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Special Issue Reprint

Inclusive Research

Is the Road More or Less Well Travelled?—2nd Edition

Edited by
Patricia O’Brien

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About the Editor

Patricia O'Brien

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

Patricia's research interests and publications cover individual supported living, housing, advocacy, quality of life, inclusive research, inclusive education, and service design. She is known for leading inclusive research initiatives in which people with intellectual disabilities are involved as co-researchers. Her work has also led to the development and mentoring of two major Inclusive Research Networks (IRN), first across the Republic of Ireland and later in Sydney, Australia, where researchers both with and without disabilities have co-designed research studies with international dissemination of findings. Also, as a strong advocate for inclusive education within university settings, Patricia introduced the "uni 2 beyond" program at the University of Sydney, through which students with intellectual disabilities can audit courses.

Patricia has co-edited three books that promote the need for value-based inclusion in both education and community-based settings. She is a Fellow of the Australasian Society of Intellectual Disability, FASID, and is a Member of the Order of Australia, AM.

Preface

The first edition of "Inclusive Research: Is the Road More or Less Well Travelled?" illustrated through publication of its 19 articles that the road of inclusive research was being more well-travelled by people with intellectual disabilities. Doing inclusive research meant that they were no longer just numbered participants responding to the researcher's questions but active collaborators in deciding who and what was to be researched.

The aim of a second edition was to continue to verify the ongoing development of inclusive research, as well as to provide an opportunity for seasoned inclusive researchers to show how they are sustaining their interest in this paradigm of research. The edition therefore opened the road for further development of both methodology and resources, as well as for the inclusion of current perspectives of researchers with intellectual disabilities and co-researchers from university, service, and advocacy settings on what it means "to develop inclusive research skills".

The 16 articles will appeal to readers who are sympathetic to: ensuring that epistemic justice is done to those with the lived experience of intellectual disabilities through the use of inclusive research strategies; learning from the expansion of inclusive research into new countries; being reminded about the power of co-creation and co-design within the scope of inclusive research; acquiring new inclusive resources and methodologies; and considering additional roles for inclusive researchers.

As a reader of this edition, you are invited to reflect on whether the road of inclusive research has become more well-travelled. Has opening it up further in this edition made a difference?

Patricia O'Brien
Guest Editor

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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.

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

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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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Article

Understanding Epistemic Justice through Inclusive Research about Intellectual Disability and Sexuality

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Abstract: Formal language: This paper discusses inclusive research and epistemic justice by using an example of a published study the authors conducted on intellectual disability and sexuality in supported living environments. Our study addressed taboos and pushed boundaries in content and methodology through two ways of inclusive research: (1) the second author of this paper who has an intellectual disability was a main researcher in the study; and (2) we interviewed people with intellectual disabilities about their own experiences as well as their desired solutions to obstacles they face in their supported living environments. Their input was centralized in the final research report. This method challenged the epistemic injustice of who have historically not been 'allowed' to produce knowledge in research. This paper offers historical insight into epistemic injustice as well as relational approaches from critical disability studies and non-Western understandings of disability that 'rethink' disability and that can thus promote epistemic justice in academic theory. By addressing both practice and theory in this paper, we aim to contribute to the growing body of inclusive research and to the epistemic justice of people with intellectual disabilities. **Plain language:** (1) Epistemology = thinking about knowledge, producing knowledge, sharing knowledge. (2) In history, people with intellectual disabilities have often been excluded from participating in this. This is called epistemic injustice. It is caused by the discrimination of people with intellectual disabilities (ableism). (3) Performing inclusive research with people with intellectual disabilities challenges this. It contributes to epistemic justice. Researchers and interviewees with intellectual disabilities can bring knowledge from lived experience into research. (4) Knowledge from lived experience has not always been valued in traditional research. That means we also need to think differently about 'knowledge', and about 'disability' and its 'value'. (5) Discrimination based on disability has a long history. For instance: during colonialism by European countries (starting in the 15th century), false ideas about 'poor health' and 'low intelligence' were already used to justify slavery. People with disabilities have often been locked away or even killed because they have been seen as 'less valuable'. These ways of thinking still exist. They influence our understanding of 'epistemology' because they decide whose way of thinking and way of life is valuable or not valuable. We need to change this way of thinking. (6) Some academic fields that help are critical disability studies, indigenous studies, and feminist posthumanism. These fields challenge ableist ways of thinking. They can help us understand disability as something that is not negative or less valuable, but simply part of what makes us human.

Keywords: epistemic justice; intellectual disability; sexuality; inclusive research; relationality

1. Introduction

In this paper, we will discuss epistemic (from 'epistemology') (in)justice and -agency while using the example of a study on sexuality and intellectual disability in supported living environments. This study was performed through inclusive research over the course of eight months from 2022 to 2023 (Kelders et al. 2023). Epistemology is a branch of philosophy that looks at what it means to *know* something. It studies *knowledge*. It asks questions such as the following: what is knowledge? How do we come to know something? And what is truth? Are there objective truths in the world? And are these truths the same for every culture? Epistemic agency is "the capacity for an individual to produce, transmit, and use knowledge" (Catala et al. 2021, p. 9015). Epistemic justice is the right of people to be heard, taken seriously and contribute to knowledge production; to turn their agency into recognized action (Fricker 2007). Epistemic injustice happens when people are not heard, taken seriously, or 'allowed' to contribute to knowledge production. We will discuss the history of epistemic injustices of people with intellectual disabilities, as well as alternative epistemologies that challenge these injustices, such as critical disability studies (CDS) and non-Western understandings of disability. Additionally, limitations of our study and their underlying reasons will be explored, as well as possible practical solutions and directions for future inclusive research.

Our study on sexuality and intellectual disability pushed normative boundaries and addressed taboos both in content and methodology through inclusive research. It was in large part performed by the second author, a researcher with intellectual disability. He brought an approach and insight into the research that would otherwise have been inaccessible for neurotypical researchers without this lived experience. His contribution to the interviews was essential for making the questions accessible and in helping make some of the participants feel more at ease. Because of his lived experience with supported living environments, he was able to ask specific and practical (follow-up) questions that could not have occurred to the researcher without lived experience. He was furthermore able to build a bridge from abstract ideas to concrete experience during the interviews and during the processing of the research results. The interviews were semi-structured. Because there were specific things we needed to know, we needed to have specific questions, so it could not be completely open. We also had a particular order of questions to bring up, which was meant to start the interview as easy and comfortable as possible due to the taboo nature of the topics. However, each participant had a different way of processing questions and answering them, and had different relationships to the topics. This meant we needed to be flexible in our language use and question order. We let the interviews turn into conversations led mostly by the interviewees, only steering the questions in a certain direction if needed. Many interviewees brought up relevant topics themselves. This helped in navigating the taboo subject and it helped interviewees to feel in control. Centering the knowledge of our interviewees with intellectual disabilities during the research and in the final report pushed the boundaries of who are traditionally 'allowed' to share knowledge in research and gave some power to people who are often marginalized.

Sexuality of people with intellectual disability is often seen as taboo and as a potential cause for unsafe situations, such as vulnerability to abuse. Common stereotypes in society and media include that people with intellectual disabilities do not have a serious interest in sex and that they are 'asexual', or that they are instead (aggressive) sexual deviants (van Doorn et al. 2019). These stereotypes are not based on true lived experience. Instead, these stereotypes assume that people with intellectual disabilities have a non-normative bodymind (a body and mind that are seen as different from the 'standard'), and that the relationship people with intellectual disabilities have with their own bodymind and that of others must therefore also be non-normative (or 'abnormal'). This leads to misconceptions about the sexuality of people with intellectual disabilities. Our study aimed to counter negative narratives in dominant (mainstream) discourse (debates/conversations in society) and to decrease stigma by focusing on interviewees' positive experiences, and on the normalization of the topics. Although focusing on the positive was possible, it was also often difficult. Many experiences our interviewees shared with us came from a place of trauma, or of not being heard or taken seriously by their environments (examples of epistemic injustice). It is important to note, then, that positive representation of sexuality and intellectual disability is not limited to unequivocally positive lived experiences. It is also about understanding and representing people with intellectual disabilities as 'epistemic agents' (people who are capable of contributing to knowledge production, such as research), who carry a wealth of knowledge about themselves, their desires, and the issues they face, as well as insight into potential solutions for these issues. In other words, positive representation of people with intellectual disabilities is not about only showing positive things about someone's life. It is about showing *all* aspects of real life, and about sharing real knowledge that people with intellectual disabilities have. Taking this knowledge seriously challenges stigma, stereotypes, and epistemic injustice.

Our study started with several months of desk research into the subject of sexuality and intellectual disability. Then, interviews were held with nineteen healthcare professionals and managers and a total of nineteen adults with intellectual disabilities who live in supported living environments. The majority of the nineteen people with intellectual disabilities we interviewed were considered by themselves and/or by their healthcare professionals to have 'moderate' to 'mild' intellectual disabilities[1]. Three interviewees were considered to have a 'profound' or 'severe' intellectual disability. All interviews were carried out through verbal communication on both sides. Some interviewees preferred to have a confidant by their side during the interview, such as a healthcare professional they were close with, because of the potentially sensitive subject matter. In these cases, we sometimes, where deemed appropriate, extended our questions to these confidants as well. Sometimes a confidant would jump in on their own accord, to finish an interviewee's story if it was difficult for them to talk about, or if they lost their train of thought (see Section 3 for a discussion on both the advantages and pitfalls of this). Questions were asked about personal experiences with sexuality in the participants' supported living environment, as well as in what ways they were able to express or hindered in expressing their sexuality and their sexual rights, and in what ways their situations could, if needed or desired, be improved. Whenever confidants were present, we used the joint dyadic interviewing method. In a dyadic approach, two interviewees participate at the same time, creating an interactive interview. This method can provide a voice to people who may need assistance in talking about something (or to people who do not communicate verbally) (Caldwell 2014). Ethical approval was obtained by the medical ethics committee of Utrecht University (#22-0627). Whenever quotes by interviewees are used in this paper, including the opening quote, they have been translated from Dutch into English. Interviewees will be referred to with a number (for example 'interviewee #1′) in order to protect their anonymity.

2. Epistemic Agency and (in)Justice

Marginalized (oppressed, excluded) people with and without intellectual disabilities have been and are continuing to fight for epistemic agency and justice. Porter et al. (2022) explain that "the behaviour of epistemic actors is shaped by contextual factors and is often characterised by an unequal distribution of power and resources. These latter political and ethical concerns have clear resonance within medical sociology and disability studies, which have in common the core concerns of an individual's situated knowledge of bodies and impairment; and critiques of professional power and knowledge over those bodies" (p. 1169). What this means is that the inequality in society of power, resources and knowledge contributes to epistemic injustice. If people are not recognized as epistemic agents, they cannot contribute to knowledge production. If they cannot contribute to knowledge production, their needs will not be known and cannot be met, and they will continue to be oppressed and excluded from mainstream society. This is a vicious cycle.

The fight for the recognition of epistemic agency and justice by people with disabilities does not always include people with intellectual disabilities. This is because our (Western) common understanding of epistemology often depends on the logocentrism of propositional knowledge. Logocentrism means that the importance of 'logic' and 'rational thinking' is emphasized in knowledge production. Propositional knowledge is the logical, abstract and verbal way of knowing that something is true. It is therefore different from, for instance, practical, tacit, embodied and affective knowing. These types of knowing relate, for instance, to feeling—both emotionally and physically—and knowledge that is gained from experience—knowledge that can be expressed non-verbally. A logocentric epistemology excludes non-propositional forms of knowing. It thereby also excludes people with intellectual disabilities, for two reasons. (1): People with intellectual disabilities are often seen as not possessing logic and rationality. (2): Some people with intellectual disabilities use types of knowing that are different from logic and rationality (Catala 2020). There is also a disability hierarchy within society that shows that both disabled and non-disabled people are generally more accepting of people with physical disabilities than of people with intellectual disabilities (Tringo 1970; Thomas 2000; Dolmage 2014). This contributes further to the epistemic injustice of people with intellectual disabilities.

The dominance of propositional knowledge in our understanding of epistemology means that this type of knowing is also dominant in the knowledge production in research. Other types of knowing, such as practical, tacit, embodied and affective, are often dismissed (Catala 2020). This means that, in order for people with intellectual disabilities to be able to gain recognition as epistemic agents, steps need to be taken on a metaepistemic level first (Catala 2020). The parameters of what constitutes 'epistemology' need to shift. This means that the way in which we understand 'epistemology' itself needs to change. Including non-propositional types of knowing in the understanding of epistemology will vastly expand the pool of knowledge to draw from. It will enable research to be inclusive of people with intellectual disabilities. Performing inclusive research with people with intellectual disabilities by including their non-propositional knowledges, based on a "presumption of credibility" (Caldwell 2014, p. 495—meaning that in research, the knowledge of people with intellectual disabilities is taken seriously) can support such a parameter shift.

Epistemic injustice has long excluded people with intellectual disabilities from participating in research as equals rather than as 'objects' of study. A brief history will follow discussing the underlying reasons for epistemic injustice. It is important to look at the historical origins of the dominance of logocentric propositional knowledge in knowledge production, in order to be able to recognize and acknowledge other ways of knowing. (Critical) disability studies (CDS) has occupied itself with the deconstruction of ableism and the concept of Disability since the 1970s. Ableism "reflects a preference for species-typical normative abilities leading to the discrimination against [disabled people] as 'less able' and/or as 'impaired'". As such, it is "one of the most societally entrenched and accepted isms". It has "[h]istorically (. . .) been used by various social groups to justify their elevated level of rights and status in relation to other groups", including through sexism and racism (Wolbring 2008, p. 253). Ableism includes 'neuronormativity', which is the "prevalent, neurotypical set of assumptions, norms, and practices that construes neurotypicality as the sole acceptable or superior mode of cognition, and that stigmatizes attitudes, behaviors, or actions that reflect neurotypical modes of cognition as deviant or inferior" (Catala et al. 2021, p. 9016). In these definitions, we can recognize what has been discussed above. Meaning that the stereotypes about people with intellectual disabilities and sexuality and epistemic injustice are symptoms of ableism.

It is through ableism's historical path that we can trace the roots of epistemic injustice. Ableism is often positioned within CDS as closely entwined and co-constitutive with other ideologies and structures that depend on the categorization of groups based on notions of inherent physical, intellectual, and cultural superiority and inferiority. This includes colonialism, racism and patriarchy (Erevelles and Kafer 2010). What this means is that societal structures (such as politics and policies) and societal attitudes that oppress and exclude women and other marginalized genders, people with disabilities, people of color, and colonized peoples, use a 'mixture' of racism, sexism and ableism to do so. These structures are each other's building blocks. For instance: historically and presently, disability has been wrongly attributed to people in order to strip them of their humanness, and consequently of their epistemological agency and justice (Baynton 2001; Kafer 2013; Norris 2014). Ideas of 'intellectual inferiority' and 'poor health' were used in North America to justify the slavery of Black people from African countries and the oppression of women (Baynton 2001). It has also been applied to indigenous and colonized peoples to justify their oppression and the use of their lands and resources, as European (settler–)colonialists placed themselves at the top of an invented hierarchy of intellectual and cultural superiority (Norris 2014). European Enlightenment ideals about rationality, logic, individualism, universalism, independence, taxonomies, classifications and hierarchization further reinforced and contributed to these structures (Norris 2014). Ultimately, when taken to the absolute extreme, these ideologies have gone hand in hand with colonial endeavors including genocide and epistemicide, as well as the state-mandated eugenics of the late 19th and early 20th centuries (Norris 2014). Epistemicide means "the killing, silencing, annihilation, or devaluing of a knowledge system [which] happens when epistemic injustices are persistent and systematic and collectively work as a structured and systemic oppression of particular ways of knowing" (Patin et al. 2021, p. 1307).

Such ideologies can be found in (epistemic) injustices to this day. The most drastic example is that forced sterilizations of marginalized people still occur, although no longer state-mandated and on a much smaller scale in places outside the public eye, such as prisons and care facilities (Baig 2021; Bauer-Babef 2022)—examples of this in our own study follow below. Additionally, disability is still often seen through a medical model, and thus as a condition that should be prevented or cured. The medical model operates on false notions about poor quality of life (Brown et al. 2019) and positions disability as something that should not belong to the human condition (Barnes 2002). Steps that are undertaken in the medical world to prevent or cure disability are sometimes referred to as 'new eugenics', as old eugenics and "the termination of human life affected by IDD [intellectual and developmental disabilities]" in modern medicine operate on the same principle (Reinders et al. 2019, p. 100). This principle entails the idea that a life with intellectual disability is not a life worth living, which ignores "alternative views, most of all the views of persons and families directly implicated who do not consider living with intellectual disability identical with a life full of suffering" (Reinders et al. 2019, p. 99). The contemporary exclusion of people with intellectual disabilities from society, from epistemic justice, and from knowledge production, is then still linked to its complicated discriminatory history.

Enlightenment ideals are still central in knowledge production and policies: "'neutrality', 'reason', and 'rationality' are fundamental components of how 'Western' scholars and policy-makers understand 'fairness,' 'equality,' and 'justice' (. . .) and how issues of global injustice are approached in policy and practice" (Wilson 2017, p. 1081). In dominant institutions, "[k]nowledge production (. . .) involve[s] epistemic violence—the work of discourse in creating and sustaining boundaries around what is considered real and, by extension, what is unable to be seen as real (or to be seen at all)" (Hunt 2014, p. 29); think of the exclusion of non-propositional knowledge. If non-propositional knowledges are 'unable to be seen as real (or to be seen at all)', and if they are considered outside the 'boundaries around what is considered real', they can never become part of knowledge production. The exclusion of these forms of knowing means that epistemic justice is much harder to reach, which can be referred to as 'epistemic violence'.

As Judith Butler explains: "[i]t is not simply (. . .) that there is a "discourse" of dehumanization that produces [dehumanizing] effects, but rather that there is a limit to discourse that establishes the limits of human intelligibility" (Butler 2004, p. 35). In other words, discourse [debates, conversations, narratives] in dominant institutions, such as the academic world and other places of research, is limited in its ability to understand a full range of human knowing. Similarly to this notion, 'hermeneutical injustice' (Fricker 2007) refers to an 'intelligibility deficit' based in the lack of a cultural framework to interpret certain types of knowledge and experience correctly. Here, the fault of misunderstanding certain types of knowing is placed with the way society views and treats certain groups of people, rather than with the supposed 'unintelligibility' of people themselves. In other words, it is the dominant discourse, cultural frameworks and types of knowledge production that are lacking in their ability to understand beyond logocentric, propositional knowledge. For our context, this means people with intellectual disabilities who can (only) share ways of knowing that are different from logocentric propositional knowing are not lacking. Instead, the world of knowledge production lacks in understanding these types of knowing, these epistemologies. For this very reason, we framed our study on sexuality and intellectual disabilities as inadequate to accommodate the type of communication and the types of knowledge that non-verbal people with severe/profound intellectual disabilities use. Instead of contextualizing non-verbal people with intellectual disabilities as 'unable' to participate in our research, we framed this as a limitation of the study. A "methodological intelligibility deficit" (Catala 2020, p. 771), rather than a limitation of the people who could not participate.

