and the lack of counselling available to students.

Teachers used a variety of teaching practices and approaches; however, they complained about a lack of accessible resources for this population. They pointed out that there is a lack of available counselling at schools for students with an intellectual disability who have been abused and/or neglected. This is similar to the findings from the study conducted by Chappell et al. (2018), where teachers emphasised that there were limited intervention and resources targeted at assisting students with intellectual disability who had experienced sexual violence or who were perpetrators themselves. There is also a dearth of resources to teach sex education to students who have more considerable support needs, such as students with moderate and severe intellectual disability.

##### *4.2. What Are the Challenges in Developing Autonomy Concerning Sex and Relationship Knowledge and Skills in Students with an Intellectual Disability?*

Students with an intellectual disability were mostly not included in Individualised Learning Plan (ILP) meetings, and many of them were not consulted about the topics they

want to be included in their sex education. Yet, the “collaborative curriculum planning process” is often referred to in the relevant syllabuses in Australia, in connection to developing an appropriate Individualised Educational Plan for students with a disability.

According to teachers, students with an intellectual disability did not receive a copy of their ILP. This is consistent with the experiences of girls with an intellectual disability, as none of 11 participating girls in study Strnadová et al.’s (2021a) received a copy of the ILP. Furthermore, they did not understand the purpose of ILP meetings, bearing in mind that only three of them took part in their ILP meetings. This is concerning, as to develop self-determination skills, students with an intellectual disability need to actively take part in planning for their learning and in developing their ILP. They also need to have an accessible copy of their ILP, so that they can revise what their goals are and whether they are achieving them. This enables students to feel a sense of ownership over the goals set and would be more likely to pursue them (Chandroo et al. 2018). More importantly, students with an intellectual disability could develop goals related to sex education, which can be included in these ILP meetings. This is imperative, as Frawley and Wilson (2016) found that youths with an intellectual disability did not find the factual and biological information they received from their parents on sex education useful. Contrarily, they needed opportunities to ask questions and explore sexuality-related topics. As such, youths with intellectual disability should be actively involved in their ILP meetings in discussing how they would like information on sex education to be delivered and what topics on sexuality they would like to discuss and learn about.

This finding regarding ILP meetings is also consistent with the fact that only three teachers highlighted the importance of students’ self-determination, and only two had strategies in place to teach their students about their disability, rights, and supports. A possible reason for teachers’ lack of focus on students’ self-determination, agency, and rights regarding sex education could be that teachers tend to view students with an intellectual disability as oversexed, innocent, and having limited ability in exercising their sexual agency and understanding sexually appropriate behaviour (Chappell et al. 2018). As such, teachers may adopt a protective approach towards students with a disability, which impinges on their autonomy (Nelson et al. 2020).

#### *4.3. Recommendations for Policy and Practice*

Numerous recommendations arise from this study. Firstly, sex education must cover topics such as diverse gender and sexuality identities. Indeed, teachers implementing sex education need continuous support to reflect upon and change their potential perceptions and assumptions that all students with an intellectual disability are heterosexual. Students with an intellectual disability also need to learn about masturbation. Instead of taking a protective approach towards students with these disabilities, a rights-based approach could be adopted.

Secondly, the participants’ common experience of students with an intellectual disability being sexually abused or subjected to domestic violence is alarming. Teachers must be provided with resources on ways to address and support students with an intellectual disability who have experienced sexual abuse. They also need to be aware of how to report cases of abuse to relevant authorities due to the high number of students with an intellectual disability experiencing abuse (Chappell et al. 2018).

Thirdly, teachers’ narratives about the way they approach sex education were predominantly risk-oriented. This is hardly surprising, given their common experiences with their students with an intellectual disability being abused. However, as highlighted by the World Health Organisation’s definition on sexual health, “sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence.” ([https://www.who.int/health-topics/sexual-health#tab=tab\\_2](https://www.who.int/health-topics/sexual-health#tab=tab_2), accessed on 6 November 2020). The European Standards of the World Health Organ-

isation further state that sexual education should in the first place be about pleasure (<https://www.bzga-whocc.de/en/home/>, accessed on 6 November 2020).

Fourthly, every student, regardless of the level of intellectual disability, can benefit from sex education, if adjustments are made to the delivery of the content, and students' strengths and needs are accounted for (Barnard-Brak et al. 2014). Sex education needs to be thought of as a skill that must be included in an ILP (Barnard-Brak et al. 2014).

Lastly, there is a need to increase teachers' awareness of accessible resources that can be used to teach sex education to students with intellectual disability. In Australia, where this study took place, there are accessible materials available. For example, the resources developed by the *Family Planning NSW* also include a resource pack on safe sex for people with intellectual disability on masturbation for boys and girls, etc. (<https://www.fpnsw.org.au/factsheets/individuals/disability>, accessed on 6 November 2020). SECCA developed accessible resources relevant to learning about relationships, sexuality, and sexual health (<https://secca.org.au>, accessed on 6 November 2020). Another excellent example of existing resources is the *Sexual Lives and Respectful Relationships* website developed by Patsie Frawley and her team (<https://www.slrr.com.au>. Accessed on 6 November 2020). However, many teachers who took part in this study were not aware of these resources.

Furthermore, there is still a dearth of resources accessible to students with profound intellectual and multiple disabilities. A consultative group consisting of teachers, parents, health educators, and the students themselves could be established to determine the resources that would be needed to teach sex education, as well as to ensure that the resources are accessible to students with intellectual disability. Students must also be consulted on the topics that they would like to be addressed in sex education, their preference for the delivery of sex education to be in single or mixed sex groups, as well as the gender of the person delivering the program. Furthermore, additional counsellors should be provided to all schools to support students who may have experienced sexual abuse.

#### 4.4. Recommendations for Research

Future research could explore the impact of teachers' beliefs and stereotypes about students with intellectual disability on their implementation and delivery of sex education to these students.

#### 4.5. Limitations

A limitation of this study is that it only explores the experiences of teachers in New South Wales, Sydney, Australia. Teachers in other states and countries may have different experiences.

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## Note

- <sup>1</sup> We use the term “desexualised” in alignment with Kim's (2011) definition of desexualisation as a process “of creating distance between sexuality and people with disabilities through the fear of disability reproduction and contamination” (pp. 482–83). We



further acknowledge that some people with (intellectual) disability are “asexual”, which is a term with a distinctly different meaning. Indeed, asexuality belongs on the sexual continuum and “presents distinct identities and embodiments” (p. 490).

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## Article

# “Digging Deeper” Advocate Researchers’ Views on Advocacy and Inclusive Research

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**Abstract:** We are the Clare Inclusive Research Group (CIRG) a group of advocates with a learning disability, funded by the Irish support agency the Brothers of Charity (B.O.C.), Clare Services. As a long-established inclusive research group we were approached to reflect on our journey as advocates and researchers. In this article we talk about our work, challenging and helping repeal discriminating Irish law regarding intimate relationships. We then talk about our understanding of advocacy and inclusive research and make recommendations to make this work more effective. Method: As a group of members of CIRG, with the coordinator of the group, we developed this article using online Zoom discussion calls to identify themes, circulating online explanations of drafts followed by Zoom reflections and finally responding to academic reviews. The direct comments made by us as advocate researchers have been retained as they were expressed. Conclusions, Limitations and recommendations: One of our team remarked “advocacy and inclusive research are twins”. We concluded that they are very close but not identical. Our work together on this article led us to create a discussion paper, Manifesto for Inclusive Research. This was adopted as a touchstone for presentations at the first webinar roundtable of the newly formed *Inclusive Research* IASSID Special Interest Research Group in March 2022. In it we set out guidelines for creating inclusive research which require accessible information and valuing our input in terms that match our status as experts by experience in inclusive research. We challenge academic inclusive researchers who explore the world of intellectual disability to stand shoulder to shoulder with advocate inclusive researchers. Through our work together, we aim to create more fulfilling lives for us all.

**Keywords:** inclusive research; research with people with intellectual disability; research with people with learning disability; advocacy; self-advocacy; manifesto for inclusive research; accessible academic literature; space and non-accessible space

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## 1. Introduction

In our article we reflect on our research and self-advocacy work, and how the two reinforce, complement, and occasionally contradict each other. We aim to show the direct link between researching issues that are important to us and advocating for change that we want to see. We are aware through studies we have been told about and of course from our own experiences, that people with learning disabilities are generally less involved in society in comparison to people who do not experience disability (Verdonschot et al. 2009).

We have been involved in Ireland in the processes of creating and promoting the United Nations Convention on the Rights of Persons with Disabilities (United Nations 2006), the aim of which is to encourage the “full and effective participation and inclusion in society” of people with disabilities (United Nations 2006). For example, Clare Inclusive Research Group (CIRG) contributed a film on “meaningful lives” at the Convention’s inception, and we have made easy read versions of the issues Ireland still has to resolve to fully ratify the Convention (IRN 2020). A key obstacle to Irish ratification was legislation in Ireland which had the effect of outlawing certain sexual intimacies for people with a

learning disability (Oireachtas Criminal Law (Sexual Offences) Act 1993). We concentrate on our work of campaigning for the repeal of these laws through our advocacy and research in the first half of this paper.

This paper is also a reflection on what inclusive research means to us as advocates for change. By being involved in inclusive research and advocacy down through the years, we have tried to make sure our views and experiences are represented in policies and service shaping government plans. For example, we trained trainers for Inclusion Ireland to raise awareness of new day service standards, known as Health Information and Quality Authority standards (CIRG 2016, p. 15).

Preparing this paper has also led to reflection about how we developed inclusive research in our group. Most importantly for us we are actively involved as participants in inclusive research which is about issues important to people with learning disabilities, and not, as happened historically having research done to us as ‘subjects’ by people with no life experience of disability.

In preparing this article we looked at how research started out as advocacy with people telling their stories in poems, artwork and the written word, “through the emergence of self-advocacy . . . people with learning difficulties have begun to speak up about their lives and experiences . . . ” (Atkinson 2002, p. 126). In our own history we also can relate to where academic researchers have written “we encounter challenges and pitfalls along the way, especially when we expect people with intellectual disabilities to ‘do the same’ as academic researchers”. (Woelders et al. 2015).

Our working closely together with the same academic partners, some of us for over ten years, has given us a chance to develop trusting relationships. Contributing to this article has led us to wonder about what parts of the research process we might need help to understand but also has helped us to affirm and value what only we can bring to inclusive research, which is our lived experience of being advocate inclusive researchers. Through doing research we feel we are “digging deeper” into the work and are becoming more able to contribute our own valuable understandings.

#### *Aims and Structure of the Article*

The aims of this article are

1. to record our understanding of our role as self-advocate researchers who have challenged and changed laws.
2. to demonstrate a facilitated debate by experienced advocate researchers with learning disability, regarding our understanding of the differences and similarities between inclusive research and advocacy.
3. to challenge the current establishment of learning disability research to genuinely commit more completely to involve and value us as people with disability in the way research is commissioned, produced and its findings typically presented.

In part one of this article, we focus on our work on relationships, leading from our early research in Clare amongst our friends, to the inclusion of new inclusive research colleagues, through to the development of national inclusive research group we helped to found, the Inclusive Research Network. We will describe how, with the IRN, we were involved in consultations and a successful campaign to repeal discriminatory Irish legislation. We then reflect on how our advocacy work, coming out of our inclusive research, has supported individuals to meet up, broaden their social circles and skills.

In part two we present our reflections on how we see the connections between advocacy and inclusive research; how the two complement each other and ways in which they are different. We conclude with several challenges for advocacy and inclusive research which we reference in our Manifesto for Inclusive Research (see Supplementary Materials), a discussion document we developed and refined while writing this paper.

