

Editorial

Second Edition of Inclusive Research: Is the Road More or Less Well Travelled?—The Open Road

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In MDPI's first edition of the Special Issue on "Inclusive Research: Is the Road More or Less Well Travelled?", people with intellectual disabilities were reported as "no longer having research done to them" but rather "being part of its doing". This second edition continues capturing what it means to work inclusively when doing research with people with intellectual disabilities.

The first edition leaned on Robert Frost's poem *The Road Not Taken* for inspiration, where in 1916, he wrote,

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

In comparison, the second edition continues to explore the inclusive research journey where Robert Frost's idea of making a difference on a road less travelled, such as inclusive research, has given way to that of Walt Whitman's *The song of the open road*, where in 1855, he wrote,

Afoot and light-hearted I take to the open road,
Healthy, free, the world before me,
The long brown path before me
leading wherever I choose.

In keeping with Whitman's inspiration ([Whitman et al. 1855](#)), the authors were invited to travel inclusively on the open road, free from the constraints of traditional research. Metaphorically, they were free to travel wherever the journey of inclusive research took them.

The choice of topics made by the authors in the second edition includes a series of common categories across its 16 articles: challenging stereotypes that have led to epistemic injustice in ignoring the knowledge of people with intellectual disabilities; bridging the gap in countries that have lagged behind in introducing models of inclusive research; illustrating the relational power of collaboration and co-design; introducing innovative inclusive resources and methodologies; revisiting the inclusive research journey and reflecting and adding to its principles and practice. The articles under these five categories are described below.



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1. Challenging Stereotypes That Have Led to Epistemic Injustice

That people with intellectual disabilities are co-researchers and co-authors in the second edition of this Special Issue testifies to the fact that people with intellectual disabilities do hold knowledge worth sharing and being responded to. This Issue includes three people with intellectual disabilities as first authors and eight as respective co-authors.

The first three articles in this category challenge a "credibility deficit" that is often experienced by people with intellectual disabilities that arises from a devaluation of their

knowledge base (Fricker 2007; Patin et al. 2021). In Article 1, “Understanding Epistemic Justice through Inclusive Research about Intellectual Disability and Sexuality”, Lesley Verbeek, Mark Koning, and Alice Schippers from the Netherlands lay out what constitutes epistemic justice and the relational role that inclusive research can play in taking the communication of people with intellectual disabilities seriously. The area they chose to explore is sexuality where taboos have often led to silencing of sexual experience and enquiry. Dual interviewing uncovered that people with intellectual disabilities express the same issues as those without, covering preferences in relationships, understanding of consent, and wishes of parenthood.

In Article 2, “Expanding Possibilities for Inclusive Research: Learning from People with Profound Intellectual and Multiple Disabilities and Decolonising Research”, Joanna Grace, Melanie Nind, Catherine de Haas, and Joanna Hope from the UK explored how “being with” people with profound and multiple disabilities can lead to sharing of inter-subjective knowledge. Their research used an individual relational approach involving a person with a profound/multiple disability and another with a background in inclusive research. Small stories were developed, from respecting and knowing one another to moving forward together to develop belonging, identity, and community.

Article 3, before Looking Back When Moving Forward: Researching Sites of Former Disability Institutions”, takes the reader into an area where epistemic justice was often a step too far, that is, in deinstitutionalising long-stay residential settings for people with intellectual disabilities. As a result, Jack Kelly, Leigh Creighton, Phillippa Carnemolla, and Linda Steele from New South Wales, Australia took up the fight to ensure that these architectural structures and land spaces are respected and recognised in relation to the stories of those who previously lived there. The authors include four advocates, including two self-advocates with the lived experience of intellectual disabilities, with all having a history of performing inclusive research within university research teams. Together, they explored five pillars of research needed to prevent the history of institutionalisation from continuing to be buried. All pillars are proposed to redress human rights, particularly those not recognised at the time of closure of these institutions, including the knowledge of those who lived in these places not being appreciated for its epistemic value.