The deliberate exclusion of what is needed to gain epistemic justice can also be referred to as 'epistemic sabotage'. Porter et al. (2022) describe epistemic sabotage in the context of the UK disability benefit system. According to them, there is a deliberate effort to "police the boundary of disability's administrative category" (p. 1183), meaning that it is a difficult process to 'prove' that you have a disability and therefore 'deserve' benefits such as (supplementary) income and specialized healthcare. This effort to treat people with a disability with distrust until they can 'prove' their disabled status contributes to a "political and popular anti-welfare consensus" (p. 1168) and thus leads to further discrimination. Disability, in such efforts, is once again categorized and placed in an individualizing medical model. Porter et al. (2022) explain that, "[f]or sociologists working at the intersections of medical sociology and disability studies, the Fundamental Principles prompt important points of reflection" (p. 1167). Among these principles is that "disability must not be individualized, meaning any methodological approach that emphasisesindividual social action (. . .) must also work analytically to make clear the role of disabling social structures" and that "all issues affecting disabled people (. . .) must genuinely involve disabled people, and must not be the preserve of a small number of non-disabled experts" (p. 1167). In other words: no political or policy decisions should ever be made without the people it concerns, in this case people with disabilities. *Nothing about us, without us*, as the famous credo goes.

As one interviewee with intellectual disability in our study explained:

> *Parliament really needs to pay attention to how people deal with disabilities, and remove the taboo from sexuality. They need to accept that not everyone just wants to share everything with their caregivers/healthcare professionals. Caregivers should live like us for a week. We need more agency. The ministry of health wants to know a lot about us, but we never see anything in return. Caregivers need to be trained better. The idea that sexuality doesn't exist among us is ridiculous.*
>
> *Tools [that are used for sex education] are often developed like 'we did it together with people with an intellectual disability and now we're done', and then it turns out it doesn't work (interviewee #2 in Kelders et al. 2023).*

In these quotes, a form of epistemic injustice and (possibly accidental) sabotage plays out. People with intellectual disabilities are 'deployed' at the start of a project, but they are not involved in the continuing, iterative development of the research or the resulting educational tools and their practical implementations. They are not involved enough in research and the development of tools for their own and their peers' actual, real-life benefit. As DS scholar Dan Goodley explains: "Disability research with participants can fall into research on participants—when the only person benefiting is the researcher and their career aspirations" (Goodley 1999, p. 43). Indeed: we have distributed the final report of our study on sexuality and intellectual disability amongst those who are interested, those who work in disability care, and our interviewees with intellectual disabilities. However, at this point in time, it is unclear whether the conclusions of our study will result in practical action that involves people with intellectual disabilities because the ball for any systemic, large-scale changes is now largely in the court of the Dutch parliament, who, six months after publication, have yet to engage with the report (note: it is possible that the delay in forming a new parliament after sudden elections plays a role in this. This does not, however, take away our concerns that the findings of our study will be low on the list of priorities for an indefinite amount of time).

3. Epistemic Justice and Relational Research

The overall underlying reasons for the injustices experienced by our interviewees (such as a lack of privacy, hindrance in starting and maintaining relationships, taboo on parenthood, and forced birth control and sterilizations) are traced back to the taboo on sexuality, and the fact that interviewees do not feel like they are always taken seriously or listened to by staff or family. One conclusion of our study was that solutions to these injustices and the issues that arise because of them could be solved by creating a less hierarchical structure within supported living environments and, simply, by listening to the residents. Creating solutions directly tackling these and other specific issues we have defined in our study are important and necessary for a direct improved quality of life for residents and staff alike, as long as these solutions are implemented, effective, and sustainable. However, several care professionals who were interviewed explained that sex education is often the first thing to be abandoned when new budget cuts hit, which has happened often during the long reign of a neoliberal political party in the Netherlands (Bertens and Palamar 2021). The decentralization of healthcare may also contribute to a lack of sustainability of new programs because of a lack of funds and differing policies in terms of implementation and effectiveness (Mulder 2019). Furthermore, our study was initiated because of a recent report on the high number of sexual abuse of residents of supported living environments (by other residents as well as staff members), while similar numbers and situations have already been known for decades (Dekker et al. 2012; Zembla 2017). As long as people with intellectual disabilities are not taken seriously, i.e., as long as epistemic injustice keeps taking place, it may be impossible to tackle the underlying structure that allows this to happen. For this reason, we not only offered practical solutions in our study to specific issues, based on input from our interviewees, but we also included a plea to the readers of the report and the governmental branch involved to be wary of the underlying root cause of these issues: ableism and its long and complex history cannot be overlooked in current systemic injustices.

Gaining epistemic justice for people with disabilities thus means tackling ableism. This means escaping the parameters of how we understand ‘disability’. As discussed briefly above, ideologies about the inherent superiority or inferiority of certain subjective qualities such as intellect, logic, independence and individualism have contributed to the categorization of human beings, as well as to a ‘hierarchy of preference’ of certain disabilities over others. Critical disability studies (CDS) scholars offer perspectives that challenge these ideologies. For instance, the concept of ‘relational autonomy’ by Davy (2019) can counter societal expectations of independence. 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” (de Haas et al. 2022). Independence, for people with disabilities, “refers not to a set of skills or being able to care for one’s self, as service professionals tend to define it, but rather refers to having control over making decisions that directly affect one’s life” (Caldwell 2014). Eva Kittay argues that true ‘independence’ does not exist for anyone, and that we are all instead connected through reciprocity and intersubjectivity (Kittay 2019). Alison Kafer offers a ‘relational model of disability’, arguing that “[t]o eliminate disability is to eliminate the possibility of discovering alternative ways of being in the world, to foreclose the possibility of recognizing and valuing our interdependence” (Kafer 2013).

Disability as a concept as well as the word itself in reference to a condition is absent from many indigenous languages (Norris 2014). Disability as a condition in indigenous worldviews is often understood as a natural variation in the human experience, rather than an exception or ‘mistake’ that needs to be prevented or cured. As expressed, for instance, by a traditional Cree woman in an interview on disability: “[t]he Creator put these people [referring to people with intellectual disabilities] here for a purpose so that we will learn from them; they are our teachers. No one is considered abnormal in our culture" (Shackel 2008). An elderly Navajo singer explains: "Before the white man came, we were blind [to disabilities]. You brought us the gift of sight. I think we were happier when we couldn't see" (Connors and Donnellan 2007, p. 279). People with intellectual disabilities in cultural understandings such as these are then inherently already recognized as epistemic agents and as belonging. However, these understandings have, since colonization, been systematically erased through epistemicide (Norris 2014; de Sousa Santos 2014).

Relationality is at the core of CDS scholarship, as mentioned above. It is also at the core of many indigenous worldviews (Shawn Wilson 2008; Tynan 2021). In indigenous epistemology and ontology, knowledge is "relational, alive, emergent" (Hunt 2014). Universalisms are often seen as too static to deal with reality, which always changes (Shawn Wilson 2008; Estes and Becker 2022). Similarly, (Western) feminist theorists have encouraged researchers to understand their own positionality and situated knowledge as subjective and relational, rather than as a vehicle towards objective universal truth (often in tandem with an emphasis on intersectionality) (e.g., Sandra Harding, Donna Haraway and Patricia Hill Collins). In a relational framework, people are not valued based on their individual ability to strive towards Enlightenment ideals of independence and rationality. Instead, relationality is a way of thinking about human relationships and disability that allows space for interdependence, reciprocity and non-propositional knowledge. In addition to CDS, it can thus be useful to engage with such non-Western relational understandings of disability for the advancement of epistemic justice and the deconstruction of ableism.

4. Epistemic Justice and Future Inclusive Research

Incorporating a relational framework in research can support epistemic justice. Undertaking research non-hierarchically with researchers with intellectual disabilities is essential. Additionally, as mentioned earlier, for our study on sexuality and intellectual disability, we used the dyadic approach to include more people with intellectual disabilities who were not able to or did not want to be interviewed by themselves. The dyadic approach can be considered to be relational. However, because we also had an interviewee who expressly did not want a staff member by their side, such a construction needs to be navigated carefully. Dyadic interviewing then has two faces: on the one hand, "the suggestion of joint interviews is inherently problematic from a CDS perspective, raising concerns regarding the potential for proxy or facilitated responses to suppress the voices of people with ID [intellectual disabilities]" (Caldwell 2014, p. 489). This could result in (accidental) epistemic sabotage, if, for instance, the second person speaks for or over the person with intellectual disability while using their own subjective view of a situation to fill in the gaps incorrectly. On the other hand, the approach "recognizes the value of interconnected relationships and contextualizes in such a way that retains focus on the person with intellectual disability as the unit of analysis" (Caldwell 2014, p. 492). It could then also be particularly useful for non-verbal participants with 'severe/profound' intellectual disabilities. In this case, someone who is closely familiar with the person in question can speak for them—as they likely need to do in daily life when, for instance, advocating for them in relation to social/civil institutions. Despite the potential pitfalls of this methodology, it could still contribute to a relational understanding of disability and of epistemology and knowledge. It would have been a valuable addition to our study, which, despite being performed on an inclusive basis, still excluded non-verbal people with intellectual disabilities and their experiences. A truly relational understanding of epistemology that is inclusive of non-verbally expressed, non-propositional knowledge and/or uses the dyadic approach can contribute to a broader scope of epistemic justice.

5. Conclusions

This article has reflected upon some of the findings of our study on sexuality and intellectual disability: the taboo around this topic, and the relation of research to epistemic (in)justice. The main conclusion is that performing inclusive research can promote epistemic justice—and vice versa. Understanding the history of epistemic justice in the context of ableism and other systemic (global) structures, including colonialism and patriarchy, is important to be able to recognize it in order to recognize alternative epistemologies. This is necessary in order to dismantle the dominance of logocentrism and propositional knowledge in our understanding of epistemology and their subsequent dominance in research; as such, this approach leaves out non-propositional ways of knowing and thereby excludes people with intellectual disabilities. This means creating a shift on a metaepistemic level. Alternative epistemologies can be sourced from critical disability studies and from non-Western approaches to disability, such as relationality. Relational approaches in research, such as dyadic interviewing and non-hierarchical collaborations with people with intellectual disabilities, can contribute to epistemic justice.

Many of the findings of our study on sexuality and intellectual disability—especially when positioned in the context of this article—appear to simply try to 'prove' that people with intellectual disabilities are 'normal' people when it comes to sexuality, but also day-to-day life. Indeed, many experiences that we wrote down in the study based on the interviews are experiences, feelings and expectations that anybody, with or without intellectual disability, could have. This includes, for instance, preferences in relationships, an understanding of consent, and wishes of parenthood. This shows that people with intellectual disabilities have already suffered epistemic disablement to such an extent that their agency first needs to be proven before justice can occur. It needs to be proven first that they are able to define the problems they face in their surroundings as well as potential solutions. Writing down people's experiences and insights, accompanied by powerful quotes, helps to clarify and specify the way people with intellectual disabilities and their peers exist in society. This might otherwise be obscured to anyone who does not work in the disability field, or anyone who does not personally know anyone with an intellectual disability, since, by definition, little is often publicly known about marginalized groups. At the same time, however, our study has excluded non-verbal people with 'severe/profound' intellectual disabilities. Additionally, the fact that the people we interviewed were willing to participate in a study that was explicitly about sexuality means that they were possibly already comfortable talking about this topic to some extent. This means that the information we have uncovered may only be the tip of the iceberg. Because of these reasons, we have provided a 'further research' section in our study.

As mentioned earlier, although our study was commissioned by a government branch, it is currently unclear if its findings are on the political agenda. And, as one of our interviewees reminded us, sometimes, researchers and clients such as government branches "want to know a lot about us, but we never see anything in return" (interviewee #2 in Kelders et al. 2023). It is a well-known fact that there exists a gap between research and practice (e.g., Westerlund et al. 2019; Joyce and Cartwright 2019; Mohajerzad et al. 2021), which can be difficult for researchers and research participants to come to grips with. The good news, however, is that we have seen a large amount of people willing to participate in our study who have voiced their interests and concerns regarding its topics. Although systemic change through governing bodies is desirable, inclusive research such as this can hopefully invigorate efforts at non-government levels. During interviews with people with intellectual disabilities as well as healthcare professionals, we not only asked questions but also shared information and resources we had come across in order to exchange something for our knowledge 'extraction'. Some people with intellectual disabilities we interviewed have described the interviews as cathartic. The participation of people with intellectual disabilities in our focus group was also experienced as positive. They were happy to share their stories with each other, recognize each other's experiences, and make new connections. This is indeed at the core of the added value of doing inclusive research: because we worked directly with people whom this research concerns, it was possible to immediately give something in return rather than having to wait for new policy in the form of creating more awareness, functioning as an outlet, and opening up conversations between people. Performing inclusive research can directly and immediately positively impact the people involved, which is why it is valuable and meaningful even regardless of the implementation of its findings on a policy level. Inclusive research is a way to bridge the gap between research and practice, and it is a way to remain hopeful.

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Note

[1] Terms that are commonly used for the categorization of intellectual disabilities are light, moderate, severe, and profound. Categorization has often been performed by measuring IQ; however, this is becoming less common as IQ is being recognized as a pseudo-science with its roots in eugenics. Instead, cultural and social factors as well as the degree and type of support needed should be considered in diagnosing an intellectual disability (Schalock et al. 2021). This means that categorization depends on socio-cultural expectations of normalcy as well as socio-cultural influences on development and support needs.

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Article

Expanding Possibilities for Inclusive Research: Learning from People with Profound Intellectual and Multiple Disabilities and Decolonising Research

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Abstract: This paper pursues the argument that finding a way for people with profound intellectual and multiple disabilities to belong in inclusive research requires starting from a deep knowledge of the people in question. This paper illustrates this idea in action showing what can be possible from building research around 'being with' people with profound intellectual disabilities, creating intersubjective knowledge together. It follows the journey of fostering a relational research space that a young person with profound intellectual and multiple disabilities can occupy, their assenting to share the space and ensuing exploring together in embodied ways. Small stories show where this particular open road of inclusive research can lead. The analysis interacts with provocations from decolonising research that demand respect for wider ways of knowing, doing research and being human. The paper invites reflection on the ways in which research needs to be deconstructed to be inclusive for all.

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

1. Introduction

In our last paper (de Haas et al. 2022), we argued that it is important to find a way for people with profound intellectual and multiple disabilities to belong in research. We concluded that to do research *with* (not *on*) people with profound intellectual and multiple disabilities, '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' (de Haas et al. 2022, p. 1). In this paper, we share an illustrative example of this approach in practice. We recognise people with profound intellectual and multiple disabilities as people possessing and experiencing meaning and provoking and providing love. We acknowledge them as people leading lives in bodies complicated by profound cognitive and multiple sensory and physical impairments, having high and pervasive support needs. We remain committed to learning from this group new ways of knowing about the world. We rise to the challenge of joining with them in closing the gap between their inclusion in the research world and the inclusion of other disabled people already making important contributions. Our work is inspired by the strong tributary of ethnography set by Mietola et al. (2017), Skarsaune et al. (2021) and Simmons and Watson (2014). We also explore parallels with decolonising research in our shared desire to relinquish established ways of knowing and be open to wider forms of meaning and knowledge construction.

This paper reports on the ongoing work of Joanna Grace (hereafter Jo) and our joint methodological and conceptual work. This is informed by the existing literature and our connections to people with profound intellectual and multiple disabilities and their families. We are conscious of ‘moving forward on a road less well-travelled’ (O’Brien et al. 2022, p. 483) and have taken particular insight from decolonising research. We acknowledge that people with profound intellectual and multiple disabilities are not an indigenous population and are not clamouring for fair treatment. However, we note parallels in their subjugation by power hierarchies and exclusion from the production of valued knowledge. The people are not analogous, but the issues are. Moosavi (2023) calls for researchers to make decolonising epistemology more all-encompassing. Our work maps a similar terrain in that our journey necessitates questioning how we create knowledge and challenges underlying assumptions about valid forms of knowing.

‘If we are committed to anticolonial thought, our starting point must be one of disobedient relationality that always questions, and thus is not beholden to, normative academic logics’ (McKittrick 2021, p. 45, cited by Rutazibwa 2023, p. 329). The normative academic logic of research inclusion is to enable inclusion within existing research processes and evaluate success on these terms (see, e.g., Bigby and Frawley 2010; Bigby and Wiesel 2019; Kellett and Nind 2001; Nind and Seale 2009; Nind 2017; Strnadová et al. 2014; Tuffrey-Wijne et al. 2008; Tuffrey-Wijne and Butler 2010; Woelders et al. 2015). Instead, by beginning from a deep knowledge of people with profound intellectual and multiple disabilities, we transform the *doing research with* of inclusive research (Walmsley and Johnson 2003; Nind 2017) into ‘being with’ people with profound intellectual and multiple disabilities in research (de Haas et al. 2022). In doing so, we are inspired by Go’s (2023, cited by Rutazibwa 2023, p. 330) anticolonial approach to social inquiry, to ‘consider a standpoint (heterogeneous though it may be) that has not yet been considered’ (Rutazibwa 2023, p. 290).

Decolonising research recognises the importance of spending time getting to know populations who have been excluded from research. Smith (2021) comments on the culturally sensitive nature of the interview format, remarking that if a Māori person consents to a standard one-hour interview then the researcher has not succeeded in involving them in research. This acknowledges how Māori people share knowledge collectively in communities, meaning a researcher must spend hours or days with them, dining with them, talking and listening and being a part of the sharing of wisdom. Yunkaporta (2019, p. 168) speaks of the kinship mind of Aboriginal people, whereby knowledge sits in the relationship between people and is best accessed together. While a Western researcher might assume they bring only themselves to research, indigenous researchers speak of carrying a responsibility towards their ancestors in all they do (Lavallée 2009; Liebert 2021). Rhee (2021) describes how knowledge is ‘grounded within our bodies, born out of our mother’s bodies, and our body bridges the past and the future’.

Inclusive researchers similarly recognise the importance of spending time with people with profound intellectual and multiple disabilities (Mencap 2011; Watson et al. 2006), getting to know them (Chalachanová et al. 2020; Lesseliers et al. 2009), working alongside them and allowing time for expression (Steve Hollingsworth 2020; Mikulak et al. 2022; Nieuwenhuijse et al. 2020; Simmons 2018). Macpherson et al. (2016) highlight how advantageous the 12 years spent weekly together was for one partnership within their inclusive arts practice. This was crucial, they say,) to their ability to be with and listen expansively to people with learning disabilities. Spending close time together is, we argue, a key resource in enabling some groups to belong in inclusive research, as in advocacy and other related work.

The inclusive research agenda also similarly recognises the necessity of being open to listening in different ways (Bos and Abma 2022; Goodwin 2013; McCormack 2017; Olsman et al. 2021; Skarsaune et al. 2021) and appreciates embodied knowing. We answer ‘now’ to Manning’s (2016, p. 4) challenge: ‘When do we honor significantly different bodies and ask what they can do, instead of jumping to the conclusion that they are simply deficient?’ In our work, we, as Van Goidsenhoven and De Schauwer (2020, p. 332) advocate, ‘explicitly honor complex forms of interdependence in thinking about voice and create modes of encounter for that difference’. We conceive knowledge not as located awaiting extraction by a researcher but as an experience of meaning shared between people, even between bodies. In going about sharing meaning, we are strongly influenced by our experiences of using Intensive Interaction (Nind and Hewett 2005), which provides a framework for connecting without leading, sharing joint focus, and mutually attuning.

The work described in this paper took the goal of inclusion, or rather belonging, in research. Here, we mean belonging in the sense of being 'related to and part of something' (Block 2018, p. xvii) and the 'familiarity, comfort and security and emotional attachment' (Antonsich 2010, p. 645) that comes with it. In a move of 'disobedient relationality that always questions' (McKittrick 2021, p. 45), Jo placed belonging as the foundation stone in her research, seeking to establish the 'being with' people with profound intellectual and multiple disabilities before anything else. This belonging is the 'being with' that opens the possibility of a research encounter. In the research, Jo establishes 'being with' and then invites questions about their subject of joint study (embodied identity) into the research space. In this paper, we describe the process of locating a space of 'being with' in which to do research with people with profound intellectual and multiple disabilities.