## 2. How We Put This Article Together

We were approached by the guest editor of the Special Issue given our history of doing inclusive research and challenging laws, to contribute an article giving our thoughts on inclusive research and advocacy. We talked together in a series of online zoom meetings and agreed the main themes from our own experiences. Notes were taken and agreed upon by our coordinator during each session and composed in draft form. The information from these meetings was distributed, refined, and finally agreed upon by participants. As coordinator I wrote the piece indicating the direct comments made by the research team which cut to the heart of their experience of the issues in question. I have retained those comments in the vernacular in which they were expressed. In both Parts 1 and 2 of the Article, verbatim comments are indicated by quotation marks.

Following what was called “peer review feedback”, we added some points and further developed our ideas. This we found very helpful as it gave us chance to “dig deeper” into our own experience and gave us some new understandings of inclusive research. As advocate researchers we did not receive any reviews from our own peers which we felt was a missed opportunity for a special edition on inclusive research.

### 2.1. The Definitions

We talked about the two main ideas of the article: Advocacy and Research.

**Advocacy:** “Advocacy is actively supporting a cause or issue; speaking up in favour of; recommending; supporting or defending; arguing on behalf of yourself or for another or others” (Birmingham 2001).

**Our definition:** “In a nutshell standing up for rights”. “losing our egos to listen to others” and “get everyone comfortable to speak up ... ” to “ ... make our voice strong”.

**Research:** We looked up *research* and found it comes from an old French word *researcher* which meant to “seek out, search closely” (Online Etymonline Dictionary 2021).

**Our definition:** We came up with “to dig deeply” “having the knowledge and how you feel about it personally and respecting the research itself”.

We then looked for definitions of inclusive research. We discussed the explanation by Kelley Johnson and Jan Walmsley (Walmsley and Johnson 2003; Walmsley et al. 2018), people we respect and have worked with. We then put their words into simpler phrases that we agreed upon together. We felt these five phrases rang true with how we have experienced doing inclusive research.

#### 2.1.1. Research to Make Our Lives Better

Research which aims to give us the chance to make positive changes for ourselves and society in general.

#### 2.1.2. Research That Makes Sense to Us

Research about issues we want to find out about and talk about, where our experience helps shape the form the research takes and makes sense to us.

#### 2.1.3. Research That Reflects Our Experience

Research which records, values, and talks about the experience of people with a learning disability.

#### 2.1.4. Research Which Supports Our Campaigns

Research where the information it brings together is accessible to, and can be used by, people with disability to campaign for change.

#### 2.1.5. Researchers Stand Together to Understand Together

Research where academic researchers co-work with researchers with learning disabilities on their issues.

### 3. Introducing Ourselves

#### 3.1. Who We Are

We are members of the Clare Inclusive Research Group (C.I.R.G.). We bring a variety of advocacy and inclusive research experiences to this work. The advocate researchers who worked on this are:

**Joe McGrath** present committee member and founder chairperson of the independent National Platform of Self Advocacy established in 2011. Recently appointed disability officer for native plant specialists Irish Seedsavers Association.

**Brian Hogan** present chair of IRNI (Inclusive Research Network Ireland) and founder member of pan-disability advocate group, Clare Leader Forum.

**Ger Minogue** is founder member of CIRG and IRNI and newly elected joint Communications Officer for IASSIDD (International Association for the Scientific Study of Intellectual and Developmental Disability) Special Interest Research Group on Inclusive Research.

**Orla McMahon** was BOC National Advocacy Council rep from 2014–17 and key focus group interviewer on “Doctors and Us”.

**Pauline Skehan**, a poet, community radio presenter and researcher, she was recently appointed spokesperson for IRNI.

**Lisa Acheson**, also a published poet, has served on BOC National Advocacy Council and is board member of Inclusion Ireland. She serves on staff interview panels, the service’s induction and our advocacy training team.

The service coordinator of this work is:

**Rob Hopkins**, MSc Inclusive Research Policy and Practice, Nora Fry Institute Bristol University, formerly Brothers of Charity Clare West Clare Regional Manager, and County Advocacy and Inclusive Research Officer since 2008.

#### 3.2. How We Started Doing Inclusive Research . . .

The first conference of Brothers of Charity self advocates was held in 1998 in Clarinbridge Co. Galway. Clare and Galway advocacy groups began attending conferences staged by Inclusion Europe from 2001. It was here we came across the idea that in-service advocacy tends to make advocates “the servants of the service” (Aspis 1997, 2002).

Comparing our experiences and ideas with other advocates in other services and in other countries gave us important insights and new perspectives. We wanted to share common priorities and issues which included doing research together about the things that mattered to us, not our support service.

In 2006 Clare BOC service director Mary Kealy invited Professor Kelley Johnson, one of the founders of inclusive research, who was working as a Marie Curie Research Fellow at Trinity College, Dublin to come and work with us as advocates in Clare to train us in the methods of inclusive research.

The trend for day services at that time was to move away from previously popular congregate day centre activities like contract work, sewing and gardening and to encourage more individual activities in the community. As a result, the group prioritised the, soon to be discontinued, in-service garden centre for a research project.

Our findings were published in the booklet, “The Garden Story” (Minogue et al. 2007). In it the group mourned the garden’s passing, hailing all the largely poorly rewarded work that was done there, which advocates feared was in danger of being forgotten. “All the people that did the work and bent their backs doing things in the garden . . . it will break my old heart” (for the garden to close) (Minogue et al. 2007, p. 6). Ger commented further in preparing this article, “Management saw it was a good thing to get people to tell their stories. It’s a great book about what people did”.

The report on the story of the garden was published by National Institute for Intellectual Disability (NIID) at Trinity College, Dublin. We could see this university connection helped make our research work valued and respected from the point of view of the service. It served to strengthen the independent voice of our advocacy . . . not to forget the garden and what was done there.

After this an inclusive research/advocacy coordinator post was created in the Brothers of Charity, County Clare in 2008, the first position of its kind within services in Ireland. We were then invited to present at the IASSIDD World Congress in Cape Town, 2008 where we attended an inaugural meeting of Irish researchers interested in inclusive research which led to the setting up of inclusive research training in Ireland.

The Inclusive Research Network (IRN) an all-Ireland umbrella group of advocate researchers with a learning disability, their supporters including academic researchers, was set up as a result of this training by FedVol (Federation of Voluntary Bodies, the umbrella organisation of voluntary agencies providing support services for people with intellectual disability and autism in Ireland) and NIID Trinity College, Dublin with its initial outcomes reported in the following documents, IRN Participatory Action Research Project (IRN 2009) & All We Want To Say (IRN 2009) Advocate researchers called for “*choice, control and support in key areas of our lives: Employment, Relationships, Money Management, Home Ownership or Renting and Communication Skills*” (IRN 2009).

Advocates wanted to pursue their interest in relationships and could see doing research with their peers could be a way to promote this idea. As Ger went on to say in a further IRN report “Doing research has given me the chance to talk about what people with learning disabilities want from their lives”. (IRN 2011a, p. 20).

#### 4. Relationships Research

Here, we present the story of our relationships research and how it encouraged us to apply our lived experience of disability to finding more opportunities for people with a learning disability to make relationships. We feel this project shows how advocacy (speaking up for ourselves and others) is clearly a major part of how we do inclusive research. It gives our research work the power to challenge and change issues we are concerned about.

##### 4.1. Campaigning to Change the Criminal (Sexual Offences) Law Act 1993

The topic of Relationships was seen as a priority for research by the first group of 10 advocates who attended the introductory IRN research workshops in March 2008. (Hopkins 2009). We now will tell you how we went about it and how it relates to our definition of inclusive research as outlined in the shorthand titles above.

##### 4.1.1. Research That Makes Sense to Us

We used a drama methodology to explore and present our ideas about relationships. Early in its formation the group was introduced to Augusto Boal’s “Theatre of the Oppressed” methods (Boal 1979), exploring social problems through drama. The process ran as follows: relationship experiences were shared amongst the group and a short play was created including elements of the group’s stories.

The joint play was performed once in front of an audience, composed mainly of peers with learning disability, friends and supporters. The situation was then performed a second time and could be stopped at any point for audience “participant actors” to offer solutions by taking the place of the main performer in the situation.

It became clear this was a method that offered immediate feedback to whatever issue was the focus of our research, creating an opportunity for a dynamic group discussion on the issues highlighted through the drama that became the source of our research findings. Our first play called “No Kissing” was based on a story of a couple who were caught kissing which ended with one of the people concerned being moved to another service. The couple were told they were not allowed to kiss.

This “something forbidden” attitude was clearly a concern expressed from our research with the national research group. Following a series of focus groups one respondent reflected, “... people have different attitudes to other people that have a disability. ... You’re kind of looked down on. You’re kind of treated like children”. (IRN 2010, p. 34).



This part of our experience of doing research was undertaken with our national inclusive research team, the IRN. We decided together to ask the question, “What do people with learning disability think about relationships, friendships and supports?” We decided to run focus groups, sharing the responsibility with a supporter. This we practiced within the group through role play which was “great fun”. When we looked at the information gathered from the focus groups, different ideas were arranged together in what the academic researchers called “themes”. “Getting embarrassed talking about relationships” was a theme as was “Being treated like children”. When we presented our research afterwards people said things like “it made me realise I’m not on my own. Other people feel like that too”.

#### 4.1.2. Research That Reflects Our Experience

CIRG went on to perform the play, “No Kissing” at a number of conferences around the country and our work came to the notice of Inclusion Ireland, the representative group of families and people with a learning disability based in Dublin. Two members of our research group, Kathleen Ryan and the present joint author Ger Minogue were invited to take part in a national radio debate on disability, relationships and the law.

Having spoken to the radio program’s researcher on the way to the interview, it was clear that the issue of sexual relationships being forbidden in Irish Law for people with a learning disability, was going to be a key aspect of the program. Rob recalled the trip to the radio station, “I realised I had to explain this to Ger and Kathleen on the train heading to Dublin. I clearly remember Ger was dumbfounded. ‘Is it because I’m Down syndrome that no-one has told me about this before?’

A second drama performance was created once it became clear to the Clare researchers that certain types of sexual activity were forbidden under the 1993 Criminal (Sexual Offences) Law Act. The play, called “Leaving Home” began with a young man approaching his parents and telling them he wants to move out with his girlfriend into a flat. An audience participant offered a comment, which led to a change in the play’s name, “Mum, I love you, but I want to be with my girl”.

In the play, despite the young man’s grandma trying to stand up for him, “listen to him he needs to make his own mind up”, his parents forbid it. He and his girlfriend then decide to run away together, only to be confronted by his support service social worker and finally the local law enforcement agents.

Staging exciting dramas to watch and participate in, offering spontaneously created solutions, brought our group to the attention of the Law Reform Commission. Advocate researchers Joe McGrath and Ger Minogue were invited into a consultation process. They referenced the IRN’s research work on relationships in a study that concluded ...

“We know it is the right of people with intellectual disabilities to have relationships like everyone else, but they feel left out of the picture. People with intellectual disabilities don’t have their own houses, they don’t get around that much, and people still treat them like children. We need to change the laws in Ireland to have the rights of people with intellectual disabilities respected ... ” (IRN 2010, p. 40.)

#### 4.1.3. Research Which Supports Our Campaigns

In relation to the campaign Joe recalled, “we told them (the Law Reform Commission) we’ve been supported to take part in community activities, work, social clubs (where) friendships might form. We were given sex education classes alright, but no one told us about this law. When Ger rang me from the train to Dublin after Rob told him about the law forbidding relationships, I nearly fell off my chair”. Similarly, Ger remembered being aggrieved, “Parents knew, staff knew, (about this law) It should have been the other way round. We should have been told about it first”.

The Law Reform Commission brought out a discussion paper with recommendations to which the IRN contributed a response, commenting:

“Please stop making us feel different. Treat our relationships with respect and respect the choices we make about our relationships”. (IRN 2011b, Criminal Law Response, p. 1).

