



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 Puyalto, 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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References

- Bonello, Isabel, Sandra Borg, Anne-Marie Callus, and Cristina Grech. 2022. Reflections on the Implementation of an Ongoing Inclusive Research Project. *Social Sciences* 11: 234. [\[CrossRef\]](#)
- Carnemolla, Phillippa, Jack Kelly, Catherine Donnelley, and Aine Healy. 2022. Reflections on Working Together in an Inclusive Research Team. *Social Sciences* 11: 182. [\[CrossRef\]](#)
- Crombie Angus, Fionn, and Jonathan Angus. 2022. Exploring My Life Path by Asking 600 People What They Love about Theirs. *Social Sciences* 11: 551. [\[CrossRef\]](#)
- de Haas, Catherine, Joanna Grace, Joanna Hope, and Melanie Nind. 2022. Doing Research Inclusively: Understanding What It Means to Do Research with and Alongside People with Profound Intellectual Disabilities. *Social Sciences* 11: 159. [\[CrossRef\]](#)
- Doyle, Caroline, Sophie Yates, and Jen Hargrave. 2022. Reflecting on the Value of Community Researchers in Criminal Justice Research Projects. *Social Sciences* 11: 166. [\[CrossRef\]](#)
- Garratt, Danielle, Kelley Johnson, Amanda Millea, Shaun Picken, Janice Slattery, and Jan Walmsley. 2022. Celebrating Thirty Years of Inclusive Research. *Social Sciences* 11: 385. [\[CrossRef\]](#)
- Herer, Alix, and Ariel E. Schwartz. 2022. How Being a Researcher Impacted My Life. *Social Sciences* 11: 127. [\[CrossRef\]](#)
- High, Rachel, and Sally Robinson. 2021. Graduating University as a Woman with Down Syndrome: Reflecting on My Education. *Social Sciences* 10: 444. [\[CrossRef\]](#)
- Hopkins, Robert, Gerard Minogue, Joseph McGrath, Lisa Jayne Acheson, Pauline Concepta Skehan, Orla Marie McMahon, and Brian Hogan. 2022. “Digging Deeper” Advocate Researchers’ Views on Advocacy and Inclusive Research. *Social Sciences* 11: 506. [\[CrossRef\]](#)
- Knevel, Jeroen, Jean Pierre Wilken, and Alice Schippers. 2022. Experiences of Inclusive Action and Social Design Research with Social Workers and People with Intellectual Disabilities. *Social Sciences* 11: 121. [\[CrossRef\]](#)
- Layton, Natasha, Em Bould, Ricky Buchanan, Jonathon Bredin, and Libby Callaway. 2022. Inclusive Research in Health, Rehabilitation and Assistive Technology: Beyond the Binary of the ‘Researcher’ and the ‘Researched’. *Social Sciences* 11: 233. [\[CrossRef\]](#)
- O’Brien, Patricia, Edurne Garcia Iriarte, Roy Mc Conkey, Sarah Butler, and Bruce O’Brien. 2022. Inclusive Research and Intellectual Disabilities: Moving Forward on a Road Less Well-Travelled. *Social Sciences* 11: 483. [\[CrossRef\]](#)
- Puyaltó, Carolina, Maialen Beltran, Tània Coll, Gemma Diaz-Garolera, Marta Figueras, Judit Fullana, Cristina González, Maria Pallisera, Joan Pujolar, and Ana Rey. 2022. Relationships of People with Intellectual Disabilities in Times of Pandemic: An Inclusive Study. *Social Sciences* 11: 198. [\[CrossRef\]](#)
- Rameka, Lesley. 2017. Kia whakatōmuri te haere whakamua: ‘I walk backwards into the future with my eyes fixed on my past’. *Contemporary Issues in Early Childhood* 17: 387–98. [\[CrossRef\]](#)
- Rojas-Pernia, Susana, and Ignacio Haya-Salmón. 2022. Inclusive Research and the Use of Visual, Creative and Narrative Strategies in Spain. *Social Sciences* 11: 154. [\[CrossRef\]](#)
- Sergeant, Sofie, Henriëtte Sandvoort, Geert Van Hove, Petri Embregts, Kim van den Bogaard, Elsbeth Taminiau, and Alice Schippers. 2022. 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. *Social Sciences* 11: 185. [\[CrossRef\]](#)
- Strnadová, Iva, Julie Loblinzk, and Joanne Danker. 2022. Sex Education for Students with an Intellectual Disability: Teachers’ Experiences and Perspectives. *Social Sciences* 11: 302. [\[CrossRef\]](#)
- Walmsley, Jan, and Kelley Johnson. 2003. *Inclusive Research with People with Learning Disabilities: Past, Present and Futures*. London: Jessica Kingsley Publishers.

- Westermann, Greta, Erin Louise Whittle, Susan Adrian, Suzanne Jessep, Melanie Nolan, Bruce O'Brien, Jasamit Pannu, Elizabeth Young, and Mary-Ann O'Donovan. 2022. Being an Inclusive Researcher in a National Consultation Exercise—A Case Study. *Social Sciences* 11: 164. [[CrossRef](#)]
- Zaagsma, Miriam, Mark Koning, Christien van Andel, Karin Volkers, Alice Schippers, and Geert van Hove. 2022. 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'. *Social Sciences* 11: 186. [[CrossRef](#)]