2. Locating a Space of 'Being with'

Jo utilised participant observation (Glaser and Strauss 1967; Patton 2015) informed by sensory and autistic ethnography (Greco 2022; O'Reilly 2012; Pink 2015) and phenomenology (Merleau-Ponty 1945) in her processes of finding a way to research identity inclusively. She focused particularly on Merleau-Ponty's (1945) idea of intention as the movement of an embodied consciousness towards the world, of 'being in and toward the world'—rather than consciousness understood solely as thought. She visited three people with profound intellectual and multiple disabilities, Becky, Felicity and Senen, spending 3–5 h with them weekly at their school. Ethics approval for this work was obtained from University of Southampton Faculty of Social Sciences Research Ethics Committee (73404) with informed consent given by the young people's parents and school. Becky, Felicity and Senen's real names are being used in line with the consent given and the argument made by Grace (2022) that protection is not always found in anonymity and that by showing their faces and speaking their names, we ensure that these people are not hidden but are recognised for their part in the research (see also Tilley and Woodthorpe (2011) for arguments against the prevailing orthodoxy of anonymity). Inclusive research commonly names, as authors or in acknowledgements, the people with intellectual disabilities involved as contributors. By naming Becky, Felicity and Senen, we are acknowledging their role as collaborators in Jo's work.

Process assent (Dewing 2007) was sought continually when working with Becky, Felicity and Senen to ensure, as far as possible, that their agency and autonomy within the process were respected. We illustrate this with a small story (a concept adapted from Bamberg and Georgakopoulou 2008) of process assent in action with Becky (see Figure 1).

Small Story 1

Becky is vibrant and curious, alert to sounds around her. She delights in textures and vibrations. She is very expressive, using her own lexicon of sounds to convey meaning and amplifying these with gestures and bodily movements, for example, waving her arms and jumping if she is happy. Hoping to collaborate with Becky to explore embodied identity, we began with exploring leaf litter. Becky's understanding of this is better than mine; today, I noticed how the leaves and sticks ping gently against the fence; it's a very pretty sound. Ordinarily, she plays with the resources in the sand pit or crouches by the fence. Today, we did both of these things; I also pulled aside a chair to sit out of the way. She chose to come over to me, and to spend a good deal of time near me, looking at me, leaning towards me, a couple of times she hugged me, and at one point, she climbed onto my lap to explore my hair more closely. I did not prompt or request her to be with me at all; she came across entirely of her own volition. To me, this indicates her assent to be with me. I will look for indicators of her assent at every juncture of our work together. Today, I felt like I got the thumbs up.

Figure 1. Gaining assent to do research together.

3. 'Being with' as a Space for Feeling

Rhee (2021) talks of starting her work from 'a feeling place'. Similarly, Jo's collaborative work starts from the presence of a space of 'being with' in which a research encounter is made possible via feeling. Two moments can look alike in movement and in expression, but one offers the opportunity of 'being with' while the other does not. Jo's detailed reflection and analysis have led us to appreciate the movements made to create a space in which 'being with' is possible and its subtle distinction from *not* 'being with' as captured in these examples of field notes:

> Even though I had not managed to 'be with' Senen, the effort of trying left me feeling like I wanted to disconnect rather than connect. The class moved into an activity dedicated to the birthday of a class member. Various articles were passed around, to be looked at, smelled, etc. I took an active role in passing these around, in wafting, moving, putting things against their hands; it is easy to feel like you are doing something without having to move towards the children with your emotional self. (Jo field notes)
>
> I looked at the maths resources and considered trying to get back into a state of being with Becky and couldn't imagine doing the emotional work to get around these things. . . . I decided to back off and to perform the teaching assistant role. I counted to 3 and threw a brick into the sandpit every time I reached three. Becky enjoyed this and bounced to show her enthusiasm. (Jo field notes)

By contrast, 'being with' is a felt space of belonging, apprehended via affect. Here, Jo describes her process to create the possibility of 'being with':

> I first locate my embodied self, attempting through focus on the here and now to occupy the time and space I find myself within, rather than the many landscapes available to me intellectually. I then seek to locate the other person, I attempt to go deeper than simply looking and listening, I pay attention across sensory systems and attempt to attune myself to their being. To create the potential for being with I lean heavily on Merleau-Ponty's (1945) descriptions of our experience of consciousness as a directed movement towards the world in which our intention is placed in things towards which we then move. These movements can be physical, they can be utterances, or they can simply be the movement of consciousness. Once I have a rough grasp on where I am and where they are, I try to work out where their intention might lie, I then try to move my intention to that place, and if I can get a match, I experience the sensation of being with them and the potential for a research encounter is created.

The following small story from one of Jo's first meetings with Senen exemplifies this process and reveals the multisensory nature of their communication (see Figure 2). By narrating this micro-interaction, we aim to provide the reader with a tangible example to illustrate the argument of this paper.

Small Story 2

Senen arrived at school asleep and was positioned on an adjustable bed for the morning routine. Partway through the morning she woke up in pain and moaned; staff all expressed their sympathy, they fitted a tube to her stomach to try and wind her and then took her out of the room to adjust her position. When she returned, she was lying on her side on the bed and seemed awake. I took the chance to go and meet her (see Figure 2). I sat alongside the head of her bed, saying Hello and saying her name. Her eyes seemed bright. I was unsure of her vision and if her alertness was to me, or to something happening in her body.

With her arms bent and one fist near her mouth, she extended a finger and put it in her mouth, chewing on it and exploring it with her tongue. I copied her facial movements and angled my head to lie as if on her pillow close to hers. I extended my tongue as she extended hers.

Her eyes continued to be bright, giving the impression that wherever she was it was a happy place, and I was keen to be invited in or to try and wheedle my way in. Outside of what seemed to be our shared gaze, the class continued with a sensory story. The longer I spent with my head angled to the pillow, the more I felt where Senen's meaning was. All of her doing was around her mouth and her extended finger. I put my own fist to my mouth and reflected back Senen's expressions on my own face. It didn't feel like enough. I wanted into her world of meaning, so I moved so that my fist rested against hers, and she seemed to notice. Her tongue protruded in a triangular point, the pointiness of it gave it a sense of purpose. I touched the end of her tongue with my finger, and so began a conversation where I told her I could see what she was doing, I told her I could hear her. I discovered the finger in her mouth was hooked around so that its tip pressed back through the skin of her gum, I pressed it with my own finger from the outside of her face. "I see your finger there, I see where you are hiding it, I see what you are doing." She appeared to smile, and encouraged I repeated the action more playfully. She extended her smile and made a faint sound, which I repeated turning my sound into a laughing rhythm; again, her smile responded, and the rhythm of the slight noise matched my own.

Her tongue came out and I felt more confident so bounced my finger against the tip of it. She grinned and her hands lifted slightly and then she shook her head from side to side (the biggest movement I had observed her making). We continued that game until after a couple of headshakes, Senen seemed to calm, and I was mindful that I wanted to be with her, so I calmed with her and did not try to provoke further responding.

There was a pause and I repositioned myself so that my hand matched against my face where hers was against her face, she seemed to look at me, but I couldn't be sure her gaze was directed. I moved closer so that our fists touched each other, as my hand touched hers, she withdrew her hand from her mouth and the fingers uncurled. I had thought they were held in the fist shapes from spasticity, so it was unexpected when she opened her fingers to a splayed high five a little way from her face. I copied and matched my fingers to hers like praying hands. She seemed pleased and I was delighted, then she dropped her hand and shook her head again. Her vocalisations this time were more audible, and I matched them back to her.

Reflection: As I have continued to work with Senen, I have found that by locating her intention and placing mine with it I can create a connection, a 'being with' that then extends to experiences outside of that place of engagement. I make sure, when doing this, to focus on my being and on Senen's being. I might notice her doing, as I did with her sticking out her tongue in the small story above. When her being and her doing seem to be in the same space I allow myself to bring a small amount of my own doing into that space, as with the tongue tap. When I do this, I focus on ensuring that my doing does not overwhelm my being. If I feel that I am doing more than being I stop my action to refocus on being. I am also mindful to ensure that my doing does not overwhelm Senen's doing. It is easy for me to join in with her activity, and to do it more than her, bigger, faster, more dramatically, etc. I aim for my doing to be second to her doing and second to my being always.

Figure 2. Senen and Jo starting out and later finding a feeling space of ‘being with’.

This is one of the ways I work to ensure Senen’s agency, as well as my own, is able to direct our work. I work to find my way to a space of ‘being with’, but I recognise that at times the people I am working with make movements towards me, we each find our own way into that space, and are each free to withdraw from that space. My ability to be, rather than to do, is key here, when an activity is taking place, it is all too easy for me to slip into just doing, the way one might ride a bike without considering one’s movements or truly taking in one’s surroundings. Being requires a presentness of self: thought and affect, and is necessary for connecting with someone in this context. Once a space of being with has been established—meaning that a research encounter is possible—I invite questions relating to embodied identity, I also respond to invitations that stem from them, in this way we both influence the research we conduct together.

We are conscious that the interaction described here is an intimate one that might cause some readers discomfort (Melanie recalls that such responses were common in the early days of Intensive Interaction). Yet the embodied nature of ‘being with’ is integral to the belonging of people with intellectual disabilities in research. For Senen, connecting via her tongue was what made the connection meaningful; for others, it would be different and personal to them. Senen was assenting and engaging with apparent comfort.

4. Different Ways of ‘Being with’

By working through rapport building, communicating using Intensive Interaction techniques (Nind and Hewett 2005) and seeking to meet in an embodied fashion via the co-location of intention, Jo attempts to create a space in which a research encounter can happen. Once that space is created, research questions can be introduced and discovered. Jois focused on the substantive topic of embodied identity, and she brings objects into the research encounter to explore this, remaining alert to the location of her collaborators’ curiosity and joining with them in their exploration of what holds meaning for them.

Catherine is keenly aware of the deep connection between families and their child with profound intellectual and multiple disabilities from personal experience (de Haas et al. 2022). In her research, because parent and child experience so much of the world together, hearing from people with profound intellectual and multiple disabilities means hearing from parents, too. This goes beyond proxy reporting of experience; it is about exploring experiences of community as merged identities. (Such intercorporeality is also evident in Jo’s work.) Like Jo, Catherine will build upon some of the techniques and mindset of Intensive Interaction (Nind and Hewett 2005), using sensory and affective awareness, together with an openness to experience the world from the perspective of the person with profound intellectual disabilities, describing how physically close bodies connect, with one body becoming an extension of the other. This draws on the work of Lindemann (2010, 2014) and Skarsaune and Hanisch (2023), recognising that people with high support needs are held, both physically and in terms of having their identities held, and narrated in relation to places, time and rituals. Her research begins with conversations with families and other allies of people with profound intellectual disabilities to gain deep knowledge of a small group of people with profound intellectual disabilities. These conversations will bring together elements of the focus group method (Kreuger and Casey 2015; Krueger and King 1998; Nind et al. 2021), the coffee shop conversations of Collis (2021), the work of Critical Communicative Methodology (CCM: Puigvert et al. 2012) and the collaborative conversations of Sandra Hollingsworth (1992). Then, she will deepen her knowledge by working directly with one or two of these people with profound disabilities and their families to access their knowledge of how they experience their communities (the substantive topic). She will also be following Skarsaune (2023), who suggests that empathy is used to grasp the perspective of a person with profound intellectual disabilities.

Catherine will use small stories employing photographs and text to attempt to translate the nonverbal experience of people with profound intellectual disabilities into a narrative format. This is more acceptable to Western culture, which valorises the written word (Smith 2021). However, in creating small stories, Catherine and her collaborators aim to respectfully borrow (rather than raid) research tools from indigenous and folk cultures in the form of yarning (Byrne et al. 2021), carving and other art forms such as weaving and knitting (Gudjonsson 2022; Smith 2021; Vidal de Milla 2000; Yunkaporta 2019). Which artifacts they produce will depend on the interests, knowledge, and skills of those collaborating in the research and on what helps them to be simultaneously doing and providing information. This approach is about encompassing knowledge from the heart and the mind (Atkinson et al. 2021; Rieger et al. 2023) and sharing meaning and emotion in mutually beneficial ways, as in oral traditions (Byrne et al. 2021). The aim is that participants/collaborators will deepen their connections by having fun and supporting each other and that they will maintain and extend their communities by putting respectful, genuine and reciprocal relationships at their heart (Smith 2021).

5. Making Sense of the Direction of Travel

We (the authors) began our collaborative work on doing research *with* people with profound and intellectual learning disabilities by focusing on belonging, identity and community. Our starting point has always been that we work from the position that this group belongs in the inclusive research movement, and from here, we seek to discover what this means in practice. Our research conversations as a group of scholars have included appreciating the ways in which our direction of travel has strong parallels with decolonising research. The decolonising research turn (e.g., Smith 2012; Chilisa 2017) has highlighted the injustices of relying on one way of knowing at the expense of other equally valid but subjugated ways of knowing. Inherent to challenging the status quo has been bringing into action and legitimising such ways of knowing (Chilisa 2017). This, Chilisa (2017, p. 813) argues, means seeing indigenous people as ‘Authors of what they know and how it can be known’.

Research with people with profound intellectual and multiple disabilities is still at the stage of raising awareness about the validity of the ways in which people can know. It can be discomforting for Western researchers to consider unfamiliar ways of knowing, such as knowing with one’s ancestors alongside (Lavallée 2009; Liebert 2021) or in ways deeply connected with one’s relationship with the land (Smith 2012). Similarly, it can be disturbing to think about the embodied ways of knowing that we are exploring as a form of knowing that is felt first and thought afterwards can leave those confident in their command of intellectual knowledge feeling out of their depth in this less certain landscape. Decolonising work has questioned ‘methodological hegemony’ and its ‘tendency to perpetuate the dominance of one race over the ‘other’ by building a collection of theories, concepts, methods, techniques, and rules designed to promote only the knowledge that promoted and profited Eurocentrism’ (Chilisa 2017, p. 814, drawing on Chilisa 2012). As we have shown, understanding this dynamic has resonance for profoundly disabled people and for those of us who are allies seeking theories, concepts, methods and techniques that not just include them but that honour them and work against their oppression.

We appreciate that we can take the connections with decolonising research too far, but there is liberation in freeing ourselves from the anchor points of inclusive research that are most familiar to enable us to think afresh. Equally, going outside Western frames of reference has taken our journey towards different ontologies such as Ubuntu, a more inclusive, communal, social justice way of understanding the nature of being human (Chataika and McKenzie 2013; Chilisa 2017; Ifejika 2006; Yunkaporta 2019). We use the African philosophy of Ubuntu because we consider all people to be connected relationally to other people, and we challenge dominant Western notions of individualism (Baggini 2019; Chataika and McKenzie 2013) because they encompass an unhelpful ontology for profoundly disabled people. Yunkaporta (2019) also highlights the Aboriginal concept of Ngal, capturing how knowledge develops inter-relationally. All this helps us to feel comfortable in the non-individualistic 'we-ness' (Nyasini 2016, cited by Chilisa 2017, p. 820) or intersubjectivity necessarily inherent in doing research with people with profound intellectual disabilities.

Kittay (2019), in discussing disability yet in common with indigenous scholars, reminds us that independence is an illusion because everyone relies on interdependence to communicate competently. Skarsaune (2023, p. 8) suggests that by 'heightening the status of embodied communication and the reliance on feelings as an epistemic resource' we can enable people with profound intellectual disabilities to be the 'subjects' of research rather than the 'objects' of research. Our argument is that in this way, they can be part of inclusive research as knowledge producers, too. We are, in effect, seeking to decolonise research for people with profound intellectual disabilities. A key concern of this paper is our process of moving away from the 'I/You relationship' (Chilisa et al. 2017) and finding connected ways of researching and knowing that is put into a historical and global context.

6. Conclusions

We have attempted to deconstruct research with people with profound intellectual and multiple disabilities such that it begins with a deep connection with the people about whom and with whom it is created and proceeds from there, respecting multiple ways of knowing and being. In this paper, in the spirit of show not tell, we have demonstrated the possibility that we introduced in our first paper (de Haas et al. 2022, p. 8) that 'being with' (Forster 2020; Goodwin and Griffiths 2022; Macpherson et al. 2016), 'could be key to doing research inclusively'. By taking seriously the possibility of people with profound intellectual and multiple disabilities being active agents within research, we reject the commonly accepted assumption that research is an inherently intellectual pursuit and therefore only accessible to people in proportion to their presumed intellectual capacity. In working with people with profound intellectual and multiple disabilities, we are attempting to hear from people previously excluded from knowledge-making and considering knowledge outside predetermined acceptable sources. This incorporates using all our senses, our bodies and our capacity to hold and narrate stories for and with people who communicate without words. It echoes the widening of ways of doing research that come from indigenous and decolonising research.

We embrace the uncertainty of not/knowing and lean into felt embodied forms of meaning, finding these disorientating as anyone accustomed to the certainty of traditional forms of knowledge production would. However, we recognise any tremulousness as a part of the process, not a reason to turn back. Treading this path is difficult, but it is essential that researchers engage with researching with and alongside populations whose meaning has historically not been valued by dominant groups. This is not only to reduce vulnerability via inclusion but also because an account of human experience is incomplete until all humans belong within it.

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Article

Looking Back When Moving Forward: Researching Sites of Former Disability Institutions

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Abstract: This article discusses an inclusive research program where colleagues and co-researchers (with intellectual disability) guide and inform future research practice to ensure research is targeted to areas of significance and relevance to them. The research program is about sites of former disability institutions. Many people with intellectual disability in Australia were segregated and forced to live in disability institutions until deinstitutionalisation efforts became mainstream in the late 20th Century. We are a team of four people based in New South Wales, Australia. Our team includes disability advocates and researchers who have contributed to a program of research exploring connections between sites of former disability institutions and contemporary disability rights. In this article, we reflect on conversations about our research undertaken so far and where the research goes from here. We explore five pillars of action informing how research relating to disability institutions can progress: 1. Current use: research exploring erasure of experiences of institutionalisation communicated through educational resources and maps about current use of sites of former disability institutions; 2. Reparative planning processes: research developing frameworks for alternative approaches to planning and heritage processes supporting alternative uses of former sites of disability institutions; 3. Official recognition and redress: research exploring perspectives on governments formally recognising and remedying experiences of people with disability who were institutionalised; 4. Community-led repair and remembrance: research identifying practices for both celebrating advocates with disability and reckoning with and repairing familial and social bonds broken through institutionalisation; 5. Community-inclusive practices: research exploring endurance of institutional practices in disability accommodation in community settings. These five pillars are underpinned by three foundational layers: advancing disability human rights; reckoning with intersections between disability institutions and settler colonialism, other dynamics of oppression, and eugenics; and using inclusive practices.

Keywords: disability institutions; disability activism; disability history; human rights; redress; reparative planning

1. Plain Language Summary

- This article is about conversations between four researchers talking about a project called “Remembering Disability Institutions”.
- The team includes disability advocates and researchers who have worked in inclusive research and disability rights.
- People with intellectual disability are core team members in this research, deciding what is important and how we can learn from the past.
- People with disability in Australia and throughout the world were often forced to live in large residences called “disability institutions”. People with disability in institutions were separated from society and treated badly.