The Law Reform Commission then published their report on Sexual Offences and Capacity to Consent (Law Reform Commission 2011), making nineteen recommendations for reform. These included the repeal and replacement of the existing law in this area (Section 5 of the Criminal Law (Sexual Offences) Act 1993).

As the IRN we began to see the potential for the law to change and for us to be instruments in the process. Joe’s comments in writing this article, summed up the need for reform well:

“We’ve the same urges, the same organs, we’re built in the same way as everyone ... we see our brothers and sisters getting married, having relationships ... we wanted the chance to have our own experiences ... fair enough? ... Support is very important. I’m always saying it. At the back of your mind, you want someone to talk to, someone who knows you inside out”.

As the debate continued, Dr Elionoir Flynn of National University of Ireland Galway was asked by Katharine Zappone, then an independent member of the Dáil, (Irish Parliament) to put together a private members’ bill calling for the Act’s repeal. Advocate researchers Brian Hogan and Ger Minogue were amongst six IRN members invited to take part in the consultation group (CIRG 2016).

This was clearly an occasion when CIRG members used their advocacy skills to make clear that the people they had been representing for many years should have their rights respected.

#### 4.1.4. Researchers Stand Together to Understand Together

Both Ger and Brian spoke at the launch of the Private Members Bill. Brian spoke with a passionate commitment, underpinned by the knowledge gained through his research activity. He recalled,

“I let them know that laws about us need to make sense to us. Easy read versions, I’ve always been strong on that. It’s hard to advocate about something, even when you have a sense something’s not right, when it’s put in words you can’t understand. I went on Drive Time (a national radio, end of day after work program) and explained about that. The interviewer just smiled but I said, ‘I’m serious, it makes no sense if we can’t understand it. It’s meant to be about our rights, yet no one had told us”.

The Law was finally repealed in 2017 but not to our complete satisfaction. There was still a special provision for “vulnerable persons” who might need extra protection. We wanted the law to apply to everyone by focusing on the need for participants in sexual activity to reasonably establish consent. Did something happen that someone involved didn’t want to happen? Ger was pragmatic, “We live to fight another day, they repealed that old law, that’s the main thing”.

#### 4.2. Supporting Relationships to Happen

Following that change in the law, Clare advocates took it on themselves to give their friends in-service information and ideas about opportunities to start up their own relationships. Ger and Galway advocate leader Marie Wolfe had been invited to Perth in 2014 to the launch of Scottish Inclusive Research, to tell them how the I.R.N. started up.

“It was there we first heard about ‘Dates and Mates’ ... Scottish speed dating and friendship events, run by advocates and supporters,” Ger explained.

### Research to Make Our Lives Better

In her role as Clare Advocacy Platform Social Secretary Orla McMahon picked up on the “Dates and Mates” idea. She helped organise and facilitate a series of similar events around County Clare. “Our research told us people wanted more chance to have relationships ... ” and “ ... in our advocacy group we organised a social event to help make this happen”.

Orla McMahon, Social Secretary of our in-service Clare Advocacy Platform talked about the value of Dates and Mates.

What do people do in “Dates and Mates”?

“We meet up together. Once we even took over a night club in town. Everyone introduces themselves and thinks of things to talk about ... favourite foods, favourite TV programs, things like that ... then we sit down opposite each other ... spend 3 min taking turns talking ... slowly we moved round the room talking to new people ... It’s great fun!”

Why we did it ...

“We thought it would be a great way for people to meet-up together ... might be the start of a relationship ... or friendship ... find someone to go bowling with or cinema, or walks say in Kilrush Woods ... someone special is really important ... ”

“I met a few boyfriends through ‘Dates and Mates’ ... it isn’t easy ... it doesn’t always work out ... friendships are important too ... you have to kiss a few frogs before you find your prince!”

“We need ... more chance to meet different people. I wanted a boyfriend for a long time. No one took me seriously but now I’m happy”.

### 4.3. Factors That Contributed to the Development of CIRG

These factors covered:

Engagement of a respected academic leader (Kelley Johnson) through Trinity College Dublin to introduce and promote inclusive research as a way of working.

Funding for the work and training of an inclusive research co-ordinator from our support service.

Being part of the IRN national network of inclusive researchers, developing friendships by meeting, training and working together around the country on research projects.

Identifying issues that mattered to us as advocate researchers.

The opportunity of having our own space, outside of our support service, to talk about and hear from other people with lived experience of those issues (in this case relationships).

Opportunity to explore issues using drama techniques that created exciting, interactive, accessible scenarios.

Backing from the support service to meet up with and make common purpose outside our own service, nationally and internationally.

Chance to have fun ... do drama ... make friends ... (have) good times together ...

### 4.4. Factors That Hindered the Development of CIRG

The nature of the focused work laid CIRG open to the charge, within our support organisation, of our being a small exclusive group of advocates who had privileges others supported by the service could not access.

In its early stages capable advocates attended research meetings with support staff. Staff support dropped off as advocates were seen as being able to attend independently. This led to a decrease in numbers able to attend as one supporter had too many advocates to support on their own.

Absence of an independent body funding inclusive research on a county and national basis. Such a funding stream would free CIRG and similar groups from constrictions of an in-service support structure.

## 5. Part Two

In this part of the article the Clare Inclusive Research Group reflect on their experiences across 11 different themes with reference being made in some parts to other articles considered relevant to CIRG's work on Inclusive Research and Advocacy.

Reflection 5.1: Research and Advocacy are Twins but Not Identical—the Focus, the Setting, and the Context are different. “Advocacy and Inclusive Research are twins but not identical twins. Inclusive Research needs Advocacy, speaking up, to let people know about our research. What sets them apart is their focus. In research we focus on one area, looking for one question like we did in the relationships research. In advocacy we have a general focus. It could be any issue that's important for an individual or a group like in our (in-service) advocacy”.

“Advocacy starts when you speak up for yourself, when you're a little one and then when you're at school. You might not have a lot of confidence, but you have to try. Then at our (in-service) advocacy you might speak up about anything, bullying, transport . . . the social activities you'd like”.

“The setting for our advocacy is usually “in-service”. We have our advocacy meetings four times a year with the Clare Brothers of Charity management to raise issues from groups around the county. It might be a complaint from an area needing a new car or something a group is doing like a campaign about adult changing facilities. Often, it's something good that's happening. You don't want to be complaining all the while, “I don't think the (advocacy) support staff like complaining in front of the managers. Some of us are good at complaining though; ‘stirring the pot’ we call it!”.

“In research, we meet separately outside of the service, and we look at one particular idea. From all the issues we raise we narrow it down. We talk together about what we'd like to find out about, then we vote on a theme, like “relationships” or “housing” or “transport” then we reduce it down again to a question. “The academics get happy about that!” Then we think of other questions to find out more about the main question. It might seem confusing but it's good to think it through to avoid as a member of our group said, “I sometimes say I'm happy (about what's decided) when I don't know if I am or not. I don't want to look stupid”.

As advocacy reps we speak up for other people. Usually, we know them. Most advocacy as CIRG members that we know about in Ireland takes place in services. Advocates are talking up across Ireland for people in services, about transport or getting represented within the service on interview panels, and staff inductions, as well as giving training.

In our research it's a different context. We still use our advocacy skills, the confidence we've learn from that, but we're involved in a bigger picture, the context is set by the fact that universities are involved. That adds weight to what we do”.

“We are still involved with people in services but not just our own service . . . our aim is different . . . We hope to make people in charge of things aware of what we recommend, people who make laws and decide on policies . . . we dig deeper”.

“We're speaking with government ministers and the HSE (Health Service Executive, the body that runs disability services.) Like we presented Our Homes research to Minister Kathleen Lynch (IRN 2016) and the Relationships issue which helped changed the law, we talked about before”.

“It's not just one person or one group's opinion. As CIRG and as members of the I.R.N. we have worked with groups nationally and internationally, for example, “Journey To Belonging” Gruntvig (FedVol 2013/4)—Ireland, Finland, Austria, France, Germany and Slovenia; Tel Aviv Beit Issie Shapiro's 6th Disability Unity Conference 2015; IASSIDD World and European Congresses, Cape Town 2008, Rome 2010, Vienna 2014, Glasgow 2019, Amsterdam—Virtual 2021”.

“Our voice is stronger when we join up with people and groups, across countries, over different services. We’re bringing our research with us and each additional voice makes what we say stronger”. (CIRG 2022, Manifesto, Pt 5).

“In research and in advocacy everyone’s opinions are important and the more people you bring with you, the stronger the voice the more the chance to make a good change for everyone. In both research and advocacy were speaking up and we’re also helping others speak up. It’s a ‘knock on’ thing”.

“In advocacy it might be easier to ‘track the changes’; follow up on issues in the minutes in your support service but it can work for research as well, like in the Relationships Bill. People told us in the research they weren’t taken seriously. Next thing we’re in the Dail (Irish parliament) and they’re making a new law ... Things do change ... . You have to stick to your guns. Sometimes you need to give people extra time, especially if they have difficulty saying what they want to say. They might get frustrated trying to get their point across”.

#### Reflection 5.2: Ethics and Grounds Rules:

“In advocacy instead of ethics we have ground rules ... Some rules are the same (like with ethics) everyone is given a chance to speak, no one should talk over somebody else, there are no right or wrong answers, ... everyone’s view is respected like in ethics, but names are not usually kept private. People often give consent for them to be used in advocacy work”.

“In research if someone breaks the ethics code ... gives out names of anonymous people or tries to get people to take part after they’ve said they want to quit, that will ruin the whole of the research. Your findings wouldn’t count, your reputation would be in tatters. That’s not quite what happens in advocacy groups ... Somebody might take over and not let someone speak or tell another person their views are wrong, but that wouldn’t mean the advocacy group was finished. The advocacy chair could call the meeting to order, remind people of the rules but in research that’d be ‘game over’.

Through the peer review process a reviewer asked, “*Does advocacy always help inclusive research?*” We had to scratch our heads about that one. CIRG members remembered ...

“In advocacy and research strong people can take over. You have to be prepared to change the situation if everyone isn’t getting chance to speak”. “We ran a research focus group. One person kept putting words in other people’s mouths, ‘we think this’ and ‘we think that’. They started taking over, not letting everyone speak, contradicting people, ‘You don’t mean that.’ But that’s not good advocacy, or good research ... that’s not respecting”. (CIRG 2022, Manifesto Process, Pt 2).

“We talked about it afterwards and agreed next time we’ll just stop the group. Do some individual interviews instead ... It’s not that easy to do that in the middle of a focus group ... or an advocacy group. In research you have an option. Change the situation to get round the problem but still get the information you wanted”. (CIRG 2022, Manifesto, Pt 13).

“In an advocacy group, when someone takes over and it’s people you know, it can be hard, even if you’ve got ground rules ... You need good support to help keep order”.

“In research one group might be influenced by one or two strong personalities ... “but the good thing about research is there’s more than one group’s views. You get a better balance ... in advocacy some strong voices can take over and try to speak for everyone else. In research you’ve got ethics ... you can’t put words in people’s mouths”.

“In research there are set rules called ethics which say what you can and can’t do”. “Working with Universities we present our ideas to an Ethics Committee for their approval. This makes our research official ... ” (like) “A person needs to know they can stop taking part in the research at any time”. “They don’t have to answer every question if they don’t want to”.

“People who take part in the research have to be told where the research will be shown after” (online, at a presentation launch, a series of workshops). “People who take part

need to know they won't be singled out for something they say. Their names will be kept private" (CIRG 2022, Manifesto Pt 7).

"Support running the group is very important in both contexts. It sets the tone where people feel comfortable, included, wanting to express their opinions but where everyone has a right to speak up if they want".