2. Bridging the Gap in Countries That Have Lagged in Introducing Inclusive Research Models

Following on from the theme of recognising how lack of recognition of epistemic knowledge silenced voices, there are two articles that illustrate how inclusive research is being introduced into countries where the process of allowing such voices to be heard has been slow. Article 4, “Cooperation with persons with Intellectual Disabilities: Reflections of Co-Researchers Associated with Conducting Inclusive Research”, indicates that it is only recently that inclusive research has gained traction in Poland. Katarzyna Ćwirynkało, Monika Parchomiuk, and Agnieszka Wołowicz lay out four relational themes to move the adoption of inclusive research forward. They covered building team relationships, pros and cons of inclusive research, institutional barriers, and recognizing the co-researcher role played by people with intellectual disabilities.

Article 5, “Will I Be Celebrated at the End of This Training?”, similarly outlines how inclusive research was pioneered in Kenya by Rachael Wanjagua as part of her PhD supported by her supervisors Lieke van Heumen and Sarah Parker Harris from the University of Illinois. The study aimed to remedy the negative image of people with intellectual disabilities, leading to outcomes that stressed the need for culturally adapted co-researcher training, support personnel to empower people with intellectual disabilities, and advocacy to change public attitudes towards people with intellectual disabilities.

3. Relational Power of Collaboration and Co-Design

Moving forward in discovering what makes inclusive research sustainable, the relational power of collaboration and co-design was abundantly covered in five articles starting with Article 6 entitled “‘The Ball of Cooperation Rolls on’: Some Personal Reflections on My Experiences as a Researcher”. Mark Koning, the first author, who has lived experience of disability led an analysis supported by colleagues from the Netherlands and Belgium: Miriam Zaagsma, Greet Van Hove, and Alice Schippers. Successful co-operation included becoming familiar with the members of the research team; collaboratively deciding the actions that needed to be taken and matching the tasks to the strengths of the team members; and defining what it means to collaborate on a project.

Trust being available for the ball of co-operation to continue rolling was also strongly supported in Article 7, “The Role of Trust, Respect, and Relationships in Maintaining Lived Experience and Indigenous Authority in Co-Designed Research with People Living with Disability”. Sharon Kerr, Roslyn Sackley, John Gilroy, Trevor Parmenter, and Patricia O’Brien, all affiliated with the University of Sydney, narrated how collaboration and co-design was influenced by the standpoint of indigenous students with disability within the first author’s PhD study. Cultural safety came through a conscious effort to involve an indigenous leader in supervising the study; an indigenous cultural broker who served as a witness to all the data collection; and an indigenous advisory council.

Article 8, “Our Recipe for Good Inclusive Research”, reinforced how, when developing an inclusive research team, time is needed to become familiar with one another and explore what each person can bring to the team. Here, Felicity Crowther, Hannah Beinke, Rachel High, Chloe Ru, and Fiona Rillotta, affiliated with Flinders University, South Australia, reported that building inclusive research teams can lead to friendship. At the same time, they identified how to successfully co-operate such as choosing a topic that everyone agrees to and reading complex articles with the aid of Easy Read.

Exploration of collaborative relationships is further deepened in Article 9, “Examining People’s Experiences of Working in Collaborative Relationships While Conducting Inclusive Research”. The account given by Kim van den Bogaard, Noud Frielink, Alice Schippers, and Petri Embregts is based on interviews with inclusive researchers with the lived experience of intellectual disabilities, and academic researchers and principal investigators of six major inclusive research studies in the Netherlands. Their findings echoed those of Articles 6–8 that equity within the context of inclusive research means that the tasks are assigned to reflect the individual strengths, gifts, and talents of all members of the inclusive research team. Ideally, there is no division based on ability; however, their exploration of the issues found that inclusive researchers with intellectual disabilities can still be subjected to deficit stereotypes.

4. Sharing and Developing New Resources and Combining Methodologies

The authors of the next four articles explored the fit of a recognised practice and/or research strategy for use in inclusive research. In Article 10, “Peer Support Provided by People with Intellectual and Developmental Disabilities: A Rapid Scoping Review to Develop a Toolkit for Inclusive Research”, the reader is introduced to how inclusive researchers with intellectual disabilities can participate in giving peer support to other researchers in the research team. Beth Pfeiffer, Taye Hallock, Luke Tomczuk, and Jessica Kramer from the United States present the findings of a rapid scoping review on peer support that were used to develop a Toolkit for Inclusive Research that introduces its users to what peer support is and its strategies. This helps in making peer support a feature of inclusive research that responds to the needs of its users.