- Many disability institutions have closed, but the experiences of people with disability who lived in these places still matter.
- Since they have closed, many disability institutions have been redeveloped or sold. This often means their history is forgotten, and people cannot find out what happened there.
- The team talked about why these old disability institution sites matter to disability rights and inclusion today, and ways we can remember and share the stories of people with disability.
- The Five Important Areas: Our conversations together showed us there are five main ways to guide how we should think about and use these old sites. These are:
    1. Current Use: Understanding what these places are used for today, and making sure their history is not erased or forgotten.
    2. Future Planning: Making plans to use these old sites in ways that respect their history and the people who lived there.
    3. Official Apologies and Redress: Asking the government to recognise, apologise for, and repair the harm done to people with disability in disability institutions.
    4. Community-Led Repair and Remembrance: Helping families and communities remember the people who lived in disability institutions and celebrating advocates with disability.
    5. Inclusive Practices: Making sure the mistakes of the past are not repeated in today's disability accommodation and support.
- The team wants to make sure the public understands what happened in disability institutions so the same mistakes are not made again.
- The research calls on governments and communities to work together to recognise the history of these places and make things right for the people who lived there.
- In the next stage of our research, we will continue to make sure people with disability lead the way in remembering these places and shaping how we move forward with disability rights and an apology from government.

2. Introduction

This article discusses an inclusive research program incorporating activities of reflection and sensemaking, where colleagues and co-researchers (with intellectual disability) guide and inform future research practice to ensure research is targeted to areas of signifficance and relevance to them.

The research program discussed in this article is about sites of former disability institutions. Many people with intellectual disability in Australia were segregated and forced to live in large-scale residential settings ("disability institutions") until deinstitutionalisation efforts became mainstream in the late 20th Century. Many of these disability institutions have now closed. After sites close, they can be sold, redeveloped, or abandoned (Abbas and Voronka 2014; Moon et al. 2015). Researchers, advocates and activists are beginning to explore connections between afterlives of these sites and present-day disability social justice issues (Punzi and Steele 2024). We are a team of four people based in New South Wales, Australia, which includes disability advocates and researchers who have contributed to a program of research exploring connections between histories and experiences of sites of former disability institutions and contemporary disability rights. In this article, we reflect on conversations about our research undertaken so far and where the research goes from here.

Since 2020, authors Steele and Carnemolla have been working together in collaboration with the Council for Intellectual Disability (a New South Wales disability rights organisation led by people with intellectual disability) on a program of research projects taking former sites of disability institutions in New South Wales as their entry point into exploring connections between disability rights, urban planning, heritage, and redress. Research was undertaken by authors Steele, Carnemolla, and Kelly (with other colleagues), listening to people with intellectual disability about how they want disability institutions to be remembered (Steele et al. 2023). Parallel to that project, Steele and Carnemolla made submissions to government in collaboration with the Council for Intellectual Disability opposing redevelopment of a site of a former disability institution (Steele and Carnemolla 2021). The submissions were accompanied by an advocacy campaign involving an open letter and Easy Read resource (Council for Intellectual Disability n.d.a). Reflecting on this work, Carnemolla and Steele have also considered ways people with intellectual disability can play leading roles as agents of activism and change in how institutional heritage is interpreted and institutional history is communicated to wider communities (Carnemolla and Steele 2024). A central objective linking these outputs has been foregrounding the views of people with intellectual disability about what the public should know and remember about disability institutions, and exploring diverse official government and community-led pathways though which this can occur. Most recently, the four authors (Kelly, Creighton, Steele, and Carnemolla) collaborated on developing a framework for future research that builds on key findings from the earlier research.

Our collaboration has confirmed five pillars of action informing how research relating to sites of former disability institutions can progress: current use of sites of former disability institutions, reparative planning processes for sites of former disability institutions, official apologies and redress, community-led repair, and community-inclusive practices.

Whilst our research is closely focused on the Australian context of disability institutions, it has relevance internationally. Worldwide disability institutions are a common feature of disability history and—unfortunately in some nations—disability presents and futures. Deinstitutionalisation and redress for institutionalisation are increasing international human rights concerns and violence in disability institutions is a topic of government inquiries in some nations. Our article offers inclusive research approaches and critical framings and connections to understand sites of former disability institutions as integral to realising disability human rights through a diverse range of policies and practices including heritage, urban planning, access to justice, and disability supports.

The article begins with an overview of disability institutions and introduces scholarship and activism engaging with connections between afterlives of sites of former disability institutions and contemporary disability rights. We then discuss the significance of people with intellectual disability narrating their own experiences. Next, the article describes how we approached our collaboration through a series of reflective discussions. We then present results of our discussions about researching, remembering, and redressing. Finally, we discuss the implications of the results for research on former sites of disability institutions.

2.1. Disability Institutions: Closure, Erasure, Endurance. . . and Disruption

Despite ongoing impacts of institutionalisation on many people with intellectual disability and their families and communities, the Australian public knows little about disability institutions and the people who lived there. In this article, we use "disability institutions" to refer to large places and buildings where people with disability were congregated, detained, and segregated from the wider community. People with disability who lived in disability institutions were often subjected to violence, neglect, and forced labour (Goggin and Newell 2005; Hallahan 2021).

We write this paper at a time when most disability institutions in Australia have closed their doors, over fifty years since deinstitutionalisation started in Australia (Hallahan 2021). Within Australia and internationally, sites of former disability institutions are often redeveloped for other uses. Their new uses do not provide opportunities for public engagement with lived experiences, memories, and social histories of these places—too often, their past is erased (Abbas and Voronka 2014; Moon et al. 2015; Punzi and Steele 2024). This is exemplified by the New South Wales Government's application to rezone for tourism and recreational use the site of a former disability institution it operated for 99 years (Peat Island Residential Centre). The government's application failed to recognise the disability history of the site and people with disability were not specifically included in the rezoning application process (Carnemolla and Steele 2024).

Even though most disability institutions in Australia are now closed, their impacts on people with disability are ignored; and practices of segregation, coercion, discrimination, and neglect that shaped treatment within disability institutions endure in the community. These practices endure in laws, accommodation and service models, professional knowledge, and staff behaviour in the "deinstitutionalised" community (Spivakovsky et al. 2020). Australia's recent Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability ("Disability Royal Commission") highlighted widespread harm of people with disability in the community, including in disability accommodation settings (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability 2020, 2022, 2023).

Continuities in harm across institutional and community accommodation settings for people with disability indicate the oppressive nature of disability accommodation is attributable to a range of dynamics, rather than simply depending on the large size of the building and high number of occupants. Indeed, Disabled People's Organisations and the United Nations Committee on the Rights of Persons with Disabilities ("CRPD Committee") have argued disability institutions are not definable by a particular size or architectural form, but rather by institution-like characteristics such as lack of control over daily routine and shared supports (People First of Canada 2010; United Nations Committee on the Rights of Persons with Disabilities 2017, 2022). People First of Canada (the national Canadian national organisation for people who have been labelled with an intellectual or developmental disability) explains what it means to experience institutional life, even beyond the closure of disability institutions themselves: "An institution is any place in which people who have been labelled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and the day to." (People First of Canada 2010). Recently, self-advocates from Australia and Aotearoa New Zealand described their lived experiences of disability accommodation settings as having institution-like characteristics:

> *"Self-advocates said that they were concerned that small group homes and supported living services have replaced larger institutions, which have almost all closed.*
>
> *Self-advocates felt that many people with intellectual disabilities, including people who live in the community do not have any choice in the support that they receive or control about how they spend their time.*
>
> *Self-advocates spoke about how special schools, respite care, and sheltered workshops could also be described as institutions because people with intellectual disabilities do not have choice and control"* (Inclusion International 2021, pp. 29–30.)

Deinstitutionalisation is central to the CRPD Committee's interpretive guidance on what governments need to do to realise the human right to independent living and community inclusion (United Nations Committee on the Rights of Persons with Disabilities 2017, 2022). This guidance identifies as important governments providing access to remedies, redress, and reparations for disability institutionalisation, including apologies and truth-telling (United Nations Committee on the Rights of Persons with Disabilities 2022). These guidelines are silent, however, on the specific issue of the future of the sites of former disability institutions. This silence is significant because buildings and the natural landscapes these buildings sit within provide "a kind of testimony that goes beyond words" (Byrne 2019, p. 413) and are powerful in their capacity to be effective agents for remembering history from multiple perspectives (Byrne 2019; Lloyd and Steele 2022).

The silence on sites of former disability institutions within the CRPD Committee's interpretive guidance can be filled with emerging research and activism exploring relationships between these sites and present-day disability social justice issues. Disability rights activists have resisted subsequent uses of sites of former disability institutions that erase lived experiences and social history. For example, using the slogan "Disability Rights Not Christmas Lights", disability rights activists in Massachusetts (USA) staged protests and led an online petition against use of the site of the former Walter E. Fernald Developmental Center for Christmas lights show: "Today, in its ruins, the City of Waltham is allowing the Lions Club to host a month-long holiday light show fundraiser that will erase disability rights and replace them with Christmas lights" (Action Network 2021; see also Green 2024). The Council for Intellectual Disability in New South Wales (Australia) ran a campaign (in which authors Steele and Carnemolla were involved) consisting of an open letter and submission opposing tourist and recreational rezoning of the former site of the disability institution, the Peat Island Residential Centre (Council for Intellectual Disability n.d.b; Steele and Carnemolla 2021). People with lived experience of disability institutions have proposed re-engaging with sites of former disability institutions in various ways to re-claim space, narratives, and humanity. Specific examples related to psychiatric institutions include creative performance and history tours recognising people's labour at the Toronto Asylum Wall, Canada (Reaume 2024) and an onsite café for informal social meetings over a cup of coffee on the grounds of the former psychiatric hospital, Lillhagen hospital, in Gothenburg, Sweden (Lindbom and Punzi 2024). Scholars propose that place-based memory practices, also called "sites of conscience", can be used to connect memories and histories of disability institutions to contemporary disability rights issues (Punzi 2022; Steele 2022; Steele and Punzi 2024). These examples of activism and research suggest that strategies directed towards increasing public awareness about disability institutions and experiences of people with disability who lived in these institutions might advance the rights of people with disability, including by bringing about changes to community attitudes, policy, and service delivery, and might also be a means for redressing some of the injustices of institutionalisation.

2.2. Personal Storytelling and Activism

Authors Steele, Carnemolla, and Kelly found through their empirical research that people with intellectual disability want the public to learn about and remember disability institutions. Learning and remembering should include recognising harmful dimensions and celebrating resistance and activism. These authors also found people with intellectual disability must be leaders in shaping both narratives of these sites' pasts and the physical futures of these sites (Carnemolla and Steele 2024; Kelly et al. 2023; Steele et al. 2023). This research resonates with the strong focus on centring lived experiences and voices of people with disability in disability history (Rembis et al. 2018). For example, the UK Social History of Learning Disability group developed practices and methods for historical research led by people with intellectual disability (Atkinson and Walmsley 2010). The Donald Beasley Institute in Aotearoa New Zealand gathered life stories of people with intellectual disability and people who are neurodivergent who had lived in institutions. These stories were reported to a public hearing of the Abuse in Care—Royal Commission of Inquiry (Stace 2022, p. 163).

People with intellectual disability remain excluded from discussions and decisions about sites of former disability institutions. Discriminatory assumptions about incapacity associated with people with intellectual disability have meant they have not been considered capable of authoring their own histories (Green 2024). Moreover, people with intellectual disability are rarely consulted on matters relating to their local communities (Carnemolla et al. 2021; Robinson et al. 2022). Similarly, people with intellectual disability have historically not been invited to lead or even contribute to discussions on deinstitutionalisation (Steele et al. 2023).

However, people with intellectual disability have authored their own accounts of institutionalisation and post-institutional life, including their resistance and advocacy. Kim Walker narrates her life story in "*Forgotten and Found: My Life Story*" (Walker 2015), a journey from childhood institutionalisation to becoming a leading Australian disability rights advocate and reconnecting with her family. The short film "*Stockton a Time of Change*", narrated and presented by Leigh Creighton (Community Disability Alliance Hunter 2016), involves interviews with people with intellectual disability—including Rob—as they were leaving Stockton Residential Centre. "*King of my Castle: Rob's Story*" by Hunter Circles narrates Rob's experiences living in the community (Hunter Circles 2022). International examples include the late Robert Martin's memoir (McRae 2014). Robert Martin was a New

Zealand disability rights advocate and the first member with intellectual disability of the CRPD Committee.

These examples of personal accounts are extremely important to understanding both institutional legacies and enduring impacts on people's lives, and pathways from disability institutions. Authors Steele, Carnemolla, and Kelly's foundational research discussed earlier in this section provides evidence that people with intellectual disability want their stories to be told. The research also indicates young people with disability who may not have had experience of disability institutions themselves recognise the importance of hearing the stories of being in disability institutions and learning about the activism of older generations of people with intellectual disability who paved the way for institutional closures and recognition of disability rights (Steele et al. 2023).

3. Our Way of Working Together

This article documents a series of conversations we held as a team reflecting on future stages of our research program on Remembering Disability Institutions and related knowledge-sharing activities. The conversations we document are a form of collaborative reflection focusing on the perspectives of team members with intellectual disability who are co-authors, co-researchers, and self-advocates.

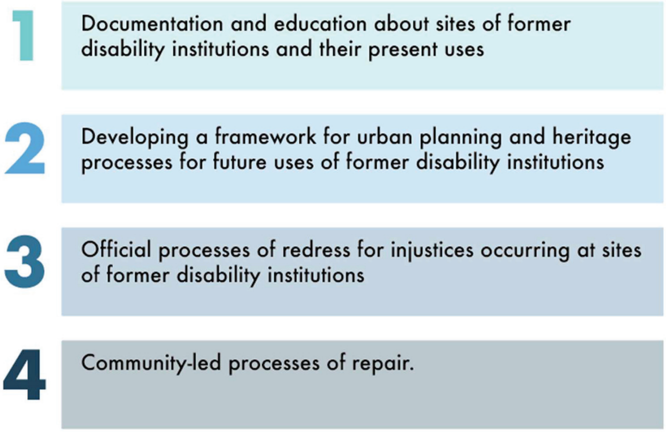
3.1. Research That Led Us to Our Conversations

The first stage of research involved authors Steele, Carnemolla, and Kelly, with a larger team of researchers, speaking to people with intellectual disability about disability institutions (Steele et al. 2023). This research project was approved by the University of Technology Sydney Human Research Ethics Committee ETH20-4755. People with intellectual disability told us the public should remember and learn about disability institutions. This was considered an important foundation for recognising what happened in disability institutions, celebrating self-advocacy, stopping further injustices against people with disability, and improving recognition of people with disability's human rights and their access to appropriate supports and participation in their local communities. Importantly, remembering the *past* of disability institutions was seen as important to *present and future* human rights recognition.

In this first stage of research, we spoke to people in New South Wales, Australia. We did not speak with people with intellectual disability who had lived in disability institutions. There are several reasons why. Some people do not want to speak about their experiences in disability institutions. Many people who lived in disability institutions may have moved away, whereas others have since died, making it very difficult to find people with lived experience in disability institutions. However, we did speak to people who identified their experiences as aligning with features of disability institutions, such as having been incarcerated in prison, studying in segregated schooling, and living in a group home. An Easy Read version of our results has been published by the Council for Intellectual Disability (n.d.a) and published in research outputs (Carnemolla and Steele 2024; Steele et al. 2023).

One finding of the research project was the importance of intergenerational learning between older and more experienced advocates, and younger people with disability. This finding provided the basis for a successful funding application by the Council for Intellectual Disability in collaboration with co-authors Carnemolla and Steele to the New South Wales Government's Disability Advocacy Futures Program. The funding is supporting a project during 2023 and 2024 identifying key lessons from disability self-advocacy in relation to deinstitutionalisation and community inclusion (University of Technology Sydney Human Research Ethics Approval ETH24-9330). The project involves focus groups with a range of self-advocates across generations, ages, and levels of experiences. Rather than focusing on experiences of disability institutions themselves, the project focuses on knowledge exchange and capacity building, and celebrating successes of self-advocacy. The project will produce two videos sharing key lessons, an Easy Read summary for self-advocates and other people with intellectual disability, and a learning resource for government and broader community to facilitate their engagement with this important history and body of knowledge.

Parallel to development of the intergenerational self-advocacy project, authors Carnemolla and Steele were interested in developing a broader program of research in collaboration with the Council for Intellectual Disability, taking forward the various threads in the findings. They had identified four areas arising from the findings of the first stage of research. These four areas take sites of former disability institutions as a lens through which to explore contemporary disability rights and inclusion. These are illustrated in the Figure 1 below:



1 Documentation and education about sites of former disability institutions and their present uses

2 Developing a framework for urban planning and heritage processes for future uses of former disability institutions

3 Official processes of redress for injustices occurring at sites of former disability institutions

4 Community-led processes of repair.

Figure 1. Four areas of interest to explore in our conversations.

We were also interested in how to situate this work in connections with First Nations people with disability, First Nations' connection to Country, and Australia's settler colonial context. These are vital dynamics of Australia's disability history, present and future (Avery 2018) we had not been able to explore in depth in our earlier work.

The program of research was timely and even urgent. Closures of remaining disability institutions in New South Wales meant the future use and processes related to sites of former disability institutions was time-sensitive. The final recommendations of the Disability Royal Commission overlooked systematic redress for people with disability who have experienced violence, abuse, neglect, and exploitation, including in the context of disability institutions. Author Kelly was particularly concerned about progressing advocacy towards a national apology (Kelly et al. 2023). Author Creighton has been a leader in the Hunter region of NSW in advocating for community inclusion for people moving out of disability institutions, including the Stockton Centre (Community Disability Alliance Hunter 2016), and our research coincides with a period of uncertainty about the future use of the site of the former Stockton Centre.

As part of continuing to develop our research program, the team (co-authors) came together in a series of reflexive and sensemaking activities. These conversations were an important step to consolidate the research undertaken to date and listen to members of the team who are also self-advocates and people with intellectual disability about how to progress activities arising from this research and guide further research projects.

From the first project, we learned people with intellectual disability agreed on the importance of sharing institutional histories more widely throughout our communities—in schools, with disability support staff and organisations, and with young people with disability. However, we did not explore in detail what content should be shared or how. We also did not explore what an apology or redress might involve. While our first project established importance of education directed towards people with intellectual disability (additional to the broader community), we did not identify principles or practices that could guide accessible and inclusive learning. Thus, we needed to further develop our future research in terms of key research questions and topics, and research outputs and outcomes. Our conversations documented in this paper are designed to inform these next steps.

3.2. Our Reflexive Approach

Underpinning this research program, and our work together in this article, is the principle that research investigating and affecting the lives of people with disability must be inclusive at all stages and shaped by input from people with disability. In line with this principle, this article contributes to the knowledgebase on inclusive research by reflecting on and documenting our processes that sit behind the substantive findings of our research project. We are reflecting on our practice together and documenting activities driving the direction of new research. Through this we are sharing how inclusive research encapsulates collectively exploring, scoping, and deciding upon what is important to remember from research already undertaken, and what research to embark upon next. Thus, we show how inclusive research is not limited to involving people with intellectual disability as research participants or co-researchers in data-collection activities such as interviews or focus groups. Reflexive approaches have been applied in many inclusive research projects to incorporate and document personal experience. For example, Carnemolla et al. (2022) reflected as a team of diverse researchers as a way of sharing what they learnt through their experiences working together. Other papers have documented or reflected on their inclusive research approaches and processes using autoethnographic writing (Milner and Frawley 2019; Schwartz et al. 2020; Schwartz and Durkin 2020). Experiences of individual researchers with intellectual disability have also been documented (White and Morgan 2012), and the process of building inclusive teams has been explored (Strnadová et al. 2014).