#### Reflection 5.3: Advocacy Issues Start Out as Local ...

People are encouraged to speak out when it's their own advocacy issue and also if a group wants to raise an issue about a service area like "use of a car" (transport) or "rules in a house like in the Pandemic ... washing your hands, taking your temperature every three hours or people feeling bullied in a service ... "

#### ... But Can Also Become National

A number of our IRN colleagues served on an anti-bullying group that brought their training around the country (NIID 2012). Our group has advocates who have experience of being in-service as well as being independent advocates; like Joe McGrath, a former Brothers of Charity National Advocacy Representative for Clare and a longstanding committee member of the N.P.S.A. (National Platform of (independent) Self Advocates). He commented, "We on the Platform committee get to know Ministers in Governments and (their) departments. We were consultants to the Department of Employment Affairs and Social Protection on projects, such as, Value for Money, Transforming Lives Oireachtas Special committee, 2020. I've made presentations to the Dail (government debating chamber) and we've published research work on housing and transport" (National Platform of Self Advocates and Centre for Disability Law, NUI Galway 2017). The connection Joe draws with presenting to the Dial as an advocate and backing this up with the research he was involved in, shows how CIRG members connect the two ideas and see them as serving the same ends: standing up for rights to improve the lives the of people with a disability (CIRG 2022, Manifesto Pt 1).

#### Reflection 5.4: Advocacy and Inclusive Research Shapes Government Policy

We have worked with the academics to make laws. We need to be strong to make sure our ideas are respected. We say "nothing about us without us".

"As members of IRN we worked on the Capacity Bill. Dr. Carol Baxter, Department of Justice & Equality invited us to her chamber and briefed us on the bill. We worked with Katherine Zappone (then independent TD) repealing the old law (Oireachtas Criminal Law (Sexual Offences) Act (1993)) which discriminated against people and their relationships ... finally replaced it with the Criminal Law (Sexual Offences) Act (2017)".

"The purpose of the research is to get a better life for a person with a learning disability. Standing up for others who might not be able to stand up for themselves ... When we do that, we make sure it's their opinion that's respected more than ours. But also doing the research should bring rewards, make our own lives better, give us satisfaction, doing something worthwhile, making good friends, meeting people from other counties. Getting paid for our work is something we keep banging on about but it ... rarely happens".

#### Reflection 5.5: Being Inclusive Researchers We Dig Deep

"Let's pretend a person can't speak, we then need to include someone in our research that can understand how the person communicates, their way of saying what they want". "Being familiar with the supporter is very important, like when Professor Kelley Johnson first joined our group, she went round the room asking people to introduce themselves. We dug deep, Kelley listened to our stories ... , us talking about what was important to us, we all listened to what people were saying, (and) ... we came up with three ideas for researching: bullying, working in the (in-service) garden centre and our cafe (Hogan et al. 2007)".

"Before the pandemic we met regularly at UL (University of Limerick) and Prof Nancy Salmon put the research data we gathered into different easy read sections ... It's easier to look at one section at a time. A group of us used to meet with Nancy earlier to decide what those sections should be". " ... with the easy reads we would divide into groups ... each group would decide what photographs would best suit each bit of the story".

After we talked in small groups about what all the different opinions might mean we then agreed on a course of action about “how to tell people what we found out, for example, (with) a drama, a presentation launch with special guests, a press release or by taking it further, like with the relationships research where we did a campaign against a bad law, finding ways for people to get more experience with relationships”.

Reflection 5.6: The Value of Academic Institutions and External Service Supports (CIRG 2022, Manifesto Pt 6)

“It’s important to have the backing of places like University of Limerick and Trinity College Dublin”. . . . “You’re working with people who can teach you something about different types of research. Like on the RAP course (Research Action Project) that some of us did at U.L. (Salmon et al. 2017), the people that taught us brought us a long way”.

“They get to know you and they can help steer you in the right direction”. Brian Hogan and Joe McGrath got mentoring jobs on the follow-up course. “They support you in such a way because they know what they’re doing. It’s in their interest to make sure the work is done properly”. “Our research won’t be accepted until it’s passed their ethics committees”.

“Also, when you’re doing a research project you have to find a way of funding it. It’s them, Academics, FedVol supporters, that set up the ethics. We can’t do that. You have to be one of these academics in the college to do that . . . (also there’s) printing off reports, . . . publishing it online, inviting ministers to the launch . . . We can help but they have the know-how”.

“We’ve had (Professor) Nancy Salmon (at University of Limerick) on the IRN team supporting us;” “From the get-go at Trinity, Professor Patricia O’Brien and then Dr Edurne Garcia gave us great training and support and ideas”.

“On the independent National Platform of Self Advocates, we have struggled to get consistent funding. We seem to lurch from one fund to another. At times when we don’t know if we’ll get funded it all seems very temporary like it could close at any time, then we get going again, we’re brought in to talk to ministers and everything is dandy”.

Reflection 5.7: Space/Non-Accessible Space—An Open and Honest Discussion of Who is Doing What

“There’s a danger if people (academics) spend too much time in their own space with their own people, they start putting words in your mouth. We all need to be helped to respect each other’s opinions. You can end up feeling like a lab rat”. (CIRG member).

We looked at Jan Walmsley and Kelley Johnson’s book, *Inclusive Research With People With Learning Disabilities, “Past Present and Futures”* (Walmsley and Johnson 2003) talking about “space” and Christine Bigby’s article (Bigby et al. 2014) which called it “non accessible space”.

It explained how academics felt it was important they share views together in a separate “space” or “non accessible space” where no people with learning disability were involved. We said we could see that it was a good for people with similar backgrounds and responsibilities to meet together. “Academic people are ‘experts by their own experience’” and “they need space to think things through together”.

Kelley Johnson and Jan Walmsley argue that “failure to grapple honestly with some of the questions underlying the struggles we and others have been pursuing in inclusive research actually limits its impact and effectiveness” (Walmsley and Johnson 2003, p.15) We agree it comes down to people being open and honest. We wondered why neither group wrote about “space” for advocacy researchers?

“We can see how people with similar backgrounds will want to work together on their own ideas and not want to upset people or make people feel left out. We think it would work for advocate researchers too”.

“Also we would like to give and get feedback in an accessible form to explain what ideas came up between us (in our own “spaces”). We would also welcome the opportunity to ‘grapple honestly’ with the underlying questions, with the added challenge of making those ideas accessible”.

“We stick to our guns ‘nothing about us without us’ but accept Bigby et al.’s (2014) words, “people with and without disabilities who work together have both shared and distinct purposes which are given similar attention and make contributions that are equally valued”. (p. 8). “We know we are not doing the same work”. Joe McGrath commented.

CIRG members pointed out in the Relationships and Supports study (IRN 2010), “In this report ... sometimes we say what co-researchers with intellectual disabilities did ... (sometimes what) supporters did ... (sometimes what) university co-researchers did ... It is important to say what each of us did so that other people can do a similar study”. (p. 8).

“As advocates on the (Brothers of Charity) National Advocacy Council we made separate space in our own meetings at one stage ... Supporters left the room and talked about their issues, the challenges they faced and we reps had our own separate meeting ... talked about our own issues, (like) what ... to put on the agenda for the meeting”. Also “we wanted feedback (on) what supporters had talked about”.

“At first we had no supporters with us ... some advocates just took control. People complained afterwards ... they felt bullied ... couldn’t say what they wanted”.

“... but people also spoke up about their own ideas ... they even contradicted what their own supporter had been saying”. “... overall we decided we needed staff support to manage the meeting and make sure everybody had chance to talk”.

“... maybe with more training and support we could have managed the group ourselves again but it sort of died out ... You have to persevere with these things ... Don’t give up at the first hurdle”.

“In our IRNI national research meetings we break into small groups to give each other more time to talk and think together. There is always a supporter or advocate in each group with us. Maybe we could try to have our own ‘space’ in those meetings sometimes?”

“We wouldn’t like to fall out with our academics. We’d be lost without them ... but they’d be lost without us ... it works both ways”. (CIRG 2022, Manifesto Pt 11).

Reflection 5.8: Anonymous researchers—GDPR gone mad!

“There’s a lot of fear about using people’s private information, their images, where they live, it’s all over the internet. The EU have this thing GDPR (General Data Protection Regulation, GDPR-EU, (GDPR n.d.)) which is all right. No-one wants to be misrepresented or taken advantage of, however in writing this article we have made sure that the profile of the authors is given in full. We have waited a long time to be heard and hiding our voice and details within this and other articles is not in keeping with the recognition we have won as inclusive researchers.

“We want our names and details visible ... It’s all about us as individuals. It’s part of the picture” ... “What will happen when we’re 6 feet under the ground? Who will know what we did? People will piggyback on the work we’ve done, and we may not get mentioned at all”.

“Doors will open a lot more for us if we get recognition and get paid for the ‘expertise’ they keep telling us we have”. (CIRG 2022, Manifesto Pt 9).

Reflection 5.9: Make the Research Accessible

“People try to put us all in one box ... it doesn’t make sense. Sometimes we do it to ourselves. People say ‘Oh I can’t do that. I’ve got a disability.’ It’s a cop out. I say ‘do the pros and cons. Work it out for yourself. Maybe you **can** do it.’ *We’re all individuals, we’re all different.* Everyone says it, but you’ve got to believe it. But it’s hard when people keep putting you in the same box”. (CIRG 2022, Manifesto Pt 5).

Articles also, “need to be put in words we can understand. If it’s about us every effort should be made to explain what’s being talked about”. “We have explained the problem when academic articles use complicated, highfaluting words”. “We called them ‘Barrier Words’ in our “In Response” piece for the “British Journal of Learning Disability” (CIRG 2022, p. 62). Also, we sometimes find that even when we work to understand the ideas they can be patronizing. For example as a group we worked on understanding an article by Tilley et al. (2020), which talked about the impact of self-advocacy organizations on a person’s wellbeing. It explored positive outcomes from people with learning disability



being involved in self advocacy groups and measuring responses against an internationally developed system called the Dynamic Model of Wellbeing (New Economics Foundation 2014). It was originally designed to look at general mental health issues in terms of people in employment in the UK. CIRG members thought this was good because the measures could be applied to people with learning disability as well. “It shows we can be included with everyone else”. The article put forward the idea that involvement in advocacy groups had beneficial outcomes for people. These were divided into different categories of *wellbeing, connectedness, increased confidence to fight for rights, getting competent in new skills*. “We liked the article when it quoted people with disability talking about their experience of feeling valued in important roles in their group. We could relate to that”.

But CIRG members said the article made them feel they were in “a goldfish bowl”. One category spoke about “Self-advocacy providing a safe psychology space for people to try new things and to *experiment with different social identities*” (Tilley et al. 2020, p. 1160).

Members could understand that being in a self-advocacy group helps people feel more confident working on common goals together but the idea of “experimenting with different social roles” was harder to understand. “Were people trying out being different people?” “It’s like someone looking at you in goldfish bowl. Hey let me out! There’s a person in here!” “Like you’re a lab rat!”, “Like someone who’s been too long in therapy,” said one member, referring to someone she knew who used similar expressions.

“We are all on a journey. We’re not clones like Dolly the sheep. We react in different ways; we have different abilities. You’re a good reader. I’m good at speaking off the top of my head. You’re good at analysing things”.

“The pressure to write ourselves off can be strong . . . (from) both ourselves and other people with disability . . . without people who don’t have a disability looking down on us”.

“We have the ability to speak up. I’m proud to be down syndrome. It gives me confidence”. “We’re nice people with lots of personality. We’re kind and funny and caring. Once you get to know us”.

“People have a right to speak up for themselves. We’re all individuals, it’s important, we’re human beings and we have the right”.