A second strategy for inclusive research can be found in Article 11, “Using Inclusive Research Methods and the Housing Pathways Framework in Future Planning and Housing Research: A Pilot Study”. Irene Belperio, Fiona Rillotta, Tim Adam, Ruth Walker, and Claire Hutchinson, all affiliated with Flinders University, South Australia, were involved in a large study looking at the planning and transition of people with intellectual disabilities moving out of their family home. This article reports on a subset of participants whose interview data regarding their house preferences was analysed using a Housing Pathways Framework. It was agreed that the framework was a useful tool for understanding/analysing the interview contribution of the participants and their families, thereby clearing the way for future use of conceptual frameworks as analytical tools.

A third strategy of disability theatre set within a critical participatory action method illustrates how inclusive research strategies can be integrated into alternative research methods. In Article 12, “Disability Theatre as Critical Participatory Action Research: Lessons for Inclusive Research”, Rachelle Hole and Leyton Schnellert, affiliated with the University of British Columbia, recount how disability theatre was enabling self-advocates to collect data and analyse it while preparing and rehearsing a play/dramatic presentation. The research outlined in the article around the theatre of *We Deserve to Work* for people with intellectual disability shows how inclusive research can be combined with disability theatre for the purpose of social justice.

A fourth strategy of lifeline interviews can be found in Article 13, “Life Story Research with People Aging with Intellectual Disabilities: An Adaptation of the Lifeline Interview Method”. It illustrates how Lieke van Heuman and Tamar Heller, University of Illinois, Chicago, adapted a lifetime interview method ([Assink and Schroots 2010](#)) to include personalised timelines with drawings and pictures. As a result, people with intellectual disabilities were able to remember issues and discuss the important things in their lives.

5. Revisiting the Inclusive Research Journey

The final three articles of the second edition bring together ways to revisit and/or expand the model of inclusive research. Article 14, “Structures of Oppression or Inclusion: What Systemic Factors Impact Inclusion in Disability and Rehabilitation Research?”, exemplifies how authors can work across international boundaries with Natasha Layton, Rachelle Martin, John Bourke, and Nicola M. Kayes pooling their Australasian rehabilitation experience. As a team from the Global South, they advocate for a cultural shift in attitudes; equity in financing inclusive research; the collection of authentic insider knowledge; and ownership of projects and authorship by those with disability.

In comparison, Article 15, “Self-advocacy in Inclusive Research” Courtney Krueger, Lieke van Heumen, and Claire van den Helder also collaborate but in support of the first author, telling her story about being both an inclusive researcher and self-advocate. Courtney’s story brings to life how the actions and strategies of inclusive research can be fused with those of self-advocacy. Such convergence is recommended as both disciplines aim to give people with intellectual disabilities a voice.

The last of the three articles in this section, Article 16, “From Inclusive Research to Inclusive Evaluation: Empowering People with Intellectual Disabilities to Shape the Services”, completes the second edition. The authors, Patricia O’Brien, Roy McConkey, Bruce O’Brien, Sarah Butler, and Edurne Garcia Iriarte from the Republic of Ireland, Northern Ireland, and Australia invite the readers to feel free to join them on the open road to extend the role of the inclusive researcher to that of inclusive evaluator. This does not mean letting go of the momentum associated with inclusive research, as demonstrated in the previous 15 articles, but acknowledging that the foundations for people with intellectual disabilities to expand their role into service evaluation has begun.

6. A Final Comment

The pioneers of inclusive research (Walmsley and Johnson 2003) appear to have taken the right road when it forked—that is, the road less well travelled. This second edition has continued to build on the credibility of the first edition, “opening” the Road to More Travellers disabilities.

Thank you to all who participated in what Whitman called, “*the long brown path of the open road*” (Whitman 2023). Thank you for *enabling* readers to travel with more certainty about what makes a difference when people with and without intellectual disabilities reach the open road together, wind on their backs strengthening the principles, policy and practice of inclusive research.

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