As a team, we could see value in finding a way to fund the conversations after the completion of the funding period for one stage of our Remembering Disability Institutions research and before the start of funding for a new stage of that research. In previous research, this “in between project” time has manifested as a funding gap (Carnemolla et al. 2022), particularly in terms of paying for labour related to developing new projects and preparing knowledge translation and research presentations of project findings of completed projects. However, for this program of research we were funded by the University of Technology Sydney Disability Access and Inclusion Fund to work in this “gap” to build the direction of the next stages of research, also providing the basis for funding applications for further specific projects. These conversations ensured all team members were recompensed for their time, and we had a process of extending and continuing the team knowledge, experience, and collaboration. These funds meant conversations could be held to support progression of our research program in ways meaningful for our experienced co-researchers, as well as people with intellectual disability more broadly. Funds also covered costs related to presenting at the 2023 Australasian Society for Intellectual Disability on the first stage of the project (by Carnemolla and Kelly) and emerging ideas related to the reflective discussions (by Steele and Creighton).

Reflections in this paper were captured between August 2023 and January 2024 as a series of group discussions in person and online between the co-authors. Jack Kelly and Leigh Creighton reflected on the four areas of further research identified above in Figure 1, drawing on their perspectives as people with intellectual disability and self-advocates, and their involvement in the first stage of the project. In the following discussion, we use initials to refer to our team members to attribute specific contributions to the discussions. First, we describe each team member and the ways each has worked on the program of research being discussed.

Jack Kelly (JK) is an Honorary Research Fellow of University of Technology Sydney and a disability advocate with lived experience of disability. JK has been involved in the program of research for 2 years. He was involved in sensemaking of empirical findings in the first stage of research, and then as a co-author on a research output related to that project (Steele et al. 2023). At the time of writing, JK is an inclusive research co-researcher, a self-advocate, and a project worker for the disability advocacy organisation, the Council for Intellectual Disability.

Leigh Creighton (LC) is a long-term advocate for the closure of disability institutions in New South Wales, Australia (Community Disability Alliance Hunter 2016). LC was involved as a research participant in the first stage of research. LC consults to the Council for Intellectual Disability and is passionate about sharing his experience as a person living with Down syndrome.

Phillippa Carnemolla (PC) is employed by University of Technology Sydney as an academic in the Faculty of Design Architecture and Building. PC has worked on inclusive research projects in partnership with the Council for Intellectual Disability since 2018 and joined with LS's initial application related to the Remembering Disability Institutions research, along with Leanne Dowse, Council for Intellectual Disability and People with Disability Australia.

Linda Steele (LS) is employed by University of Technology Sydney as an academic in the Faculty of Law. She was previously a lawyer at the Intellectual Disability Rights Service and now serves on its board. LS initially applied for funding to undertake the first stage of the Remembering Disability Institutions research following an earlier project on sites of conscience in the context of child welfare institutions in collaboration with the Parramatta Female Factory Precinct Memory Project (Steele et al. 2020).

Group discussions (between PC, LC, LS, and JK) were intended to explore JK and LC's perspectives as advocates and researchers on the four areas identified from findings of the first stage of research (see Figure 1), in order to shape future direction of the research program. Perspectives were specifically sought on research outcomes and what outputs should be focused on and who these should be for. For each discussion, PC and LS framed a list of open questions designed to explore JK and LC's perspectives on important next steps. Notes were taken at each discussion, and questions asked were framed around:

How should we progress our research and who should be involved as researchers and research participants?

In what ways should we share our research findings? What types of research outputs should we design and how?

The questions related to three themes—overarching aspects of research practice, research areas related to current and future uses of sites of former disability institution, and official and community-led redress for institutionalisation.

4. Reflections

In this section, we present the contributions of JK and LC to the conversations. Here we document responses to questions posed in Table 1.

Table 1. Semi-structured questions used to guide our conversations.

Discussion Topic	Sample Questions
Research Method, Outcomes, Outputs	What is important for us to learn more about through our disability institutions research? How should we involve people who have lived in disability institutions in our research? Who should we work with? And why? What are your thoughts on disability accommodation given our research findings linked these settings to institutional experiences?
Remembering (existing and future uses of sites)	What should we prioritise in our research on ways to remember people who lived in disability institutions who have died? Maps: Discuss the value of a map of former disability institutions, who is it for, what is included, where should it be displayed? Books/Stories/Education: Discuss thoughts on sharing more stories about disability institutions from the perspectives of people with intellectual disability.
Redress (official and community redress)	What should we prioritise in our research on what government should do for people who lived in disability institutions? Should we explore how people who lived in disability institutions can have a say in what the government does?

4.1. Researching

Ensuring people with intellectual disability are engaged in future research and decision-making related to the Remembering Disability Institutions research was of the utmost importance in the conversations.

In reflecting on what is important for us to learn more about with our disability institutions research, JK wanted to share information about what happened in institutions. This information should include stories from people with intellectual disability who lived there. JK also wanted people with disability to have a say about what happens to disability institutions that still need to close.

In reflecting on how we involve people who have lived in disability institutions in our research, JK advised we need to connect with people with intellectual disability from around Australia working towards an apology. In further research, we can talk to more people with intellectual disability who live in disability institutions. We should ask them what they want people to know about the institutions.

In our first research project, group homes and prisons were also identified by research participants as types of institutions (Steele et al. 2023). For this reason, it was important for us as a team to consider how former disability institutions may link to people with disability's current experiences of disability support, incarceration, community participation and living arrangements. JK and LC had strong and clear views on this, seeing exploration of this connection between former disability institutions and contemporary disability accommodation as vital to ensuring research on the past can shape current living conditions. Emerging from these conversations is recognition that remembering and learning about disability institutions and understanding links between historical narratives and current structures is important for repairing past wrongs and reshaping government and societal understanding of truly inclusive places and practices.

Drawing on his experiences as a leading self-advocate and peer supporter in the Hunter region who has been involved in supporting people transitioning out of the Stockton Centre into disability accommodation, LC said the government apology for disability institutions must include people living in group homes. LC referred to group homes as mini-institutions. Some group homes have security fences. Some people who live in group homes cannot get out and spend time with friends. Some people who live in group homes are being bullied and abused. LC emphatically stated people living in group homes might have a disability, but they are people first.

In contrast, JK reflected on the connection between former disability institutions and the Australian National Disability Insurance Scheme (NDIS)-funded disability support and accommodation. The NDIS is Australia's national funding scheme that provides funds for people with disability. Funds may include accommodation, supports, and services, and are allocated based on assessments of eligibility and individual need (NDIS n.d.). JK highlighted the importance of choice in living arrangements as being an ongoing issue for people with disability, even under the National Disability Insurance Scheme. JK reinforced the need for better quality and safeguard systems in place to prevent providers from making housing decisions based on financial viability of models linked to disability support type, not considering the compatibility of housemates, or not prioritising the living arrangement preferences of the people with disability to whom they provide support.

4.2. Remembering

As a team, we reflected on how we communicate the histories of disability institutions. It was agreed there were two main ways of sharing knowledge with wider communities. One way is using maps and timelines to communicate information about buildings and sites to provide place-based disability history. The second way is by sharing stories of people who lived in disability institutions.

In the conversations, we discussed how mapping former sites of disability institutions could be a useful way to give visibility to the prevalence of disability institutions in particular locations, given many are no longer physically apparent because they have been closed and reused. Mapping was proposed by PC and LS in light of other projects around the world (Cultural Heritage Online n.d.; Reparations Task Force 2023; Justice for Magdalenes Research 2017; Palomba 2020; Carnemolla et al. 2023), and broader approaches to radical cartography. PC and LS were particularly interested in how mapping could communicate lived experiences and how maps could be made accessible (Carnemolla et al. 2023).

Design and sharing of an Australian map of all former disability institutions was discussed in detail to explore what types of institutions should be included on such maps; what information could be shared on a map and why; where such a map is displayed or accessed (e.g., online or in a book); what area the map covers; how the map is designed and who contributes to it; and who the main audience is for a map (including if it is for people with intellectual disability).

JK and LC agreed any mapping process should be available to the public. The idea of the map published as a book was also discussed, with a clear position that books play an important role for specific audiences, and the map should be available to wider audiences and be able to be updated. For example, JK reflected that a public version of a map should not be in a book, because it will get stuck on a shelf somewhere. The map could be online so it can be edited and updated as more information about disability institutions is discovered. LC advised the map could have photos and images about when each disability institution opened and when it closed. He also suggested a similar map of disability segregated schools.

We considered the audience of a map of former disability institutions and how that would inform the way we communicated information. JK suggested two versions—one for researchers such as PC and LS who want detail, and one for people such as JK and LC who want something more useful and beautiful. LC agreed on two versions, including with a version in Easy Read that could be downloadable and printed at home.

We also considered thinking beyond a printed map. We explored the idea of a map as an installation. We all agreed this would be a unique opportunity to engage with the wider community in a museum or gallery. LS discussed the floor map in the District Six Museum in South Africa, where former residents of the racially segregated District Six and their families could add information to the map. LC and JK supported a similar approach with a floor map of institutions at the front door of the museum, which could be made by people with disability.

A sensitive approach to information was a key concern in our discussions. Throughout our conversations, JK and LC were very clear that each act of knowledge sharing about disability institutions comes with great sensitivity. LC acknowledged some people would not like to read this information and some people would. JK noted we would have to make sure information on a website is respectful and knowledgeable and is not too graphic and would not open old wounds for people with intellectual disability. On the other hand, JK noted knowledge sharing involved a fine line because we would not want to shy away from what has happened in disability institutions. Similarly, LC was of the view he did not want knowledge sharing to require people who lived in disability institutions to open old wounds associated with their experiences. He emphasised it is important to remember people keep on having nightmares about when they lived in disability institutions. If we talk with them about disability institutions, they could get upset and think about suicide. People who do not communicate through words might have difficulty expressing their feelings. Ultimately, LC concluded talking about disability institutions might be hard, but it is important we talk about them and hear stories of people who experienced them.

4.3. Redressing

We focused part of our conversations around the role and actions of governments in recognising the histories (both individual and collective) of disability institutions. This was particularly important given governments' roles in funding and operating disability institutions, and making laws and policies about disability institutions. Here, we reflect on our opinions about redress, apology, and who should be remembered.

The clear message arising from these conversations is governments should be involved in redress, including apologising and providing compensation to people with disability who lived in disability institutions. JK felt strongly about the need for a government apology. JK explained Australia cannot make the disability system better until past harms are acknowledged and accepted, and sorry is said for what happened in the past to people who were forced to live in disability institutions. JK talked about an apology being a clear and public acknowledgement that past ways of treating and institutionalising people with disability were wrong; it is an important starting point for change and is relevant today, even many years after disability institutions have closed.

LC emphasised governments should give a public apology to all people who have been in disability institutions. Apology was necessary because people were locked away and their lives destroyed. They screamed to get out, but their screaming was seen as a behavioural problem, and no one helped them. LC was also of the view governments should also give compensation to people who lived in disability institutions who are still alive. They need compensation because their lives were taken away from them. They missed out being in the community. They had their independence taken away. They missed doing things everyone else does. LC proposed we must also remember the people who lived in institutions who have died in order to acknowledge what they contributed during their lives. LC drew on his personal experiences of having a cousin who lived in the Stockton Centre and passed away.

LC reflected on whether people who lived in disability institutions have a say in what governments do with former sites. He advised they must help decide how disability institutions are remembered because they have lived experience of disability institutions.

5. Discussion

We had the opportunity to create a space for conversation about, and reflection on, our disability institutions research. Through our conversations, we considered some difficult questions about why this is a sensitive research topic, and how we progress this important body of community-led work. Our discussion confirmed the necessity of a trauma-informed approach and being careful about the content we share, the way research is conducted, and the audiences we seek to engage with and guide.

Together we shared information and exchanged ideas to shape our future work together and how we share this knowledge with the wider community, including:

- Importance of continued efforts towards a formal apology by government to people who were forced to live in disability institutions.
- Ongoing trauma-informed approaches—the sensitivity of the information and the need to carefully consider audiences of future knowledge-sharing.
- Ongoing relevance of institutional practices now, in relation to disability support and disability accommodation.
- Creation of new ways to communicate institutional histories, such as maps or books, must be engaging and meaningful for people with disability, and be available in relevant formats to researchers, government, and wider communities (of all ages, and both disabled and non-disabled).
- People with intellectual disability are end-users of research, and thus research outputs should always be designed with their needs in mind.

Our reflexive discussions provided nuance and depth to the four areas of research that emerged from the first stage of the Remembering Disability Institutions research. During our discussions, we used a visual representation of the four areas of research that emerged from our research—this was drawn by LS and used as a visual reference during our conversations. As a result of our discussions, we revised our four areas into five areas, with co-author PC drawing a new diagram. A key addition was a fifth area on community-inclusive practice to capture the significance of using disability institution experiences and histories to transform practices in current disability accommodation settings and wider communities. This addition was confirmed with JK and LC and is illustrated in Figure 2 below. This forms five action pillars, which provide our planned research path to continue our inclusive research program about looking back when moving forward from disability institutions.

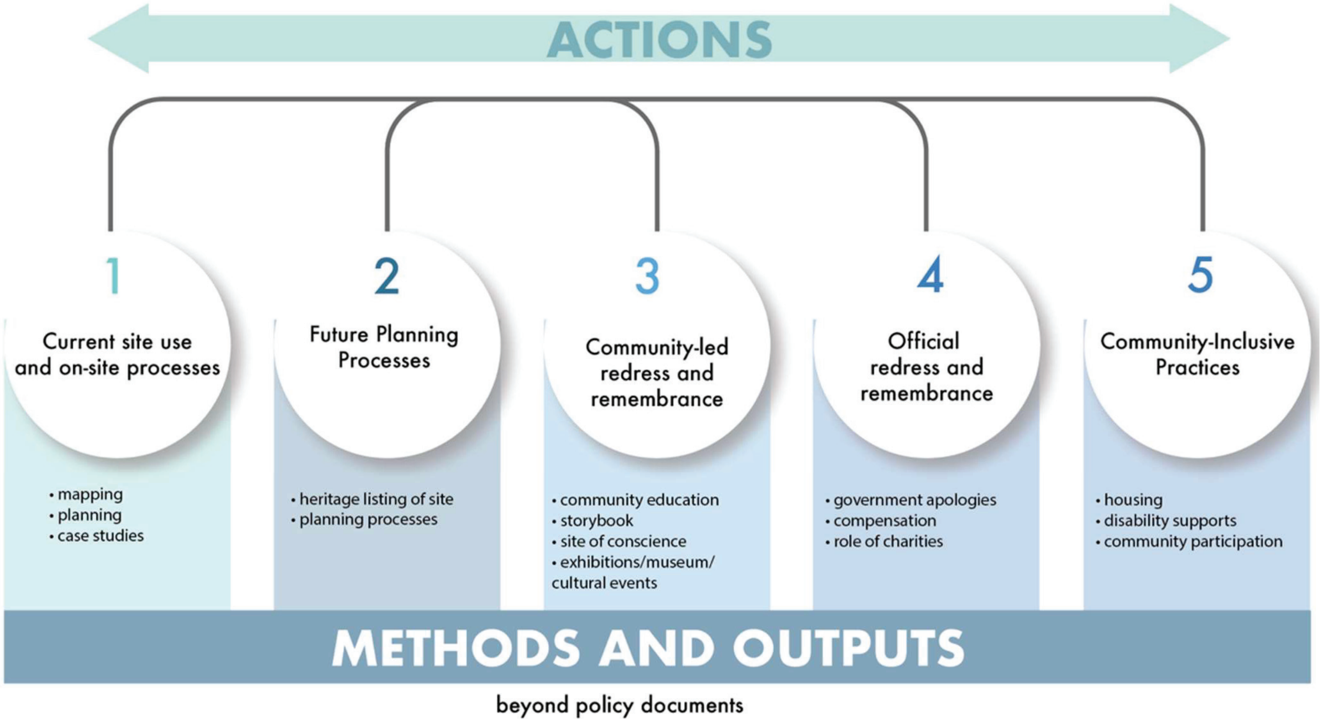


Figure 2. The five action pillars related to remembering and repairing based on reflexive discussions about disability institutions.

The five action pillars are:

1. Current use: research exploring the erasure of experiences of institutionalisation communicated through educational resources and maps about the current use of sites of former disability institutions;
2. Reparative planning processes: research developing frameworks for alternative approaches to planning and heritage processes supporting alternative uses of former sites of disability institutions;
3. Official recognition and redress: research exploring perspectives on governments formally recognising and remedying experiences of people with disability who were institutionalised;
4. Community-led repair and remembrance: research identifying practices for both celebrating advocates with disability, and reckoning with and repairing familial and social bonds broken through institutionalisation;
5. Community-inclusive practices: research exploring endurance of institutional practices in disability accommodation located in community settings.

These five pillars are underpinned by three foundational layers: advancing disability human rights; reckoning with intersections between disability institutions and settler colonialism, other dynamics of oppression, and eugenics; and using inclusive practices.

Our discussions as a team also highlighted research having concrete outcomes in the present-day lives of people with intellectual disability. For PC and LS, this underscores the importance of accountability in research to people with intellectual disability and ensuring research is always directed towards change (Veitch and Rinaldi 2024). Prioritising concrete outcomes gives rise to an additional way of structuring our program of research around three interconnected outcomes driving research—remembering, repairing, and reshaping illustrated in Figure 3 below.

Figure 3. Research outcomes based on the reflexive discussions.

6. Conclusions

This paper highlighted reflexive and sensemaking activities arising from a diverse research team working on inclusive research with people with intellectual disability. More specifically, these activities centre on team discussion to guide the future of our research program of Remembering Disability Institutions (Carnemolla and Steele 2024; Steele et al. 2023; Kelly et al. 2023). This paper discusses the perspectives of researchers (and co-authors) JK and LC, who are also disability advocates, on what are important aspects of ways forward in our research and community knowledge sharing.

Together, the co-authors reflected on the research that they had undertaken so far, and LS and PC asked JK and LC what was important to them as we discussed together the next steps and, as disability advocates, how they thought knowledge from the research we collaborated on should be shared beyond this project. Of primary importance is that conversations such as these will ensure investment in research is targeted to areas of significance and relevance to PC and LS's colleagues and co-researchers' lived experiences and extensive expertise in disability advocacy on institutionalisation. This reflection contributes to the development of ideas, as well as shapes the direction of future funding applications and research projects. It is important for us as a team to progress the research responsibly, and this approach is one way we build in accountability to the community to which our research relates.

As we work toward the next phase of our program of research, PC and LS are beginning to engage with communities connected to specific sites of former disability institutions across Australia. JK, PC and LS are building connections with researchers and self-advocates overseas. We are also, as a team, working alongside advocacy organisations to hold conversations with local government members, State government members, and government property managers. We are focused on using our research to help guide these leaders and departments on ways to ensure processes to determine the future uses of former sites of disability institutions engage with and are led by people with disability themselves. The conversations documented in this paper are significant in locating future work together in a disability-led reparative framework. This framework moves forward from disability institutions in a way that properly recognises the experiences and expertise of people with intellectual disability and positions them as best-placed to lead our communities towards a future where disability institutions and their practices are not replicated. While focused on the Australian context, our research provides inclusive research approaches and critical framings and connections to re-imagine the afterlives of disability institutions in other countries and show how research can contribute in new ways to global efforts to realise the human right to independent living and community inclusion.

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editing, L.S.; Funding acquisition, P.C. and L.S. All authors have read and agreed to the published version of the manuscript.