#### Reflection 5.10: Advocacy and Research—Who’s Really in Charge?

As independent advocacy representatives and inclusive researchers CIRG members said they felt more “in charge”. “Being separate from the support service is important for the CIRG . . . I feel myself it’s my own people I represent”. “In in-service advocacy there’s a hierarchy. You bring something up with a team leader then it gets brought up at a county level. Often enough it’s something supporters have suggested . . . say something about a weight problem and keeping fit . . . so we talk about it and we agree to do fitness training or a dance workshop. I’m not objecting . . . it’s probably a good thing, but it’s come from them. That’s well known”.

“It’s the same with my \_\_\_\_\_ (local independent pan disability group). You need leaders . . . (in that group) two people with disability took over . . . I said, ‘you’ve got to let everyone have their say.’ They put new people forward now . . . People need reminding everyone has a right to speak up (and) be heard. Leaders can get stuck in their ways . . . think it’s up to them”.

“With the research we make sure it’s our agenda . . . (Professor) Kelley Johnson set us on the right road with that”. “The research should always be about what we want to work on”.

But CIRG members pointed out there’s still a power imbalance “the leaders (academic researchers) lead us when they advise what they think will work best. They’ve got the knowledge. They’ve had the training. It’s hard to argue against them... Like (when we have to decide) should it be a focus group, an interview one to one or a survey”. “It’s something we need to remind everyone about” . . . “It’s all about us, each of us, in the project, the academic inclusive researchers and the advocate inclusive researchers, the supporters, we (all) have to speak up for ourselves, . . . make sure no-one takes over” (CIRG 2022, Manifesto Pt 5 Stand Together).

### Reflection 5.11 Being Future Focused

“We’re setting up the IRN as a registered business so we can take advantage of the reputation our group has and help us get paid . . . ” and following our long association with IAS-SIDD, we recently were founding members of the *Inclusive Research S.I.R.G.* (International Association for the Scientific Study of Intellectual and Developmental Disability, Special Interest Research Group for Inclusive Research). “We have plans to promote best practice in inclusive research”. “We aim to learn about disability work in different countries, stage (online and in-person) international events to promote inclusive research and advocacy work”. “We have produced a discussion paper we’ve called, *A Manifesto for Inclusive Research*” “(this) . . . was used as the framework for the SIRG’s first Webinar in March 2022”. “We have attached the manifesto as an Supplementary Materials to this paper. (CIRG 2022, Manifesto). The ideas for it developed from the work we have recorded here”.

### 6. Limitations

“We feel like we’re being left out and something major needs to change”. The CIRG members wanted to say that an article written for an academic journal such as this one for Social Sciences is . . . “not written for us”. “I don’t read the articles”. . . . “It’s confusing and too long . . . ” “(I) only talk with you about it, (this article and the other references we were advised to look at) . . . it’s more understandable to me then”. “People read by pictures, not always words and long sentences. We need to keep that in mind . . . They won’t though”.

One CIRG member said “some people have a short attention span” so information has to be “put in the language they’re used to”. The same member said, “Academic researchers also need to talk in their own language but how do you marry the two?”

As the coordinator of the CIRG I feel a weight of responsibility and clearly I am the filter deciding what information is relevant to the researchers, what to ask questions about, what words to record that people have said and what particular parts of other academic references to select and translate. A document with more visual content, fewer words and more clearly explained complex words would be of some value to the people I am working with. This is a conclusion and a recommendation as well as a limitation of this article in its present form.

### 7. Conclusions

Through the process of putting this article together we were directed towards several articles about advocacy and inclusive research by reviewers and our academic supporters. We added further reflections on hearing about these articles and CIRG members felt they wanted academic writers to hear about their views for future reference when working with people with learning disability. “That’s why we put the Manifesto together”.

“Through our Manifesto for Inclusive Research we have laid out our ideas for creating good research”. “Our experience of advocacy for most of us is within our service, the Brothers of Charity, Clare (in-service self-advocacy) . . . though “two of us have experience of working with independent advocacy groups” (one national the other local). “Through both types of advocacy . . . ” we feel, with good support and encouragement . . . (we) explore our own issues (and) we have gained valuable experience and confidence in our ability to work together on issues and speak up . . . We carry this into our inclusive research work . . . (where) . . . we have shown that it is possible, in league with our academic colleagues and our supporters, to challenge and change laws (and) use the confidence we have gained . . . (asserting) our rights, to create (in service) activities such as ‘Dates and Mates’ to give people more chances to have relationships”.

“We still need more accessible information about policies and laws and research that effects our lives . . . if we are to continue our work positively affecting lives of people with learning disability”.

The struggle to create this article is in itself an illustration of the dilemma being involved in inclusive research processes. CIRG members said they felt a distance between themselves and academic researchers. “We feel we are made to feel different when we hear

‘highfaluting’ language”. “When words aren’t explained clearly, we feel it stops us from being equally valued as partners in the work”.

“We feel if we can get the opportunity to explore the idea of ‘Space’ or ‘Non-accessible Space’ with our academic partners we would have something worthwhile to contribute to the conversation”.

We conclude that advocacy and inclusive research are closely related, they are twins. They are not identical as they operate in different contexts in different settings with a different focus, one narrow (research) the other more general (advocacy). We believe our academic research holds more weight than in-service advocacy because of how the research is done with ethical approval and includes more voices from people outside our own services.

Therefore, “in inclusive research we say we ‘dig deeper’” though “we use our advocacy skills to speak up about what issues we want to raise” and “we gather our data” and “work out together what it means”, and then “we use our advocacy skills again to promote our findings and wage our campaigns for change”.

“When we all feel openly trusted and comfortable with each other . . . as advocate researchers, academics and responders . . . the information we collect is richer, deeper, more authentic and powerful”.

In both research and advocacy work, “guidance and support are very important”. Supporters, academic researchers and advocates and researchers with learning disability have to “make sure no-one takes over”.

As people with learning disability working as advocates and as researchers, “we can be very good at giving each other guidance and support as trusted friends and work colleagues”. The IRN is separate from in-service advocacy. “It gives us the chance to look at issues outside our own service,” “find out about other services in Ireland and many places around the world”. . . . “We know we’re working on our own agenda (whereas) . . . in the past we have not always felt in control of in-service advocacy . . . in terms of issues raised and how they get sorted out . . . or not”.

“We may need more support to maintain and value our (advocate researcher) work and our relationships . . . to give us a chance to strike a balance (between) work inside services where we have friends we like being in contact with, and outside of services where we can become part of local communities . . . and make more of an impact with our national and international groups”.

“Research and Advocacy work can be fun and effective”. “It’s a communication exercise . . . we have to grab attention . . . and make people bite” but not let the fun make the issue seem trivial” “ . . . we have to be serious when it’s about more sensitive matters”. “How information is communicated should be accessible, like when we use drama, poetry, artwork and social media”. “We should be taken seriously . . . When we are, we can tell because we see how it can help change how people (with a learning disability) are seen and valued” and “We feel better about ourselves”, “We can hold our heads up high”.

## 8. Recommendations

1. Research to explore the relationship between advocate researchers and the academic world such as the idea of separate “Space” . . . for Advocate Inclusive Researchers similar to the idea of “Space” identified by Academic Inclusive Researchers. CIRG members ask academic researchers to consider including advocate inclusive researchers in “discussion spaces” on the merits of individual advocates where possible and not purely on the basis of a person defined by a label.
2. CIRG members request Irish Republic government to provide assured mainstream funding to the independent National Platform of Self Advocates and to fund independent county groups to feed into the national group to establish advocacy countrywide.
3. CIRG members call for the development of career paths for advocates in services and advocate researchers in the inclusive research community. People supported by services can be actively involved in co-creating structures through participation in

- service and research planning. This is in line with the ambition of UN CRPD that states bodies should make provision for disabled people to experience “full and effective participation and inclusion in society” (United Nations 2006, Guiding Principles (c)).
4. CIRG members call on national and regional self-advocacy bodies to develop their own inclusive research arm to strengthen their accredited independent voice when looking to influence government institutions and support service organisations.
  5. CIRG members call for the academic community to use accessible language in inclusive research work and where difficult words have to be used they should be clearly explained. Where “accommodations” have to be made (which we understand to mean where something has to be modified or adjusted) it should be the people with most privilege who should accommodate the more disadvantaged. We understand this can create big challenges, but we would value the chance to grapple with these issues.

#### 9. Our Final Recommendation Is to Read Messages Embedded in the Two Poems Inspired by Members of the Clare Inclusive Research Group

##### *The Group To Flourish The Group To Replenish*

*it helps prevent people from being in the lurch  
 I am an advocate and I have a calling;  
 when people ask me for help I hear their calling,  
 I am with The Clare Inclusive Research Group,  
 They are a nice group of people and it is a lot of work,  
 I am experienced I have the ability;  
 to help people with disabilities,  
 Some people are in trouble and taken advantage of sometimes;  
 Some people are often belittled; it should be considered a crime,  
 For the Clare Inclusive Research Group it's a job;  
 to help people with disabilities where they are in trouble when they sob,  
 The Clare Inclusive Research Group have the ability  
 to help people in trouble and seal the rift and add stability,  
 Since the COVID-19 we've done our work on Zoom;  
 The Clare Inclusive Research Group work from home.  
 I meet a lot of interesting people on Zoom;  
 I enjoy my work my heart to assume,  
 I hope The Clare Inclusive Research Group continues to flourish;  
 and we're helping people to replenish,  
 It's enjoyment to me and the day is sunny and clear  
 Suffice  
 by Pauline Skehan*

##### *The Encouragement Poem*

*It's in our sights,  
 Each step we take,  
 Towards our freedom of words.  
 To express our dreams,  
 To experience our dreams,  
 To have a right to dream.  
 It's the sound of our hearts,  
 Beating through our chests of gold,  
 Towards our love for dreaming.  
 To imagine a dream is coming true,  
 To fight for our dreams,  
 To not stop believing in ourselves.  
 It tastes of bravery,  
 Each time we try something new,*

And it leads towards new opportunities.  
 To learn from each other,  
 To develop new friendships,  
 To have fun even though life is hard sometimes.  
 It touches us every time,  
 With each moment that we experience,  
 While our dreams are coming true.  
 To be truly happy,  
 To be us as people with freedom,  
 To be free of doubt.  
 It smells like fresh air,  
 Each breath we take,  
 Towards breathless moments.  
 To express our dreams,  
 To trust in our dreams coming true,  
 To not stop believing.  
 by Lisa Acheson

**Supplementary Materials:** The following supporting information can be downloaded at: <https://www.mdpi.com/article/10.3390/socsci1110506/s1>. CIRG 2022 A Manifesto for Inclusive Research—Update 2.

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## Article

# Inclusive Research and Intellectual Disabilities: Moving Forward on a Road Less Well-Travelled

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**Abstract:** In reflecting on the title of the special issue: Inclusive Research: A road less or more well-travelled, this paper reviews the strengths of inclusive research that have augmented the global knowledge about the lives of people with intellectual disabilities across the lifespan. The successes of inclusive research are outlined with the respective ongoing individual challenges discussed. Authors will draw upon their own experiences of inclusive research, together with the seminal and current literature, as well as the dialogue between them. The conclusions of the article are in the form of recommendations aimed at increasing the traffic on the road of inclusive research through: 1. expanding its purpose and parameters across all forms of disability research; 2. developing systems for sustaining inclusive research as a funded model; 3. creating capacity to enable people with intellectual disabilities to be employed as researchers directing research projects; and 4. establishing bridges and crossroads with policy and practice through its findings.

**Keywords:** inclusive research; intellectual disabilities; capacity building; policy; and practice; funding; co-design; co-researching

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## 1. Introduction

“Two roads diverged in some wood, and I—  
I took the one less travelled by,  
And that has made all the difference.”