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Article

Cooperation with Persons with Intellectual Disabilities: Reflections of Co-Researchers Associated with Conducting Inclusive Research

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Abstract: Traditionally, persons with intellectual disabilities in Poland have been researched on and treated as not competent enough to research with. Despite its scientific merit and practical usefulness, inclusive research involving persons with intellectual disabilities as co-researchers has only recently become a subject of interest in this country. The added value of inclusive projects should be analysed from two standpoints, i.e., those of co-researchers with disabilities and co-researchers without disabilities. In this article, we discuss the latter perspective, focusing on Polish researchers without disabilities who have experience in conducting inclusive research with persons with intellectual disabilities. The key aspect of the analyses was to highlight the potential of persons with intellectual disabilities as co-researchers. As a result, we have determined several important aspects of inclusive research in the relational perspective involving co-researchers with intellectual disabilities and co-researchers without intellectual disabilities and the community perspective. The analyses identified four superordinate themes: building relationships in the research team; opportunities and constraints associated with the implementation of inclusive projects; institutional barriers; and the importance of the role of a co-researcher without intellectual disabilities. Implications for further research and practice are discussed.

Keywords: inclusive research; intellectual disability; co-researchers; empowerment

1. Introduction

1.1. Evolution of Inclusive Research

Scientific research should allow for the diversity of a society with respect to its social and cultural characteristics. This means taking into account the perspectives of groups that qualify as diverse not only in terms of age, gender, colour, ethnicity, or cultural and social backgrounds but also in view of different abilities. Intellectual disability is an important but often ignored facet of diversity (Hart et al. 2020). Traditionally, persons with intellectual disabilities have been the subject of research from the perspective of parents, social and support workers, teachers, psychologists, and other professionals (Adderley et al. 2015). Recent years have seen a shift in this approach, reflecting a substantial interest in inclusive research involving persons with intellectual disabilities (Bigby et al. 2014).

The change in the research perspective towards recognising the importance of self-report exploration, which, to some extent, can be associated with the tendencies of emancipation, self-determination, and normalisation, is not free from many methodological and ethical challenges. Even though it is declaratively recognised in scholarly discourse that persons with intellectual disabilities are full-fledged members of society, they are still treated in practice as passive recipients of knowledge, care, and power imposed by people without disabilities. Adopting the perspective of a human rights-based model of disability means not only acknowledging the agential potential of persons with intellectual disabilities and their expertise in the field of their everyday experience but also embracing the ethical imperative to conduct research in a manner which situates the reflections and experiences of that group in the centre, as opposed to privileging the knowledge of the researcher.

1.2. Benefits and Challenges of Inclusive Research

Inclusive research may be an answer to the social exclusion experienced by such individuals and the lack of their full participation in different spheres of life (Kramer et al. 2011). It has been noted that this type of research enables persons with intellectual disabilities to be empowered, to step out of the role of research subjects, and to assume the valued social roles of leaders and research experts (Walmsley 2001; Lloyd et al. 2019; Aubrecht et al. 2021). By being both research participants and co-researchers, persons with intellectual disabilities feel valued and included, experience equality, and improve their self-esteem. They also have the opportunity to take on new challenges, learn new things, and demonstrate their skills (McDonald et al. 2016). This changes the nature of the relationship between researchers without disabilities and persons with intellectual disabilities. They become more democratic, relying on respect and partnership (Lloyd et al. 2019).

There is abundant literature demonstrating the added value of inclusive research projects (Björnsdóttir and Svensdóttir 2008; Bigby et al. 2014; Armstrong et al. 2019). Inclusive research involving persons with intellectual disabilities not only offers better insights into the experiences and opinions of those with intellectual disabilities but also fosters a positive image of persons with intellectual disabilities (McDonald et al. 2016), thus contributing to social change (Rojas-Pernia et al. 2020) and helping to build a society in which groups identified as excluded begin to function as its integral parts (Walmsley et al. 2018). One of the foremost benefits of inclusive research is that it has a significant impact on improving the quality of life of persons with intellectual disabilities (Nind and Vinha 2012; Walmsley et al. 2018).

Inclusive research also entails challenges. One should consider the risk of exploitation and manipulation of persons with intellectual disabilities in research, which might result from their vulnerability and powerless position in these particular circumstances (Juritzen et al. 2011; McDonald et al. 2017). Therefore, co-researchers without disabilities should accept responsibility for safeguarding the rights of participants and co-researchers with intellectual disabilities so that they may exercise autonomy and enjoy freedom from harm (Northway 2014). The fact that the research subject has little relevance for the lives of persons with such disabilities may also be a problem. Indeed, a premise which is often underscored in inclusive research is recognising that it should make a positive contribution to the image or life of persons with intellectual disabilities (cf. Nind and Vinha 2012; McDonald et al. 2016).

1.3. Different Approaches to Inclusive Research

With regard to the organisation of inclusive research, it is a crucial requirement to ensure that the research, as well as the tools and the material used, match the capabilities of persons with intellectual disabilities (Nind and Vinha 2012). Finding ways to empower vulnerable populations (Moll et al. 2020) and put persons with intellectual disabilities in control (Walmsley 2001) may be another major difficulty. It is underlined in the literature that the key principles and practice of co-design, as well as the extent of inclusion of people identified as disadvantaged (Moll et al. 2020), still lack clarity. Over the years, several approaches to inclusive research have developed (see Swain 1995; Bigby et al. 2014). Bigby et al. (2014) distinguish three basic modalities: advisory, leading and controlling, and collaborative group, which are characterised by varying degrees of participation of persons with disabilities, including intellectual disabilities. The collaborative group approach offers the highest level of participation.

1.4. Organisational Requirements and Strategies for Inclusion

To be truly inclusive, research should meet certain criteria. Walmsley and Johnson (2003, p. 64) suggest the following five principles: (1) the research problem, although it may be initiated by co-researchers without disabilities, should be formulated by co-researchers with disabilities; (2) the research should further the interests of co-researchers with intellectual disabilities; (3) people with intellectual disabilities should be involved in the research process and (4) have some control over it; and (5) the research questions, research process, and research reports should be accessible to people with intellectual disabilities.

The diverse strategies which facilitate thorough inclusion of co-researchers with disabilities include nurturing positive relationships (even before a person enrols in the project), acknowledging that they are experts by experience, allowing them to work at their own pace or use alternative, creative methods and teaching resources (e.g., photographs, illustrative materials, and recordings) (Moll et al. 2020). There are also a number of specific ways that may help deliver the successive stages of a research project. For instance, visual representation of data, group analysis (using focus groups in which co-researchers with disabilities participate), and familiarity with data collection are recommended in the process of analysing and interpreting collected research data (Kramer et al. 2011).

Although reports and studies describing inclusive research involving co-researchers with intellectual disabilities can indeed be found in the literature, few studies are concerned with non-English-speaking countries (not least because such research is not as widespread there) (see Rix et al. 2020) and allows for the direct viewpoints of co-researchers without disabilities as they reflect on the research process in its different phases. This report aims to partially address this gap.

2. Methodology

2.1. Study Design

The aim of this paper is to analyse the co-researchers' without disabilities experience of designing and conducting inclusive research, which involved persons with intellectual disabilities. The first two authors were involved in the study that was carried out as part of the project "Nothing about us without us. Inclusive research involving persons with intellectual disabilities", whose aim was to explore the experiences of people with intellectual disabilities associated with their self-determination. The project was conducted in cooperation with trained co-researchers with intellectual disabilities. One of the principal elements in the research process was the application and verification of the methodological and ethical premises of the participatory method in research concerned with intellectual disabilities. During the whole project, the first two authors (co-researchers without disabilities) prepared field notes and kept observation diaries to facilitate the process of this verification. As such, we wanted to reflect on our experiences regarding the training for prospective co-researchers with intellectual disabilities and inclusive research conducted in collaboration with trained co-researchers with intellectual disabilities, focusing on ethical and methodological considerations. The involvement of persons with intellectual disabilities in the conduct of the research made it possible to determine analytical categories formulated by the persons with whom the study was concerned and to preserve the meanings that research participants attributed to their views, actions, and experiences (Charmaz 2006).

2.2. Procedure

Collaboration with persons with intellectual disabilities was undertaken in February 2022 in two groups, composed in part of self-advocates who were affiliated with the Polish Association for People with Intellectual Disability (PSONI). Prospective co-researchers with intellectual disabilities were recruited through institutions dedicated to persons with intellectual disabilities, i.e., occupational therapy workshops and vocational activity centres, both of which come under PSONI. Initially, three meetings were held at PSONI facilities located in two Polish cities to introduce the aim and the objectives of cooperation. Out of the three approaches to inclusive research identified by Bigby et al. (2014), the researchers in the current study were all involved in collaborative groups. Those interested in participating consented in writing and agreed on the rules of mutual communication as well as on the frequency, location, and time of meetings. As the first element of collaboration, researchers without disabilities delivered training (eight meetings spanning 17 h in total). Its scope was not limited to research issues, but, having a broader dimension, it served to enhance the social skills of the co-researchers so as to boost their functioning in different roles, including self-advocacy (Parchomiuk et al. 2023). The training was followed by two focus interviews to explore the experiences of prospective co-researchers with intellectual disabilities (Żyta et al. 2023). Those who were still interested in working together joined two research teams that operated in two cities in Poland but remained in close contact with each other. The teams jointly established the objective of the first project, centred around the self-determination of persons with intellectual disabilities.

The whole process of training and conducting the inclusive research was not free of numerous challenges related mainly to organisation (e.g., providing space and choosing time and dates of meetings), communication (among persons with disabilities, professionals working in institutions and and co-researchers without disabilities), and ethics (obtaining informed consent from participants and co-researchers with intellectual disabilities). At the time of writing this article, the project had been completed. Co-researchers with and without intellectual disabilities conducted and analysed three focus group interviews and 13 individual interviews with persons with intellectual disabilities. The results, communicated in an easy-to-read text, were published and presented at a conference involving persons with disabilities. The teams of co-researchers embedded in two Polish cities have already decided on two further research topics.

2.3. Data Analysis

Data were examined and interpreted using Braun and Clarke's six-phase approach to qualitative thematic content analysis to examine researchers' experiences related to the design and implementation of inclusive research (Braun and Clarke 2006). The information was based on field notes and observation diaries kept by co-researchers without disabilities (the first two authors). To provide a more holistic view of the collaborative experience, further research will include the perspective of co-researchers with disabilities.

The first phase of the analysis consisted of familiarising oneself with data, reading data, and noting down initial ideas. In the second phase, initial codes were generated, whereby interesting features of the data were coded systematically across the entire data set, and data relevant to each code were collated. The codes were discussed by the authors, who suggested multiple coding if there was no consensus. In the third phase, topics and subtopics were proposed to group the codes; codes were collated into potential themes, while all relevant data were gathered under each potential theme. In the fourth phase, a step backwards was made once the topics and subtopics had been obtained so as to review the codes or even extracts of information to refine them and ensure that they were consistent with the data, whereby necessary adjustments were made. Here, the intention was to verify whether the themes were valid in relation to the coded extracts and the entire data set, generating a thematic map. In the fifth phase, the themes were defined and named. Ongoing analysis was carried out to refine the particulars of each theme and the overall story emerging from the analysis in order to arrive at clear definitions and names for each theme. Finally, a report was produced. Subsequently, we arrived at a clear and concise determination of the main themes and their respective constituent themes, the role each one plays, and a set of literal examples that helped us to describe and understand the themes.

3. Findings

The analyses identified four superordinate themes (building relationships in the research team; opportunities and constraints associated with the implementation of projects; institutional barriers; and the importance of the role of a co-researcher without intellectual disabilities), each followed by several constituent themes (Table 1).

Table 1. Superordinate and constituent themes.

Building relationships in the research team
Building trust and gradual integration of the team Conflicts between co-researchers with intellectual disabilities Setting boundaries
Between (1) challenges and (2) potential of co-researchers with intellectual disabilities: opportunities and constraints associated with the implementation of projects
Constraints: - Discouragement; - Difficulties in remembering, reading, and reacting flexibly to the answers from the respondents Opportunities: - The knowledge of researchers with intellectual disabilities about the community of persons with disabilities; - Bridging the gap in research involving persons with intellectual disabilities; - Developing competencies; - Discovering one's capabilities and using previously acquired knowledge; - Nurturing responsibility; - Empowerment
Institutional barriers relevant to the participation of persons with intellectual disabilities and the quality of cooperation
Selection of participants for the co-researcher team Limitations of access to certain potential research subjects Interference by institutional staff in training and inclusive research design
The importance of the role of co-researcher without intellectual disabilities
Tailoring tasks to the abilities and needs of persons with intellectual disabilities Sustaining motivation in researchers with intellectual disabilities Negotiating one's own role in an equal/unequal relationship with co-researchers with intellectual disabilities—resolving the question of the limits of interference Doubts concerning the inclusive nature of research Enhancing one's own competency and commitment

Source: own research.

3.1. Building Relationships in the Research Team

The first superordinate theme concerned the relationships within the co-researcher team. In this respect, an analysis of the collected material yielded three constituent themes. One of them is the issue of gradual trust building and team integration. The process was initiated already during the training course when the participants (who had no previous opportunity to get to know each other better) started working together. Undoubtedly, the word "cooperation" gained increasing significance as persons with intellectual disabilities became familiar with one another and improved their skills. As early as the training phase, participants would collaborate, help, and take mutual interest in each other:

> *Magda*[1] *practices writing in Word. She quickly developed the ability to write Polish characters. It is difficult to tear her away from this activity. She is instructed by Anna and a little by Karol. We show Magda how to enlarge the font, change its format, insert a chart, a table (Anna remembers how to insert a table). (Training #3)*

Anna sees *Magda's difficult behaviour and tries to correct it by bringing it to her attention. (Training #4)*

The second constituent theme revolved around tensions and conflicts between co-researchers with intellectual disabilities. The relationship dynamics within the research teams did not always follow a linear path towards full inclusion and collaboration. Tensions and conflicts with varying degrees of severity arose between persons with intellectual disabilities at different stages of the work (especially during training):

> *Carolina was absent today. Other participants commented openly on her absence, stating that it was good that she was absent, that she was too conflict-prone and insincere*

> *(running others down), and that it would be better if she did not come to project meetings anymore. (Training #4)*

Conflicts made it necessary to nurture positive, symmetrical relationships. It was vital to conduct activities without competitive elements to satisfy the need to be appreciated and to promote co-responsibility for the research.

Another constituent theme generated in the relationship analysis concerned the demarcation of boundaries between co-researchers with disabilities and co-researchers without disabilities. One note reads:

> *Marek became very involved in conducting interviews. In the course of last week, he invited three of his colleagues to participate in the research, and we conducted the interviews together, each time in the late afternoon after work. He calls frequently and asks when we could make an appointment with another person. Today, he called after 9 p.m. I think he feels a little offended when I suggest we talk about it at our regular meeting. (Project Meeting #6)*

In the situation described, the co-researcher without intellectual disabilities was presented with a dilemma: to benefit from Marek's commitment and devote more time to the project (at the expense of time for other commitments, family life, etc.) or to set boundaries and define a reasonable time for project collaboration. In these circumstances, there was no obvious solution. Marek seemed to lack people close to him with whom he could spend his free time. The research group met that need to some extent, but he expected more involvement from others, not only with regard to research tasks but also in terms of informal relationships or friendships. It was necessary to establish certain general rules within the group (e.g., arranging interviews a week in advance, taking into account the preferences of each co-researcher and interviewee, as well as the times we could contact each other by phone).

3.2. Between Challenges and Potential of Co-Researchers with Intellectual Disabilities

The second of the generated superordinate themes focused on persons with intellectual disabilities. It comprised two constituent themes: (1) constraints and (2) opportunities associated with the implementation of projects. First, we learned about the challenges faced by persons with intellectual disabilities both during training and while the research project was in progress. Such issues had multiple backgrounds, including learning challenges (in terms of memory, attention, perception, and abstract ideation) and emotional issues on the one hand, and the closely linked obstacles in their surroundings, which resulted in the absence of various life experiences (such as using a telephone or computer).

> *Karol got tired because he had a lot of problems understanding. It was apparent that he was unable to understand longer verbal communication (approx. 3–4 sentences). When he did not understand, he'd switch off. (Training #2)*
>
> *Anna is very nervous and reacts . . . often swearing to noises from the outside. (Training #4)*
>
> *It turns out that both [Magda and Anna] are unable to use a traditional watch. They cannot tell the time. (Project Meeting #4)*

The second, more extensive area relating to the implementation of inclusive research involving co-researchers with intellectual disabilities underscored their ability to participate in the project. The categories identified here included the knowledge of the researchers with intellectual disabilities about the community of persons with disabilities and bridging the gap in research involving persons with intellectual disabilities. In this respect, the potential of persons with intellectual disabilities was high and enabled a better design and implementation of the project:

> *Anna helps the most [with selecting potential interviewees]: she has much knowledge about people from OTWs, and by interacting with them, she obtains a picture of both their character and their skills as well. (Project Meeting #1)*

Our experience has shown that persons with intellectual disabilities demonstrated their capabilities from the very first training sessions.

> *[Co-researchers with intellectual disabilities] stepped into the role of researchers brilliantly. I didn't expect that at the first meeting. Everyone found a person at the VDC [Vocational Development Facility] they conducted a mini-interview with and were able to talk about it. (Training #2)*

Their skills increased with the training and subsequent stages of inclusive research; for instance, most learned how to use email and a voice recorder, and they knew what rules should be followed when conducting and analysing interviews:

> *We listen to the recorded interviews, looking for errors. Almost all of them are identified by Magda and Anna. When, in one of the interviews, the researcher forces the respondent to answer, citing his consent, Karol points out that since the respondent has given his consent, he must answer. Magda immediately notes that the researcher's behaviour is inappropriate. (Training #7)*

> *Magda demonstrates a remarkable ethical stance. When Karol's and my comments go beyond acceptable norms, Magda responds by making a remark to Karol. I also acknowledge my mistake and emphasize Magda's positive approach. In the course of the collaborative process, I continually noticed Magda's progress related to her participation in the project. (Project Meeting #2)*

> *In the beginning, Anna had a problem switching from external, critical evaluation, which was required when analysing the transcription, to establishing what the respondents said, but she's gradually learning to do so. (Project Meeting #5)*

Systematically, as the training went on, we also observed growing intrinsic motivation for work among persons with intellectual disabilities, which concretised itself in increased activity ("Their activity in the training sessions steadily increased as they continued", Training #1) and self-sufficiency ("Aleksandra, who previously always avoided speaking in front of others, today volunteered to conduct the interview herself", Training #2).

Over time, the co-researchers also showed an increasing sense of responsibility for their behaviour and the performance of the team. We believe that this was one of the key achievements of the training and the project.

> *It is a testament to their responsibility and commitment that they managed to do the interviews after the first meeting, where homework—such as conducting interviews—was only preliminarily mentioned. (Training #1)*

The responsibility and growing maturity of the co-researchers with intellectual disabilities was evident in their approach to the meetings and tasks. Gradually, we reached a point in our collaboration when one of the participants became responsible for arranging a meeting and conveying important information.