—(Frost 1915)

Inclusive research offers another road of travel, but one less taken. Walmsley and Johnson's introduction of inclusive research as a paradigm in 2003 followed on from the ethos embedded into the disability movement in the 1990s when it lauded that no longer should research *be done to* people with disabilities but rather that they should *be part of the doing* (Zarb 1992; Clough and Barton 1995, 1998; Stone and Priestly 1996; Barnes and Mercer 1997; Oliver 1997, 1999; Moore et al. 1998). Participatory research emerged that challenged the hierarchical divide between the researchers and the researched. Emancipatory models followed, moving the dialogue into research that would lift social oppression and disable life barriers. Making research accountable to disabled people and giving voice to their concerns was in line with a view expressed by Oliver (1996) that research needed to be “*more relevant to the lives of disabled people and more influential in improving their circumstances*” (p. 141).

These approaches, however, had much less impact socially and politically around intellectual disability (Goodley and Moore 2000; Chappell et al. 2002). In part, this reflected



a perception that people with the label of intellectual disabilities lacked the cognitive ability to understand research methods. More pertinently, they were marginalised even within the disability movement that was dominated by people with physical and sensory disabilities. Walmsley and Johnson (2003) took up this challenge and offered a framework to make research accessible to people with intellectual disabilities. They proposed five principles for their engagement with and ownership of the research process through one or more of the following:

- Being collaborators in doing the work.
- Exercising some control over the process and outcomes.
- Having access to questions, reports, and outcomes.
- Producing research outcomes that further their interests.
- Producing research outcomes most associated with participatory action or emancipatory paradigms (pp. 9, 10).

As a result of Walmsley and Johnson's work, the concept of inclusive research was born. In keeping with the theme of the papers in this special issue, the aim of this article is to provide an overview of the reach of inclusive research to date for persons with intellectual disabilities. Within the article, its successes and challenges will be identified, as well as its future resourcing, policy, and practice needs. We draw upon relevant literature, as well as our own research and experience. The article is a reflection piece that brings with it the limitations and biases of self and group reflection. We have aimed nevertheless to balance these by also embracing the current research of peers who are notable for their work within the inclusive research space.

## 2. The Authors' Approach to Writing the Article

It is important to acknowledge the terminology used to refer to inclusive researchers. Together, we determined our preferences. The three of us with university affiliation would be referred to as university co-researchers and the two of us with intellectual disabilities as co-researchers with intellectual disabilities.

The university co-researchers each have over 15 years' academic experience in inclusive research as principal investigators of inclusive research projects, authors of journal articles, and facilitators of inclusive research groups. All three academic researchers were experienced with both quantitative and qualitative methods within inclusive forms of inquiry.

The co-researchers with intellectual disabilities are foundation members of an inclusive research group in Australia with over 10 years' experience of contributing to a diverse range of research projects, conference presentations, and training workshops, as well as co-authoring papers and video making. Therefore, as a group, we all shared an insider's perspective of inclusive research and a commitment to its development and sustainability. It is from these personal experiences and through a dialogical approach that we have developed the content of this article. We all share a human rights-based approach to disability, where persons with disabilities are right holders. As co-researchers, we all chose to have our full names used initially within the text, followed by only our first names where the narrative reflected our verbatim contributions and/or personal experiences.

The following sequential approach was taken to writing the article. The three university co-researchers engaged in a series of discussions to identify key issues for the article, drawing from our personal experiences with inclusive research, as well as a critical overview of the literature. We met via Zoom on three occasions and Patricia took notes that were then distributed for discussion in time for the second and third follow up meetings, respectively. We then organised the notes into themes that were added to each following meeting. The themes worked as content areas for the article, with each of us taking responsibility to expand the written ideas for certain sections. It was not until this stage that we invited two co-researchers with intellectual disabilities, whom one or more of us had worked with, to join the writing group. As we had not worked together as a writing team, we aimed to make the invitations to join us as meaningful as possible. Hence, Patricia developed a set of power point slides showing both the points of success

and the challenges associated with inclusive research, which we discussed as a group of five co-researchers. Our hour-long conversation was audio-recorded. A second draft of the paper then incorporated the verbatim voice of the two co-researchers with intellectual disabilities on the issues we had reviewed. Further discussion of this draft via Zoom again used a set of accessible slides and further changes to the content were agreed.

The ongoing journey of inclusive research over the last two decades is framed within the article as a series of successes with accompanying challenges that need to be addressed. We then reviewed two essential requisites in looking to the future: funding for inclusive research and policies relating to it. We end with a series of recommendations for extending the approach of inclusive research, ensuring its sustainability, and increasing its influence in policy making and the delivery of life-enhancing service supports.

### 3. Successes and Challenges of Inclusive Research

Five successes of inclusive research are now presented with the respective ongoing challenges outlined.

#### 3.1. Success 1: People with Intellectual Disabilities Have Participated as Co-Researchers in a Range of Research Studies across All Stages of the Research Process

A major success of inclusive research is that the principles outlined in the original model (Walmsley and Johnson 2003) are evidenced within the peer-reviewed literature. A recent review (Jones et al. 2020) revealed 53 studies undertaken between 2006–2016 that all indicated partnership with people with intellectual disabilities with one of the most reported tasks their involvement in data collection through facilitating focus groups (10), interviewing participants (9), photovoice (7), telling one's own story (5), administering surveys and questionnaires (3), and journaling (2).

Furthermore, the Jones et al. (2020) analysis recognised that most articles reported on were collaborative projects between co-researchers with and without intellectual disabilities (41); however, only a minority (4) were being led solely by co-researchers with the lived experience of intellectual disabilities. Nevertheless, the outcomes of the review demonstrated that inclusive research as a paradigm has provided an alternative for people with intellectual disabilities from having *research done to them* to being involved in the *doing of it*. (Blinded co-author), in her role as both co-author and co-researcher with intellectual disabilities, shared that, as a result, people with intellectual disabilities are seen differently, *“as researchers with disabilities, advocates, and people always”*.

Likewise, co-researchers with intellectual disabilities brought added value to a large-scale survey of what life was like for people with intellectual disabilities in Ireland (O'Brien et al. 2014). Survey participants reported that they were more confident in speaking up in response to questions being asked by an interviewer with similar experiences of disability.

This value of co-researchers with intellectual disabilities as interviewers also surfaced in the dialogue between us as a group of co-authors, particularly in relation to where three of us, (Sarah Butler, Bruce O'Brien and Patricia O'Brien), had worked on a series of studies as members of the Centre for Disability Studies (CDS) Inclusive Research Network (IRN) examining the impact of the Convention on the Rights of Persons with Disabilities (CRPD) on the lives of people with intellectual disabilities (O'Brien 2018). Sarah commented: *“Rather than somebody who's a university researcher, they told me more and they felt comfortable rather than with a service provider.”*

#### Ongoing Challenge of Actively Involving People with the Lived Experience of Intellectual Disabilities and University Staff as Co-Researchers

Identifying the added value of inclusive research does, nevertheless, raise the question as to whether such value is enough to keep university researchers open to working with co-researchers with intellectual disabilities. Inclusive research projects take a long time to bring to completion, which arises from the need to support co-researchers with intellectual disabilities and training for all involved. Time commitment and the need to incorporate multi-dimensional strategies in working inclusively is not always recognised in the tradi-

tional assessment of research outputs for university researchers; instead, they are judged mainly on an active build-up of publications. University co-researchers engaged in making inclusive research happen should be acknowledged for their leadership, innovation, and collaboration with stakeholders with intellectual disabilities. This is beginning to happen. The League of European Research Universities (LERU) is calling for the contextualisation of research profiles when assessing university researcher outputs and will recognise that how and where research is undertaken is also important (Overlaet 2022).

Although people with intellectual disabilities are involved in undertaking research, there is still a great emphasis on having “research done” to them, as is illustrated by only 53 articles on inclusive research being selected in a scoping literature review covering a 10-year period between 2006–2016 in the Jones et al. (2020) review and, similarly, only 52 articles in a literature review by Walmsley et al. (2018) across the years 2003 to 2016. Consequently, there is a danger that many of our current research endeavours fail to focus on the expressed concerns of people with disabilities. Instead, issues relating to professional practice and service delivery are privileged and then justified on the grounds that they indirectly affect the lives of people with disabilities.

It seems that there is still much to live up to if the promise of ‘nothing about us without us’ (Charlton 2000) is to be achieved within the disability research community. There is still much space on the road for disability researchers to be joined by peers with the lived experience of intellectual disabilities.

### *3.2. Success 2: Acknowledgment of Being an Inclusive Researcher in Academic Publications*

In 2013, McDonald et al. (2013) made the point that people with intellectual disabilities had “regrettably few opportunities to voice their opinions on aspects of research with which they have had direct experience” (p. 216) and called for more respect to be shown to them as participants. Walmsley et al. (2018) continued the call for respect, but this time between co-researchers with and without disabilities. In 42 of 52 articles selected by them for review, voice was attributed to co-researchers with intellectual disabilities through a range of approaches, the most common being the use of quotations or reported speech from co-researchers with intellectual disabilities. There were examples of where “we” was used, or use of a first-person account in the voice of the co-researcher with intellectual disabilities, or divided sections between the voice of researchers with and without intellectual disabilities. However, extending the acknowledgement to co-authoring articles and reports on the findings appeared more aspirational than real. Although the names of co-authors with intellectual disabilities could be listed, an explanation of how their contribution was achieved was rarely given. Walmsley et al. concluded their review by encouraging research teams to agree on how to enable and recognise co-researcher voices at the outset of the project in relation to the writing and publishing of the findings.

### *Ongoing Challenge of Active Involvement of Co-Researchers with the Lived Experience of Intellectual Disabilities in Co-Authoring Publications*

Four of the five authors of this paper, (Patricia, Sarah, Bruce and Roy Mc Conkey) were involved in a study that aimed to identify the perspectives of inclusive researchers to writing with co-researchers with intellectual disabilities. Eleven authors who had published in this space were selected by the CDS Inclusive Research.

Network (IRN), based upon the group’s knowledge of the authors’ work that had been discussed in reviewing articles at the monthly IRN meetings. Or authors they had met at conferences, local universities, and public seminars. To be eligible they needed to be available either face to face or by phone, either in Australia and/or overseas (Riches et al. 2020). Interviewing was done by a co-researcher couple, with one university co-researcher and one co-researcher with intellectual disabilities. Only one of the 11 authors acknowledged having a disability, which was sensory, and the overall experience of the group in co-authoring with co-researchers with intellectual disabilities was limited. The study concluded that more research skills in co-writing were called for, as well as a participatory

reframing of how outcomes needed to be written up and disseminated. The need for training was well-expressed by Sarah, who emphasised that it needed to be practical and embedded in “a course funded at the university for research for people with disabilities (with) course members getting all the assistance they need to complete the course”. Edurne Garcia Iriarte has also found this to be relevant in a recent study where she, with co-researchers with intellectual disabilities, examined learning in inclusive research, stating that “the way we learn is practical, we get stuff done alongside learning” (García Iriarte and Donohoe 2022).

### 3.3. Success 3: The Reach and Networking of Inclusive Research around the Globe

A stronghold of evidence has begun to surface as the journey of inclusive research has deepened and diversified. A search on Scopus from 2004 to 2021, the start date being a year after Walmsley and Johnson (2003) introduced the principles of inclusive research, was done across five journals on disability research selected for the level of their impact factors (IF) and/or being known for accepting articles on inclusive research. They were *Disability and Society* (F 2.567), *Journal of Applied Research in Intellectual Disability* (IF 2.700); *Journal of Intellectual and Developmental Disability* (IF 1.347); the *British Journal of Learning Disabilities* (IF 0.633); and the *Journal of Intellectual Disability Research* (IF 2.424). The Scopus search was done using the specific journal as source and with “inclusive research” being searched for in the title, abstract, and keywords. The contents of abstracts were eyeballed across such entries to validate their relevance. Table 1 gives the details of the number of articles per journal, as well as the number of countries represented by the respective authors. The countries most represented in this analysis were the United Kingdom and Australia, followed by Ireland, Spain, the United States, and the Netherlands. Although such demographics are only from the one search index of Scopus, it does speak to the adoption of inclusive research internationally, at least among more affluent countries, while highlighting that certain journals seem to be more disposed to publishing inclusive research papers than others.