> *Anna is already waiting for me and has been informed that the session is being held in another room because the other one is occupied. She organizes the others. She also informed me that some people have gone to see one of the participants (who took part in the group interview) who does not want to attend the workshops to talk to her. (Project Meeting #4)*

Towards the end of the training, one could see that the co-researchers with intellectual disabilities had grown into the role they were to perform. They had ceased to be randomly selected persons who were faced with a task which, being completely unfamiliar, was a challenging one. They understood (perhaps largely intuitively) what research was and what their role would be in the entire undertaking. They gained proficiency in referring to their life knowledge. It turned out that such knowledge and interests may prove important for one's tasks as a researcher:

> *We brainstormed the question: what do our interview questions need to be? Everyone was able to contribute something on their own. Magda, known for her medical interests,*

> *highlighted sensitive issues, such as asking about illnesses, cancer, and medication taken. Karol elaborated on the issue of the researcher's sensitivity (he used the phrase "they must be alert") to the emotions of the respondents. With my guidance, they considered people who cannot speak or cannot hear. (Training #6)*

As the sense of responsibility on the part of co-researchers with intellectual disabilities grew, the role of the head of the institution in arranging project meetings became superfluous. When co-researchers with intellectual disabilities happened to be committed elsewhere, they would comprehensively justify their absence or lateness. They were upset about events which made it difficult for them to attend the meetings:

> *At the beginning only Anna is present, Karol and Magda have gone shopping. We review what we did before (Anna says she remembers). Magda and Karol, both late, come into the room, apologizing for not being on time. They're clearly agitated because one of their friends delayed them. Magda states that she needs to report this to the therapist. Karol says that he won't get involved. (Project Meeting #6)*

On the one hand, participation in the training and the project offered an opportunity for the co-researchers to develop their potential and discover it, while on the other, it enabled them to apply the expertise deriving from other forms of social activism (e.g., self-advocacy):

> *Anna has ideas for research with a broader dimension. You can see her experience in social activities (she's currently at the radio). Her only problem is formulating thoughts. When I ask about something, she considers it very thoroughly and usually suggests the right answer with a movement of her head. [...] Interestingly, that intuition works quite well. (Training #5)*

> *Karol and Magda step into their roles better and better, and they're more open. Karol has knowledge from different areas of life (it is not structured). It is apparent that issues related to studying (university work) are familiar to him. This is evident in the terms used (professor, defence, BA thesis). Anna recalls the skills they once received training in (perhaps as part of self-advocacy). Magda has a rich vocabulary and broad interests. (Training 3)*

The knowledge and the skills of the co-researchers with intellectual disabilities would occasionally surprise us as researchers:

> *I don't know where she [Magda] got such knowledge from, e.g., one of the research questions [which she has formulated] was about the concerns in one's first pregnancy and fear of abortion due to defects in the baby. There was also a question about the use of oral surgery, the procedure and the subsequent symptoms. (Training #6—research design)*

> *Karol knows words such as "prelegent [lecturer/speaker]". I am surprised at his perceptiveness when I cannot decipher an abbreviation while he associates it with the full designation provided previously. (Training #8)*

Another category related to the challenges and opportunities of inclusive research concerned the empowerment of the co-researchers with disabilities. Throughout the course of the training, the research tasks became less challenging for the co-researchers with intellectual disabilities. It was crucial still to divide the research tasks relative to the individual traits of the co-researchers with intellectual disabilities, which, suitably situated in subsequent research work, became a resource (e.g., the reticence of the researcher affords the respondents space to speak). We began to realise that each person with intellectual disabilities would not respond to the same set of tasks, and instead, we opted for more flexible study paradigms.

> *Anna and Karol are very animated and interested, you can see the positive changes over time. Karol is keen to remember what needs to be done at home, and this does not need to be written down. He really enjoys transcribing in Word. (Training #4)*

> *I didn't think that [the trainees] would engage that much in the exercises involving other people. It turned out that conducting "mini-interviews" with their colleagues from the Vocational Development Centre was an opportunity to test oneself in a new role—that of a researcher and to interact with someone of their own choosing. Although the topic was imposed (they were to find out about the interviewees' previous experience of participating in scientific research), it seems that the ability to choose who to interview and to act as an expert was important for them. (Training #2)*

3.3. Institutional Barriers in the Process of Research

Another superordinate theme concerned institutional barriers relevant to the participation of persons with intellectual disabilities and the quality of cooperation, in which three categories were identified. Selecting participants for the co-researcher team was the first of those. In the project discussed here, the initiative to carry out the training and the project came from the researchers without disabilities. Having obtained permission from the institutions working with persons with intellectual disabilities, we—as university researchers—had to rely on the decisions of the competent officers and therapists at those institutions regarding persons who would be asked to participate in the project:

> *It's yet another meeting [with the representatives of the institutions] about the planned training of potential co-researchers with disabilities. We [university researchers] provided an estimated number of participants in the training and described what our work would involve. We were given information about the potential participants, whereby emphasis was placed on their skills (which were higher compared with other participants). We argued that we were not interested in having only such [more competent] persons on board.*

Ultimately, the persons to join the team of co-researchers were selected largely by the representatives of the institutions. They did so based on their own criteria, probably considering the cognitive and social skills of the prospective participants. The selection was thus dictated in the sense that both researchers without disabilities and those with intellectual disabilities had to comply. Such a practice is self-evident within the institutional framework. Admittedly, persons with intellectual disabilities voluntarily consented to participate in the training activities and, theoretically, their consent was an informed one. However, one may ask about the extent to which persons with intellectual disabilities who joined the training were aware of the expectations and the tasks ahead, having never participated in such an undertaking. A number of persons with intellectual disabilities have no opportunity to gain experience in independent decision making. These obstacles are not only due to the challenges of having an intellectual disability but also to the environmental attitude towards the independence and autonomy of that group. The socialisation within institutional living to which persons with intellectual disabilities are exposed most often leads to dependence and lacks of a sense of agency, which impairs proactive strategies for coping with the challenges of daily life and compels them to adopt a passive approach. They have to confront entrenched notions, which determine their life situation and which can prevent them from becoming active as individuals.

Limitations of access for potential respondents made another constituent theme. It was to our advantage that, having completed the training phase, we were already more embedded in the institutions as researchers and were familiar not only with the trainees themselves but also with other charges of the institutions; in addition, we were able to rely on the knowledge of the co-researchers with intellectual disabilities about potential research subjects. Nevertheless, the approval of the staff member responsible for cooperation was required whenever a person was invited to be interviewed. Although this was not a major obstacle in reaching potential research participants, we felt that we were not completely at liberty in this respect.

Another constituent theme relating to institutional barriers concerned the interference of institutional staff in training and inclusive research design:

> *At the outset, I received information from the Head of the institution that participants get nervous before meetings. She suggests using biscuits and reducing the requirements (?). It turns out that there is a problem with Magda, who clearly does not want to participate. When I suggest that she withdraw, the Head vehemently denies it, claiming that they should get accustomed to duties. The problem is that so far, no one has introduced Magda into dealing with duties, and everyone is filling in for her. (Training #4)*

In this sense, we were doubtful about who actually made decisions regarding the participation of persons with intellectual disabilities in the project. Although we applied the principle of double consent (the consent of the institution directors was a prerequisite, but it was neither a sufficient condition nor was it the same as the consent of the persons with intellectual disabilities themselves), we were uncertain whether the decision taken by the persons with intellectual disabilities did not result from an asymmetrical, hierarchical relationship or involve any form of obligation or coercion or the use of a privileged position by the staff. Because persons with intellectual disabilities are used to complying with the decisions of the personnel employed in institutions, we took particular care to convey that the activities proposed as part of the research were not compulsory and that they could opt out. For some persons, being invited to join the team was initially a task they were expected to complete because such was the decision of the institution's head or a parent. Perhaps this should be seen in positive terms as promoting dutifulness or counteracting passivity. However, it is difficult for us to assess how much being obligated in this fashion by a superior contributed to enhancing one's sense of responsibility and how much this was due to the growing satisfaction after successive team meetings.

During our meetings, the institutions which the co-researchers attended did not display any particular interest in the project. Usually, we would not be faced with obstacles or negative attitudes (apart from the occasional reluctance to carry out project-related tasks for organisational reasons, e.g., lack of a suitable room), but we also received no support or clear signals from the staff, which would confirm that our endeavours were meaningful and useful. When an easy-to-read text was produced as a measurable outcome of our undertaking, there was no interest in posting it on the websites of the involved associations or institutions. Perhaps assisting other participants with homework may be seen as a form of supporting them in what they were doing. Still, in some cases, the participants were not supported in their work, but instead, the tasks were completed for them, which demonstrates that the staff failed to acknowledge the capabilities of persons with intellectual disabilities and implies that a medical, care-providing model of disability still applies.

It turned out that homework was not independent. It was done with extensive help at the OTW. (Training #2)

One can hardly speak of cooperation with the staff, but over time, they noticeably expressed appreciation of our activities, though only verbally. Surprisingly enough, the staff failed to recognize that our activities could be integrated into the institutional system aimed at the social rehabilitation of persons with intellectual disabilities. It appears that our research proceeded on the sidelines of the main current activities, sometimes even interfering with them.

3.4. The Role of Co-Researcher without Intellectual Disabilities

The last of the identified superordinate themes concerned the importance of the role of a co-researcher without intellectual disabilities. Within this area, four constituent themes were singled out. The first was flexibility and adaptation of tasks to the abilities and needs of persons with intellectual disabilities. To avoid information overload, we divided the training into separate modules (e.g., data collection and data analysis). In order to minimize engaging with abstract material, the training sessions were designed to enable persons with intellectual disabilities to work on transcribed interviews and prioritised conversations on topics related to the researchers' knowledge, everyday events in which they partook, or specific interviews that they had conducted. When working with persons with intellectual disabilities, it was vital to remain sensitive to their needs, to recognize signs of a low sense of agency, or to respond to behaviours that might lead to withdrawing from the project:

> *He is very active, although as the session goes on when I speak, he switches off slowly and resumes his stereotypical activity (plucking at his trousers). He would like very much to talk about his experiences, not necessarily related to the subject. Once again, I find out that the exercises need to be as practical as possible. This is important for the future editions of the training. (Training #8)*

Another constituent theme centred around negotiating one's own role as a co-researcher without disabilities. The role of the researcher without intellectual disabilities changed in the subsequent stages of collaboration. The training stage was dominated by the non-disabled researcher, who decided on the topic of instruction, selected the methods and the means to deliver it, set specific tasks, and expected them to be completed. The essential premises and training modules had been designed even before the co-researchers with disabilities were selected. Once the participants had been enrolled and the training started, it became apparent that flexibility and modifications were needed at various points in view of the participants' skills and their responses to particular tasks. Openness to modification was pivotal for the subsequent tasks, as it helped to build mutual understanding, reduce the anxiety of persons with intellectual disabilities, and reinforce a sense of empowerment in the persons involved. Modifications were introduced by persons without disabilities and included extended time to cover a particular module (e.g., disseminating results, attending conferences, and conducting mock interviews), either due to a high interest in the module or the difficulties experienced, replacing tasks with others (e.g., more specific ones), dispensing with homework that might be difficult, or abandoning a task if its completion—in the opinion of the participants—was beyond their capabilities and prompted discouragement. Already during the training stage, the co-researchers with intellectual disabilities would gradually recognise that they had distinct capabilities and could contribute differently to prospective research. Also, they began to influence the content of the training themselves, as illustrated in the following note:

> *Today, we continue to practice digital skills. Jan [the oldest participant, aged 64] seems disgruntled from the outset. He is a leader in the self-advocacy group, but this is the area in which he feels least capable. While the others are engrossed in texting each other, setting up email accounts and using voice recorders on their mobile phones, he can't keep up. He has an early-type phone—it's not a smartphone, it doesn't have internet access, and it's difficult to write texts on it. He uses other people's devices, but he's clearly annoyed. He eventually refuses to be helped with texting and reading messages and asks to be called when needed. He will happily work with text (being a skilled reader) but wants it printed out for him. We accept this request. We affirm that it is normal that everyone will use different resources. (Training #5)*

As authors of the training proposal, we made efforts to involve the participants and to learn about their potential and needs in order to respond in the most adequate fashion. However—as articulated in our notes—we feel that we did not provide a sufficient number of activities, which would evoke positive emotional responses, which relied on specific experiences (such as the interview simulation), incorporated elements of humour, or provided an opportunity to relieve the tension that may have initially accompanied persons with intellectual disabilities. Another issue was taking continual care—especially while conducting the research—to ensure that the voices of persons with intellectual disabilities, who had by then become co-researchers, counted as thoroughly valid. That influence was evident at various stages, but an eloquent situation during training evinced something contrary to the desire of persons with intellectual disabilities for decision making. It may be interpreted twofold: as a manifestation of subordination to a superior, but also as a learned life attitude which assumes that non-disabled persons know better and, therefore, have power:

> *The researcher (myself) was conducting the research (training role plays) while Anna was the respondent. The situation showed all possible violations of ethical principles, e.g., that consent was only given by the, staff but the person with disabilities was not asked. "The researcher" assured the "subject" that they should fill in the questionnaire because the consent was given by the institution. Following the role-play, questions were asked about the inappropriate behaviour of the "researcher". It was decisive for Anna that consent had been given by the institution, and she stated that it had been given she should complete the questionnaire. In my opinion, this is another manifestation of subordination to non-disabled people. What the manager says is conclusive, even if it provokes internal objections. (Training #2)*

When we listened to the stories from the lives of researchers with intellectual disabilities, we had the impression that they had been poorly equipped to claim their independence and their capacity to decide and take advantage of "shared decision-making" on an equal footing with co-researchers without disabilities. Persons in the most immediate surroundings of persons with intellectual disabilities tend not to believe that they are sufficiently competent, which is why they feel entitled to make decisions on their behalf, "for the good" but not always "with the consent" of those concerned. This ultimately leads to an absence of initiative, submissiveness, or an internalised image of oneself as a "recipient" of support. This typical socialisation pattern within family and institutional environments also resonated in our project:

> *In Magda's case, there's tremendous dependence on her parents' will. She has a parental lock put on her computer and is afraid to open an email account. When medical examinations are discussed, she states that it is the parents who take care of everything and decide about everything. She never gets to consent (nobody asks her). (Training #3)*

Creating a research team involving persons with intellectual disabilities compelled us to rethink the role of our own ability and the resulting unequal relationship. Situations where power relations changed were an interesting experience. From time to time, we would be confronted with the limitations of what is seemingly a privileged social position; for instance, our status in research into intellectual disability was questioned. On more than one occasion, it was thanks to the researchers with intellectual disabilities that we gained visibility and trust in certain communities (which was important in recruiting research participants).

The misgivings on our part related to the above as to whether the research was genuinely inclusive and became one of the themes identified in the course of analysis:

> *We started the meeting with a brief reference to a recent interview. Since Karolina was additionally participating today, we drew her attention to the fact that she should remember not to judge the respondent's statements during the interview. I had the impression that Karolina did not consider it an element of good practice in general but as a task she has to do because she is told to. I am not sure that the conducted research really affords a sense of agency to everyone. Sometimes, I feel that for some, it is a chore or an opportunity to escape doing daily tasks at the Workshop. (Project Meeting #5)*

The final constituent theme focused on the opportunities to enhance the potential and commitment of researchers without disabilities. For us, collaboration with persons with intellectual disabilities as researchers was an opportunity to boost our own research skills. In the first place, this means acquiring more extensive knowledge of how persons diagnosed with intellectual disabilities tackle tasks that were previously unavailable to them or to which they were not invited. We found that the researcher has to be highly sensitive to indirect communication, seemingly unrelated to the issue at hand. What may appear to deviate from the topic is sometimes a substitute (or "circular") attempt at talking about it. Our assessment of the statements made by persons with intellectual disabilities can often be too precipitous and thus fail to interpret them in a broader context:

> *Today, we were analysing a group interview. I [co-researcher without disabilities] read excerpts from the transcript, and the co-researchers with disabilities commented on the*

> *statements. Sometimes, those were simple recapitulations, but more often than not, they went much further than I would have thought on my own. They inquired and looked for reasons, citing their own experience, the experience of a particular respondent or the general situation of people with disabilities, who are often dependent on others: families or therapists. Sometimes, they questioned the answer, suggesting that someone might be ashamed of certain behaviours or their incapacity to decide for themselves. (Project Meeting #8)*

> *Her [Magda's] statements repeatedly feature comments such as "they're afraid", it's about leaving the family home, living somewhere else, or starting a family. (Project Meeting #5)*

> *I'm glad that we are finally starting the actual project [after the training]. In today's session, we selected our topic. [. . .] I'm not alone in this process, but rather encouraged [by co-researchers with disabilities] and empowered that there are others who feel the same way. (Project Meeting #2)*

We are convinced that the participation of persons with intellectual disabilities as co-researchers enabled more accurate interpretations of the material we obtained during the interviews. We have learned to hear that voice, appreciate the sensitivity, and take the non-obviousness of interpretations into account. Not unlikely, what we would have previously attributed to want of attention or interest may have been an attempt to satisfy the need to be heard, to use the voice that one was granted. Persons with intellectual disabilities are more often required to be listeners. They seldom have the ability to share their opinions and thoughts, and even more rarely are they invited as experts (even on their own affairs). This research collaboration provided them with such an opportunity, which entailed sharing knowledge that is important to them, issues which have been essential in their lives, and which make up their life experience. However, the benefits do not end there, as the collaboration was also "an empowering journey" for the co-researchers without disabilities. We came to feel important in the process because, by listening to the voices of persons with disabilities, we became convinced that we could truly make a difference together.

4. Discussion

4.1. Collaboration in Inclusive Research

The analysis of the collected material demonstrated the major importance of collaborating with co-researchers with intellectual disabilities at different stages of research from planning to analysis and dissemination. It is clear that co-production is a relational process, and as such, special emphasis should be given to ensuring that the process does not perpetuate inequities.

In the current project, substantial attention was paid to building positive relations between co-researchers. We tried to be responsive to the needs of co-researchers with intellectual disabilities and concentrate on their strengths, not deficits. This is an important aspect of all-inclusive studies involving persons with intellectual disabilities (Townson et al. 2004; Kramer et al. 2011), but, based on the findings of this study, it is not always easy and straightforward. It is important to be able to set boundaries to avoid situations in which members of a team of co-researchers might feel personally neglected. On the other hand, creating occasions to build an integrated and cohesive team is of crucial significance. The findings indicate that both co-researchers with and without disabilities value not only their professional roles as researchers but also making new friends, and informal contacts that can be built. Collaboration between co-researchers has begun to transcend the formal dimension as we have become friendly. Our meetings started with discussing life issues, which we considered important. We know one another quite well, as much as our joint willingness to share experiences allows. This is no obstacle to project-related activities. Teams of non-disabled researchers also see progressive integration, which is not unique to our experience (Nind and Vinha 2012; Riches et al. 2017).

4.2. Benefits of Inclusive Research

We have observed that the project had positive significance for the co-researchers with disabilities, the co-researchers without disabilities, and the quality of inclusive research.

The project tasks carried out by co-researchers with intellectual disabilities had an enriching effect on the latter. Some assumed multiple roles, which enabled them to show their potential (e.g., acting in a theatre), though in certain instances, the scope of their tasks was limited. In either case, participation in the project expanded their repertory of skills (e.g., communicative, digital, and social) and contributed to empowerment. Meta-analytical studies and investigations addressing the experience of inclusive research confirm that participation in such undertakings creates opportunities to enhance the potential of persons with intellectual disabilities (Dorozenko et al. 2016; McDonald and Stack 2016; Puyalto et al. 2016; Frankena et al. 2018; Armstrong et al. 2019; Hewitt et al. 2023).

Co-researchers without disabilities were also subject to a development process. One of the important objectives of our analyses was to determine the role researchers without disabilities play in ensuring that co-researchers with disabilities have a genuine impact on the study and at each stage of its activities. Our findings indicate that the participants with intellectual disabilities conformed to the decisions of others and were overall non-critical and dependent. In therapy and education alike, their refusal or disapproval is approached as a manifestation of disturbed behaviour rather than agency. The arbitrariness of intellectual disability and the medicalisation of behaviours are tools of social control and power relations. The question which arises in this context concerns the possibility of changing the social standing of persons with intellectual disabilities. It is construed as a vital element in the added value of such research (Walmsley et al. 2018; Beighton et al. 2019; Georgiadou et al. 2020), but it seems that the expectations involved do not always correspond to realities, at least in Polish circumstances.