**Table 1.** Range of countries of authors of articles on inclusive research, 2004–2021.

Country	Disability and Society N = 28	British Journal of Learning Disabilities N = 43	Journal Applied Research Intellectual Disabilities N = 37	Journal of Intellectual and Developmental Disability N = 5	Journal of Intellectual Disability Research N = 9	Total
Australia	6	6	10	3	1	26
Austria		1			1	2
Belgium	2	1				3
Canada	3		1		1	5
Iceland		2			1	3
Ireland		7	4			11
Malta	3	1				4
Netherlands	1	1	3	1	2	8
Norway						
Singapore					1	1
Spain	4	1	4			9
United Kingdom	7	19	12	1	2	41
United States of America	2	4	3			9

Doing inclusive research brings with it the potential for networking across countries that could lead to joint research projects and publications. Such a model was introduced by

the International Initiative on Disability Leadership (IIDL), (<https://www.iimhl.com/iidl-homepage>, accessed on 25 August 2022). This is a vehicle created by participating national governments to link leaders across international participating countries on many diverse aspects of disability. Exchanges are co-ordinated between members to meet between the bi-annual conferences to work on projects of interest that are then presented at the conference. This model could be transferred into active networking between those who are publishing inclusive research and is co-ordinated by an international association or a consortium of journals.

Core to the success of the journey of inclusive research has been the development of co-researchers, both with and without disabilities, forming initial inclusive research teams, many of whom have matured in research capacity and leadership, culminating in their sustainability. The work of the following two groups exemplifies what is possible. Ten years of work of the Irish Inclusive Research Network has been reflected upon by its members (García Iriarte et al. 2021). Such reflection coincided with a long-running network working to become a registered organisation directed by its self-advocate members who, for years, had been responsible for choosing what is to be researched and for the choice of data collection, analysis, interpretation, and dissemination strategies, including accessible reports (García Iriarte et al. 2014). Similarly, in the story of the Centre for Disability Studies Inclusive Research Network (Riches et al. 2017) discussed how they acquired their skills and abilities for becoming and being inclusive researchers. A major theme was the support they gave one another in coming together as a group to be mentored by more experienced researchers. As the group stayed and developed together, its members with intellectual disabilities in turn became the mentors of new members. Social capital was gained through being a member of an inclusive research network.

Networking internationally has added to the potential of inclusive research becoming a credible research paradigm, particularly with the launch in December 2021 by the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) of a special interest research group (SIRG) on inclusive research (IASSIDD 2021). The purpose of such a group is to advance inclusive research by creating an international forum for discussion and debate and a safe space to share knowledge based upon the lived experience of disability where researchers with intellectual disabilities are, as envisioned by Sarah “*talking to somebody with a disability; and they have the same experience and the same interests as what they enjoy doing and many know from you what your experiences are, what your values are*”. Only time will tell if the SIRG has success in impacting not only its membership but also succeeds in raising consciousness of all IASSIDD members in how to approach all disability research inclusively.

Ongoing Challenge for Researchers with the Lived Experience of Intellectual Disabilities to Gain Equal Opportunities to Network at Conferences and Other Events in Step with Other Researchers Who Are Not Disabled

A major opening for inclusive researchers to network has been that of attending conferences and presenting findings crossing state, national, and international boundaries. The number of such groups presenting at conferences has risen over the last two decades with both the Irish and Sydney inclusive research groups being trailblazers, presenting not only in their home countries, but internationally in multiple countries across Europe, as well as New Zealand, Japan and South Africa. Bruce and Sarah both shared the challenge of presenting in other countries where not everyone spoke English, but it also taught them about other cultures. Sarah indicated that when you hear people face to face in their own countries talk about their research, you get a better idea of “*what they did*”.

However, even before COVID-19 struck, the costs of registration, flights, and accommodations were creating a barrier for attendance of co-researchers with intellectual disabilities. Sarah discussed the issue by saying, “*It’s definitely a problem and if people are on a funding package it’s a problem in that the NDIA (Australia funding agency) is not always open to see conferences as reasonable and necessary . . . and they see it as more of a holiday and they expect the*

people with disabilities to pay for it out of their own costs rather than there being grants available for people to be able to attend without having to afford from their own pocket."

Nevertheless, lack of such funding has not necessarily hindered conference presentations on inclusive research, as can be seen in an annual edition of the *Journal of Intellectual Disability Research* that presents the IASSIDD conference abstracts. The question nevertheless remains as to how often co-researchers with intellectual disabilities are at the forefront of such presentations. Sarah has thrown some light on this: "Rather than people with disabilities (speaking) on the research, support workers come along, speak on behalf of people with disabilities rather than speaking with them." Equity in funding has yet to be achieved. Inclusive researchers with intellectual disabilities are rarely funded by university or employer grants, unlike their nondisabled team members. Inclusion would surely demand that all members of an inclusive research team be treated equally; otherwise, co-researchers with intellectual disabilities may travel on the same road but in a second-class carriage.

### 3.4. Success 4: Making Inclusive Research Accessible to All Co-Researchers

A range of different training models has been developed to make inclusive research procedures accessible to both co-researchers with and without intellectual disabilities. Nind and colleagues (Nind et al. 2016) identified five such approaches for capacity building in inclusive research, including an apprenticeship model, a lifelong learner model, a challenging inequality model in which researchers with and without learning disabilities learn together, a deficit model in which gaps in the learner's knowledge are upskilled, and formal training involving a curriculum. Nind et al. argue that immersion in the research context and dialogical learning approaches are more suitable to inclusive research. Moreover, we, as a group of co-authors all experienced in working inclusively, would stress that the insider perspective of researchers with intellectual disabilities on what constitutes training needs to be foregrounded, whichever training options were undertaken. That said, both Saran and Bruce felt that the content of the training should be no different to what other researchers without disabilities are offered. For Bruce, this fitted the equality model, which he reflected was "more inclusive".

Another aspect of accessibility beyond that of training can be seen in the development of materials that promote inclusive research. The University of New South Wales recently produced a set of guidelines on how to create inclusive research using co-production as an equaliser with illustrated accessible graphics (Strnadová et al. 2022). Similarly, the Research for Development Impact (RDI) Network, which is a collaboration between the Australian Council for International Development and Australian universities, has published, with a free download, a resource entitled *Research for all: Making research inclusive of people with disabilities* (RDI Network 2020). This resource goes beyond working inclusively with researchers with intellectual disabilities providing tools and resources to ensure the best inclusive research practices across disabilities in general, broadening the scope and generic impact of inclusive research.

The adoption of accessibility can also be seen in the way the *British Journal of Learning Disabilities* (BJLD) has encouraged people with learning disabilities to respond to published research articles under the heading, *In Response*. Here, authors with intellectual disabilities can critique articles through writing text in easy-read formats, and/or other digital responses including video blogs. This is a breakthrough in supporting people with intellectual disabilities to contribute to discussions in academic journals.

Similarly, other journals have published articles in plain English language with pictures such as in the 2012 special issue of the *British Journal of Learning Disabilities* (e.g., Bane et al. 2012). Equally, *Disability and Society* now requires a plain English summary. Video abstracts across many journals are a new feature, indirectly resulting in making the articles' information verbal, briefer, plainer, and more accessible.

### Ongoing Challenge to Make Research Publications Accessible for People with the Lived Experience of Intellectual Disabilities

Even though in Bruce's words accessibility "*was happening right now with programs in easy English*", inclusive research reported in academic journals continues mostly to address academics and professionals through a required academic style, usually resulting in inaccessibility of the contents for people with intellectual disabilities and, possibly, many other non-academics. As a research paradigm, inclusive research has succeeded in becoming visible, but advocacy is now needed within the broader disability research community. Its members need to be encouraged to start making their publications accessible through incorporating alternative forms of digital accessibility as, "*written words don't help, when language is too difficult, it can pass people by*" (García Iriarte et al. 2022).

The internet and technology have significantly improved the communication accessibility for people with intellectual disabilities. Currently, this has been evidenced in enabling researchers with intellectual disabilities to attend and participate in Zoom meetings (and other online platforms) during the COVID-19 pandemic from 2020 onwards (Puyaltó et al. 2022). Nevertheless, the potential in using such technology to make research information more accessible is still untapped. This could be enhanced by a shared training course on advances in IT and accessibility for both co-researchers with and without disabilities. Journals could also promote awards for disability access in publications following the trend set in gender equity by the Athena Swan awards (<https://www.sciencegenderequity.org.au/athena-swan-awards>, accessed on 25 August 2022). Similarly, journals could be acknowledged for their approach to equity, diversity, and inclusion (EDI). For this to happen, an advocate body needs to emerge, a role that the International Association for the Scientific Study of Intellectual Disability (IASSIDD) has started with the introduction of its Inclusive Research Special Interest Group (SIRG).

### 3.5. Success 5: A Changing Conceptual Model

The uptake of inclusive research is a tribute to the vision of Walmsley and Johnson (2003), whose initial foundational principles triggered a growth in the conceptual development of inclusive research. Bigby et al. (2014a, 2014b) proposed a three-level framework of inclusive research that ranged from an advisory role to that of collaboration between co-researchers with intellectual disabilities and those without, and to that of researchers with intellectual disabilities leading and controlling the research process. Subsequently, Nind and Vinha (2014) and (Riches et al. 2017) identified a less divided landscape, placing importance on inclusive research being characterised by shared learning, mutuality, and reciprocity among the inclusive research team. Riches et al. (2020) heightened the value of such characteristics by additionally reporting a sense of belonging that came from being a member of an inclusive research team, encapsulated by Bruce in five clear words: "*of giving me more confidence*".

Johnson and Walmsley re-joined the conceptual debate in 2018, updating their original definition by calling for the second generation of inclusive researchers to work towards social change, campaign for others, and stand with them on issues they deem to be important (Walmsley et al. 2018). Likewise, Milner and Frawley (2019) have called for space for a third wave of inclusive research in which the focus is placed on a research praxis that is self-directed by the researcher with the lived experience of disability. Such methodology aims to circumvent the "othering" that can come from the unquestioned expectation that co-researchers with intellectual disabilities will fit into the mode of traditional research data collection methods. The evolving theoretical frameworks underpinning inclusive research augurs well for deepening the understanding of both the rationale for and the ongoing development of the concept of inclusive research.

## Ongoing Challenge to Translate into Paid Reality the Concept of People with the Lived Experience of Intellectual Disabilities Being and Becoming Researchers

Co-researchers both with and without disabilities expend much time and effort in undertaking research together. During our conversations about the types of methods that we had all been involved in, the traditional ones in the applied social research of focus groups, interviews, recruitment through running information sessions, coding and member checking were all mentioned. Bruce also spoke of being involved in data analysis, describing it *“as breaking up information into categories and then deciding which categories the guy’s comments fitted into”*.

But for both Bruce and Sarah the challenge was not so much on learning how to acquire new skills like coding but more on experiencing the value of being an inclusive researcher. Bruce’s comments on inclusive research, no-ed that *“it gives people a voice . . . people can be heard”*, as similarly s Sarah’s comment on how it *“helps you with speaking up for yourself and learning the skills of self-advocacy.”* What they considered was missing related more to its potential impact on quality of life and specifically on being employed as a researcher. summed up a major issue as, *“They (the government) don’t see people with disabilities as researchers and able. If you have a look at good jobs as researchers, it’s doing research the whole day like if you were working.”* Sarah and Bruce agreed that if they had qualifications in research, that would not only help them get employment but would also help inclusive research groups get funded. Bruce shared his thoughts: *“I reckon that would definitely help with the funding with the researchers because people got the qualifications and that’s what the government looks for.”* Such commentary touches on the provision of equal opportunities that are core to the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2006), thereby raising the question, *“What needs to be done to ensure that inclusive researchers, their employers, and funders work together to mitigate any discriminatory practices associated with undertaking and being employed as an inclusive researcher?”* The issues of funding and policy implementation are now explored in the next two sections, with the aim of enabling inclusive research to become a more well-travelled road.

## 4. Funding Inclusive Research

New sources and paradigms are needed for the funding of inclusive research: an issue that is hardly addressed in the literature. However, funding remains indispensable for any research endeavour and even more for research that is conducted in partnership between university co-researchers and co-researchers with intellectual disabilities who are generally unemployed and lack access to research resources, for example, by way of third level institution affiliations. Universities need to be encouraged to support inclusive researchers with the lived experience of intellectual disabilities. The Marie Skłodowska-Curie Actions (MSCA) programme is a prestigious fellowship programme in Europe that provides fellows with a generous salary, plus a family allowance, an international mobility allowance, and a *“Special Needs Lump Sum”* (up to EUR 60,000) for accessibility accommodation. Inclusive researchers with intellectual disabilities would benefit from winning or being associated with such a fellowship, particularly if the accessibility accommodation allowance could be additionally used to cover costs of a research coach for the fellow.

Notwithstanding sensible demands for payment, to their credit, people with intellectual disabilities have generally participated in inclusive research on a voluntary and nonpaid capacity. Both Bruce and Sarah had experienced intermittent limited payment as co-researchers. The need for payment was well expressed Sarah, who said that there *“should be some sort of payment for their time throughout projects . . . so that people felt like they’re getting something not just making friends or giving up their time to be able to share the findings from the research project”*. Lack of payment aligns with Wolfensberger’s concept of devaluation reinforcing the image of people with disabilities as *“objects of charity”* (Wolfensberger 2013) working for no fiscal recognition. In recent times, however, there has been an increase in acknowledging the need of payment to researchers with intellectual disabilities hired as



part-time or casual employees, as evidenced in projects coming out of both the Netherlands (Frankena et al. 2019) and Ireland (Magee et al. 2018).

Conversely, to enable inclusive research to develop, the funding needs to sufficiently cover not only the costs of researchers with intellectual disabilities but also to take into account the indirect hours that need to be deployed to support researchers with intellectual disabilities. This then raises the question as to “What is the incentive for funders to cover these costs if research in the area of intellectual disabilities can be conducted without the participation of co-researchers with intellectual disabilities?” The evidence gathered so far indicates that when people with intellectual disabilities are involved as part of the research team, the focus of the research addresses the real needs of people with intellectual disabilities and methods used to gather information are more accessible and better tailored for the research informants (O’Brien et al. 2014). In spite of this, the development of accessible interview tools, for example, the use of large print, picture prompts, and other digital audio guides (García Iriarte et al. 2021) requires additional funding.

An investment in inclusive research means that its reach has the potential to spread outwards to many more people and contexts, particularly when co-researchers with intellectual disabilities are self-advocates or connected to broader advocacy groups. In essence, inclusive research, if funded adequately, can answer the challenge of meeting needs more swiftly, especially when local groups of inclusive researchers with intellectual disabilities are available to follow through on local changes to policy and practice. Such immediacy provides an alternative to relying on a common strategy of top-down government and/or government-funded policy implementation, which can take much longer, if it happens at all.

The challenge of inclusive research *to move the decision-making dial from a top-down approach to bottom up* needs to be viewed as a dynamic phenomenon where the journeying aims to refine and reframe the translation of research outcomes into evidence-based practice with co-researchers with intellectual disabilities playing a major funded role. One example of such is the consensus statement developed by Frankena et al. (2019) around what constitutes inclusive health research. Seventeen experts without and 40 with intellectual disabilities met through a series of three roundtables, with representatives from across Europe, the UK, and Australia, thereby reinforcing the global nature of inclusive research as a paradigm. The consensus statement covered the attributes and potential outcomes, as well as the reporting and publishing strategies associated with inclusive research. The work of Frankena et al. illustrates a process that has provided a framework for inclusive research to flourish, but not so well if ongoing funding is elusive.

## 5. Policy Development and Implementation

In considering policy development, we were able to reflect on inclusive research projects that we had all respectively been involved in or aligned with that had led to change in legislation and/or development and implementation of policies. The first example was a project that occurred in Ireland where the Inclusive Research Network conducted a study on relationships and supports (Bane et al. 2012) at a time when legislation on sexual offences that criminalised people with intellectual disabilities for having sexual relationships was being discussed by the Irish Government. A report by the Irish Inclusive Research Network gave additional credence to self-advocates who had been campaigning for equality in this area and who were invited to discussions with the Law Reform Commission on the necessary legislative changes. The Criminal Law Act (2017) (Sexual Offences) was enacted in 2017, as part of a programme of legislative changes to align with the CRPD, which Ireland ratified in 2018.

A second example was in Sydney where in 2015 the CDS Inclusive Research Network evaluated how the policy of closing a state government department that covered disability, arising from the introduction of the National Disability Insurance Scheme (NDIS), was impacting employees who were disabled. The involvement of co-researchers with intellectual disabilities in such projects speaks to the recognition of their strength as peer reviewers,

but what often follows is waiting on the road for the next policy review opportunity which can cast a long shadow. Nevertheless, as commented by Sarah there is enthusiasm within inclusive research circles for raising issues with politicians: *“Going down to Canberra is a great idea, I mean getting to meet them and have the day being able to talk to them and get them to learn and understand and know what they can do to make the systems work better for people that find it hard to access services and the support they need.”* The relationship between doing inclusive research and relevance to the work of governments can also be seen emanating from the Irish Inclusive Research Network’s voice *“We have not done research that is not relevant, that stays in the shelves, that is forgotten about, but research that is fundamental for the needs of governments, that contributes to what they do”* (García Iriarte and Donohoe 2022). As a group, its members acknowledged the value of involvement in specific research projects as catalysts for other investigations uncovering the need for change in policy. This link was expressed as follows: *“in the process of doing the research you hear stories and you realise maybe that’s not the way things should be done”* (García Iriarte and Donohoe 2022, in press).

Another incentive and opportunity for inclusive researchers to impact the policy scene would be involvement in monitoring service implementation. For this role, researchers with intellectual disabilities will have personal service experiences to draw upon, as well as those from networking with other people with disabilities and organisations. This was clear when Bruce and Sarah in 2016 were involved in a CDS Inclusive Research project entitled *Quality Checkers and Organisational Person Centredness: An Inclusive Research Approach* (<https://cds.org.au/research-development/research-projects/>, accessed on 21 July 2022). Members of the Inclusive research team all received training in checking the quality of residential services and support in implementing such strategies within a large NFP organisation. Bruce was part of the team that reported on the outcomes of the project with members of the service agency at the ASID (Australasian Society for Intellectual Disability) Annual Conference in Queensland in 2018, thereby promoting the praxis value of inclusive research.

Up to now, inclusive research has not been able to compete with traditional procedures for acquiring research funding as grants are based on the credibility of those leading the research—usually university staff—and the peer review process that tends to value commonly used methodologies familiar to the reviewer. Even so, it is debatable whether the policies and practices for funding research have resulted in effective and actionable guidance on policy development as this is rarely a topic for research across health and social care, still less with respect to disability. However, the need to do this is recognised in the UK by NICE (<https://www.nice.org.uk/>, accessed on 17 July 2022) and SCIE (<https://www.scie.org.uk/>, accessed on 17 July 2022), which produce evidence summaries to support their recommendations around treatments and services relevant to disability, although the implementation of such guidance is insufficiently studied. Nonetheless, opportunities are emerging that inclusive research could exploit more fully. Public patient and service-user involvement in policy making is more widely accepted and systems are in place to ensure that it is present when research proposals are being considered for funding. That is a necessary beginning, but the case needs to be made for the ongoing involvement of service users rather than entrusting the study only to professional researchers, given the many operational decisions required as a study gets underway that would benefit from the voice of those affected by the targeted research questions.

This same thinking can be applied to those with responsibility for formulating policy. Research that is inclusive would bring them into direct contact with the people who stand to gain most from the policy development, as well as ensure that the research addresses the issues on which decisions for better systems and lives must be made. This is of relevance when inter-sectoral policies are the focus of interest. People with disabilities do not live their lives within the silos that administrative systems have created. For example, decisions around housing are taken separately from policies on employment, which in turn gets ignored when mental health is the focus of policy development. People with lived experience of disability have had to integrate the intended—and unintended—

aspects of ‘silo’ policy making, which is possibly a major contributor to failures in policy implementation.

To realise the advantages of inclusive research, new ways of commissioning and undertaking research are required. This may place extra demands on the inclusive research teams for which grant-writing training is needed that includes an understanding of both the implications of research for policy development and implementation, as well as funding resources. On-the-job training for inclusive co-researchers with intellectual disabilities goes beyond methodology to active mentoring, also in grant writing.

## 6. Moving Forward on a Road Less Well-Travelled

In returning to the title of this article, inclusive research has been framed by an examination of its successes and the challenges still being faced on a road of research less well-travelled. We end by summarising the main recommendations to emerge from our review of the past two decades of inclusive research involving people with intellectual disabilities as co-researchers. We are confident of the knowledge base that exists to take us further along the road, strengthened by our own enthusiasm and commitment to take the road that will, as described in the opening poem, “make all the difference”. The “how” of the recommendations will be left up to you as readers as you partner with other stakeholders of inclusive research who are known to you as or who are potential travellers.

It is recommended that:

1. Key stakeholders of inclusive research both within and across geographic boundaries combine to offer workshops/events to raise the consciousness of all researchers to what it means to partner with co-researchers with intellectual disabilities through, for example, national service organisations/bodies, universities, and self-advocacy groups.
2. Training in inclusive research should be more widely available as part of research method courses within universities, other tertiary education, and private training settings. Features of such training are to include:
  - (a) Training in inclusive research practice is developed as a joint course undertaken by co-researchers both with and without disabilities. Such training is to be open to support staff and family members as allies in making research more inclusive.
  - (b) Co-researchers with intellectual disabilities act as tutors within training courses.
  - (c) Inclusive research training covers not only methodology but also co-authoring articles and reports, as well as the development of accessible training materials.
  - (d) Government policy relating to research enables on-the job research training for people with intellectual disabilities, as well as a paid career structure.
  - (e) How to engage in consultation processes on national research strategies raising awareness with researchers in government, universities and discipline associations.
3. Inclusive research is recognised for its accessible methodologies in identifying the issues affecting the quality of life of people with intellectual disabilities. Hence, the lack of equal opportunities locally, nationally, and internationally for people with intellectual disabilities to gain employment as inclusive researchers must be addressed.
4. The ‘bottom-up’ approach of inclusive research in the selection and development of research proposals needs to be recognised and supported by the traditional ‘top-down’ management systems used by university, government, and NGO organisational leadership.
5. Policy makers are to be invited to partner with people with intellectual disabilities in developing, implementing, and evaluating disability policy and the commissioning of research.
6. As part of partnering with policy makers, funding is made available for researchers with intellectual disabilities to be resourced for doing both the research and for the

dissemination and implementation of the findings, including conference presentations.

7. The global community of inclusive researchers should be invited by IASSIDD to discuss what it would take for inclusive research to have an impact on overall disability research, policy, and practice.

Finally, in conclusion, we return to what Bruce and Sarah see as the first steps needed if they are to continue on the road of inclusive research that they have valued to date. For Sarah, the first signpost needs to cover that “people with intellectual disabilities are equal partners in conducting the research”, particularly in “asking the questions”, and that they get paid for their time. For Bruce it was “getting a research qualification and being supported to complete it”. They both agreed that their journey of inclusive research to date, in response to Robert Frost’s opening poem, has made a difference.

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