The reach of inclusive research is still considerably limited, whether in educational and rehabilitation environments or in the scientific milieu. In the latter, they are regarded as a kind of experiment and a curiosity. In the former—as reported above—such research is no more than an ancillary activity, which hardly fits into the established institutional agendas. According to Nind (2016), it is possible for the paradigm of inclusive research to combine sound science with good practice. The status and significance of such research situate it at the intersection of practice and science. Buchanan and Walmsley (2006) note that such research must not become an exclusive undertaking that remains separated from the broader research community, approaches, and debates. Its integration into practice and science may, on the one hand, promote a change in societal attitudes towards disability, yet on the other, it requires a cultural change within various milieus, a shift oriented towards diminishing the primacy of experts and researchers (cf. DiLorito et al. 2018). Intensification of inclusive research in Poland—in view of its relevance for the policies that benefit persons with disabilities—would require large-scale financial support as well as the formation of future researchers and practitioners (students) who would conduct such studies (O'Brien et al. 2022).

We believe that the inclusive nature of the research makes it particularly valuable. The very choice of the topic and research problems was informed by the needs of persons with intellectual disabilities, which were not approached from an external (non-disabled researchers) but an internal perspective (researchers with disabilities, so persons who had experienced disability themselves and could more easily "step into the shoes" of the respondents) (cf. O'Brien et al. 2022). In this project, the co-researchers with intellectual disabilities turned out to be very creative in developing research topics. We wanted to determine what kind of research they wished to have performed and conducted discussions, which showed that the greatest challenge was barriers to their self-determination. This led to designing the research problems and the whole study. In their interpretations of the material, the co-researchers with intellectual disabilities drew on their own experiences and life attitudes, enriching the analytical process. Similarly to the co-productive research conducted by Armstrong et al. (2019), we see the added value of our research primarily in the fact that each co-researcher was able to make full use of their knowledge, skills, and experience, while the research yielded a useful outcome (recommendations were developed). There is a certain risk associated with addressing difficult matters which can personally concern co-researchers with intellectual disabilities, as it might affect their well-being (Richardson, in Bigby et al. 2014). The authors recognised that the co-researchers in the project were capable of keeping their own experiences separate from the data collection process, which allowed them to remain objective and prioritise the experience of the respondents (Rojas-Pernia et al. 2020). However, it remains unquestionable that the discussion on the well-being and comfort of the co- researchers should have its due place within inclusive research (cf. García Iriarte et al. 2023).

4.3. Overcoming Challenges

Collaboration with co-researchers with intellectual disabilities has also entailed dilemmas. When analysing such projects, it is advisable to avoid over-generalisations that may lead to a kind of instrumentalisation of inclusive research and co-researchers themselves (Goodley, in Björnsdóttir and Svensdóttir 2008). Inclusive research represents a domain of social participation for persons with disabilities that is accessible to few, just as is the case with non-disabled researchers. Goodley and Moore (2000) drew attention to the entanglement of non-disabled researchers in a highly abstract discourse that focuses on noticing individual and collective development of co-researchers, which may be an attempt to seek justification for such research given the multiplicity of other traditional approaches. Such an entanglement carries the risk of departure from the core objectives of inclusive research, the determination of which are, after all, central to the collaboration between co-researchers with and without disabilities. At this point within this study, we became aware of the imbalance of the data being collected only from the co-researchers with intellectual disabilities. It was therefore crucial to create a space for personal and collective evaluation of engagement, which we created through joint reflection on participation in the project. This resulted in a paper (Chamera et al. 2023) developed in an accessible format and published in a major journal in the field.

Just as other researchers (e.g., Björnsdóttir and Svensdóttir 2008; Lloyd et al. 2019), we also found it challenging to empower co-researchers with intellectual disabilities to exercise control over the research process and the reporting of findings. To ensure that control, we sought to comply with the interests and choices of co-researchers with intellectual disabilities (regarding research problems, research participants, and research location). Publicising research findings in an easy-to-read format proved an important solution. The prospect of publishing a paper in a scientific journal was not attractive to the co-researchers with intellectual disabilities, but they were very interested in creating (as co-authors) a text for a magazine that is well known in the community of persons with intellectual disabilities. Indeed, they saw it as a major achievement, as the work of collecting the results and analysing them became more tangible, while the final publication of the text in the magazine (with photographs and bios of the authors) became a source of satisfaction and pride. This demonstrates that the benefits associated with inclusive research are not equivalent, whereas any comparisons of the kind miss the mark, even though they are attempted, especially with respect to remuneration and promotion (Nind and Vinha 2012; Strnadová et al. 2016).

4.4. Limitations

The study presented here is not free of limitations. It should be underlined that it concerns only one research project and a small, homogeneous group of co-researchers with and without intellectual disabilities. It would thus be worthwhile to undertake investigations with other co-researchers with and without disabilities, who would be diverse in terms of socio-demographic characteristics as well as experiences in conducting inclusive research (different approaches to inclusive research and varying length of time spent conducting such investigations). It would also be valuable to expand the study groups to include co-researchers with intellectual disabilities as well as self-advocacy and other activist communities dedicated to persons with intellectual disabilities. Alternative methods of data collection, such as photovoice, would also be necessary to enable the participation of persons with severe and multiple disabilities (e.g., Wos and Baczała 2021; Rojas-Pernia and Haya-Salmón 2022).

4.5. Implications

As for practice, the study may serve other researchers who are currently engaged in research with persons with intellectual disabilities or are considering undertaking such studies. First of all, the endeavour is worthwhile, as it benefits not only the research itself (high degree of practical utility, significance for the community of people with disabilities, easier access to research subjects, and sometimes greater openness of the respondents thanks to the presence of co-researchers with intellectual disabilities) but also the co-researchers with disabilities (empowerment, mobilisation, activation, and development of competencies) and without disabilities (increased awareness and a sense of purpose). Secondly, the project demonstrates that training co-researchers with intellectual disabilities is an important step in the process of inclusive research. Not only does it integrate the group of prospective co-researchers, but it also enables them to discover their strengths or equips them with the necessary skills to conduct research. Thirdly, this study makes it possible to formulate guidelines for the inclusion of persons with intellectual disabilities in research. In our opinion, it is vital that the researcher without disabilities continually strives to ensure that persons with intellectual disabilities may exercise control in ongoing projects, from identifying research problems (brainstorming, discussion, and voting among members of the research team proved productive in our project), through the research process itself (taking care that co-researchers with disabilities feel empowered to decide who will participate in the research and what questions will be asked) to reporting research results (ensuring that the reported findings are accessible to persons with intellectual disabilities). Accessible publications both in high-impact journals as well as communicating the results at a conference, on the institution's website, or in a popular scientific magazine are equally indicative of achievement for co-researchers both with and without intellectual disabilities.

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Note

[1] For the purposes of this paper, the names of persons involved in the research have been changed.

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Review

"Will I Be Celebrated at the End of This Training?" Inclusive Research in Kenya

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Abstract: The development and practice of inclusive research with people with intellectual disabilities is complex, revealing challenges and lessons that inform innovative and novel methodological approaches. In Africa, inclusive research still lags for various reasons. First, due to societal misconceptions that portray people with intellectual disabilities as unable to self-advocate or as lacking agency and self-determination; second, due to a lack of trained researchers and ethics committees on inclusive research practices. This paper critically reflects on and discusses the strategies and methods used to conduct an inclusive research study in Kenya. The focus was on the methodological approach of including people with intellectual disabilities as researchers in Kenya. Two people with intellectual disabilities were trained as research assistants. This paper describes the experiences with Institutional Review Boards, the processes and experiences while training this research assistants using a UK-developed curriculum, and fieldwork experiences while piloting interview guides, conducting interviews, and conducting focus groups with this research assistants. This study findings indicate the need to culturally adapt co-researcher training, the importance of working with support personnel who empower researchers with intellectual disabilities, and the need for greater advocacy to change negative attitudes towards people with intellectual disabilities that hinder their participation in research.

Keywords: inclusive research; Africa; intellectual disabilities

1. Introduction

People with intellectual disabilities have historically been underrepresented in conducting research as researchers (Fulton et al. 2021; Harrison et al. 2021; Zarb 1992). Additionally, research methods have traditionally been developed and implemented in inaccessible ways that prevented people with intellectual disabilities from being researchers and instead were only researched (Oliver 1992; Nind et al. 2016). Disability studies scholars and activists with and without disabilities have advocated for people with intellectual disabilities to have a voice in the ways their experiences are collected, analyzed, interpreted, and represented (Bourke 2009; Goodley 2018; Zarb 1992). This requires people with intellectual disabilities to be part of research processes that investigate their experiences (Nind et al. 2016; García Iriarte et al. 2014).

The aim of the field of inclusive research has been to produce knowledge with and by people with intellectual disabilities, enabling them to shape their narratives in ways that are relatable to their experiences and realities (Bigby et al. 2014; O'Brien et al. 2014; Nind et al. 2016; Purcal et al. 2019).

Inclusive researchers have been collaborating with people with intellectual disabilities to develop accessible research and dissemination methods (Bigby et al. 2014; Bigby and Frawley 2015; Dowse 2009; O'Brien et al. 2014). The field of inclusive research also addresses issues of power dynamics between researchers with and without intellectual disabilities and supports the empowerment and representation of people with intellectual disabilities in research, as well as their fair remuneration (Di Lorito et al. 2018; Fletcher-Watson et al. 2019; Nind and Vinha 2014; Walmsley et al. 2018; Woelders et al. 2015). Reflecting on how people with intellectual disabilities have participated in inclusive research and consequently improving their level of engagement has made the field's output more meaningful, relatable, and utilizable for people with intellectual disabilities (Bourke 2009; García Iriarte et al. 2014; Hacker 2013; Nind 2014; Strnadová et al. 2016).

Inclusive research practices have steered the field in a direction where it becomes possible to imagine an intellectual disability epistemology informed by people with intellectual disabilities themselves (Walmsley and Johnson 2003). In this paper, intellectual disability epistemology refers to the knowledge and perceptions that emanate from the meanings that people with intellectual disabilities make of the world. The exclusion of people with intellectual disabilities from knowledge production strengthens ableism (Friedman and Owen 2017; McDonald et al. 2023) and contributes to the erasure of intellectual disability as part of human diversity. It becomes difficult and complex to imagine an intellectual disability epistemology when ableism is normalized. An intellectual disability epistemology is essential to the pursuit of social justice for people with intellectual disabilities (Purcal et al. 2019; Walmsley et al. 2018; Ouellette 2011). This is because they continue to be negatively impacted by the systemic devaluation of what it means to exist and live with an intellectual disability (Wilson 2022). People with intellectual disabilities experience disparities in access to health care, education, employment, leisure activities, civic participation, and basic needs such as food and shelter, and these can be compounded by race, ethnicity, nationality, and gender (Elder 2015; Kabia et al. 2018; Moyi 2017; Opoku et al. 2017).

Situating and affirming inclusive research as the dominant and expected approach to research with people with intellectual disabilities can promote an intellectual disability epistemology, one where people with intellectual disabilities are reshaping the knowledge about their identities and disabilities as a part of human diversity, not as a problem or limitation. The work of reimagining knowledge production together with people with intellectual disabilities has gained traction in most Western countries but has barely begun in non-Western countries (Kahonde 2023). In Africa, this is in part due to the negative attitudes, medicalization, and infantilization of people with intellectual disabilities (Bunning et al. 2017; Kahonde 2023; McConkey et al. 2016). Additionally, Kahonde (2023) notes that African researchers and ethics committees may lack knowledge on how to conduct research inclusively. Intellectual disability is poorly understood in Kenya. Census reports indicate varied conceptualizations of intellectual disability in Kenya (Global Disability Rights Movement 2020; Kenya National Survey of People with Disabilities 2008; Kenya Population and Housing Census 2009; Status of Disability in Kenya: Statistics from the 2019 Census 2019). Efforts to conduct inclusive research are often undermined by the negative attitudes and gatekeeping of ethics committees, governments, disability organizations, researchers, parents, and guardians, leading to a challenging environment in which to develop, practice, and promote inclusive research.

In the spirit of no one being left behind, there is a need to explore what inclusive research would look like from an African perspective since contextual differences may impact and influence the practice. There may be differences in the lived experiences of people with intellectual disabilities, cultural practices and beliefs, academic practices, and government policies, or lack thereof, in Africa compared to Western countries. To ensure that Africans with intellectual disabilities also have a voice, it is important to create spaces where knowledge about intellectual disabilities is being co-created with people with intellectual disabilities in the African context.

This paper contributes to the global discourse on inclusive research by describing the lessons learned from the implementation of an inclusive research study in Kenya conducted in 2023. The primary investigator of this study, though currently living in the United States (U.S.), is Kenyan. Additionally, they have worked with and lived with people with intellectual disabilities for eight years in the setting where this study was conducted.

This ethnographic qualitative study facilitated the participation of Kenyans with intellectual disabilities as research assistants in this study's data collection and dissemination.

The aim of this study was to explore the support needs of people with intellectual disabilities and caregivers of people with intellectual disabilities in Kenya through a combination of interviews and focus groups. This paper describes the complexity of developing and conducting this inclusive research study. The focus is on the innovative methodological approach of inclusive research in Kenya, including the implementation of this study, particularly the process of obtaining ethical approval for this study, the recruitment and training of this research assistants with intellectual disabilities, the collaboration with a local Kenyan disability service organization, and the completion of fieldwork. This paper offers reflections on what lessons were learned to better inform and prepare future inclusive research teams in non-Western contexts.

2. Background of This Study

This project was a qualitative ethnographic study with the aim of determining the services needed by people with intellectual disabilities and their families in Kenya. Three research assistants with intellectual disabilities were trained. A total of twenty people were interviewed: 10 people with intellectual disabilities and 10 caregivers. Key findings about the support and service needs of people with intellectual disabilities and caregivers in Kenya will be reported in a future publication. Preliminary analysis indicates that people with intellectual disabilities and caregivers in Kenya hope for greater visibility and information about available services. Additionally, people with intellectual disabilities want to get more involved in advocacy and decisions about services provided to them. This study is one of the first known attempts to develop and implement an inclusive research project in Kenya. This study was a new experience for Institutional Review Boards (IRBs), the local disability service organization, Kenyans with intellectual disabilities, and caregivers. Since Kenyan IRBs are not well informed about people with intellectual disabilities conducting research, implementing this study was challenging. This section below describes the steps involved in obtaining IRB approval for this study and this study procedures.

2.1. Navigating Institutional Review Boards

A primary challenge that this research project experienced came at the genesis of this study, with multiple barriers in obtaining Institutional Review Board (i.e., ethical) approval to conduct this study. This included the perceived "vulnerability" of this study population, language and training barriers, and discordant perspectives on inclusive research. The ethics of involving people with intellectual disabilities as research participants and researchers has been an area of attention and ongoing research (Dalton and McVilly 2004; McDonald and Kidney 2012; McDonald et al. 2013; Stack and McDonald 2014). Conducting research with people with intellectual disabilities as researchers has been a new frontier for ethics committees to consider (McDonald and Kidney 2012). According to the Helsinki declaration, people with intellectual disabilities have been considered a vulnerable population requiring research protections (General Assembly of the World Medical Association 2014). These protections have sometimes placed limits on the opportunities for self-determination and autonomy of people with intellectual disabilities, preventing them from taking on roles as participants and co-researchers in research projects (Friesen et al. 2023; Ouellette 2011).

In addition to challenges to the inclusion of this population in research, there were practical barriers. For example, the Institutional Review Board (IRB) at the authors' U.S.-based university required all research personnel to complete the CITI training (CITI Program n.d.). This training lacks a Swahili version and hence cannot be completed by Kenyan research assistants (RAs) with intellectual disabilities who do not speak English. Additionally, at the time of this study, the content of the CITI training was not available in an accessible language for people with intellectual disabilities (see next section for further discussion on training of RAs). This study was approved by the U.S. IRB with the assurance that RAs would work with and be supervised by the primary investigator. Research personnel with intellectual disabilities were not allowed to independently hold responsibility for any of this research activities.

The U.S. IRB also required approval from a local Kenyan IRB since this research was being conducted in Kenya. This research study plan was submitted to a local Kenyan IRB. After their review, the Kenyan IRB recommended changes to this research study plan that were antithetical to the philosophical and epistemological foundations of inclusive research. The recommendations were grounded in traditional approaches to research, which were highly medicalized and individualized, drawing on positivist frameworks of research. For example, a description of the primary researcher's positionality in this research was labeled "unscientific", the primary investigator was asked to include the "medical causes of intellectual disability", and a demand was made to remove the role of research assistants with intellectual disabilities from this research study plan, arguing that they were "not trained academically".

A rebuttal was submitted to the Kenyan IRB with explanations of the principles of inclusive research, including an articulation of the value of Kenyans with intellectual disabilities having a voice in research that is about them. After extensive follow-up and attempted engagement with the Kenyan IRB and no response, this study was unable to continue with the approval process. The U.S. IRB instead collaborated with the local disability service organization where this study was to be conducted. The service organization provided a letter of support and signed an IRB authorization agreement, which meant that the organization would rely on the review, approval, and continued oversight of the U.S. IRB. The multiple challenges in obtaining an IRB created significant delays in starting this research project.

2.2. Recruitment and Consent Procedures

This study was conducted in collaboration with a disability service organization in Kenya that employs 13 staff members who support 357 people with disabilities through a variety of residential and nonresidential services. Partnering with an on-site organization that was familiar with people with intellectual disabilities was critical to the success of this study. This section describes the recruitment process and the support this study received from the disability organization staff.

Once this study was approved, recruitment of study participants was conducted in conjunction with the local disability service organization. The organization's director and human resource manager provided permission for this research to be implemented in collaboration with the organization's staff and provided a support person for the RAs. The social workers of the organization helped to share information about this study with potentially suitable participants. All individuals who were approached by the social workers expressed interest in participating and contacted the primary investigator, who set up individual meetings to introduce this research team, explain this study, and obtain informed consent.

Although the primary investigator presented all potential participants with accessible information sheets written in Swahili, which included bullet points and pictures illustrating this research, they seemed to rely more on the verbal explanations of this research provided by the primary investigator and research assistants. Given that this was the first time these individuals were engaging with research, they were curious about its benefits. Despite the fact that the primary investigator described this research as having mostly indirect benefits, such as informing services and policies on intellectual disabilities in Kenya, the participants still expressed a willingness to participate and contribute information. All participants gave their consent to participate in this study. Guardians of participants with intellectual disabilities who did not require support during interviews were made aware of this study, but they did not participate in the interviews or focus groups. In addition to individual consent, guardians of participants with intellectual disabilities who required and requested the support and presence of their guardians during the information meetings, interviews, and group meetings also signed consent forms. In such instances, the person with intellectual disabilities had to approve having their guardian present during interviews and group discussions.

2.3. Data Collection Procedures

Once recruitment was completed, data collection started. This research team agreed to start fieldwork at 9 a.m. each day and that the primary investigator would bring lunch and water for the team. The support person ensured this research assistants' parents and work supervisors were aware of the fieldwork schedule and that they had permission to be away on the required days. The majority of this research activities were conducted in Swahili and Kikuyu. Swahili was understood by all participants, but some individuals were more articulate and comfortable communicating in Kikuyu.

The primary investigator and the RAs with intellectual disabilities (see section below on training and engagement with RAs) jointly conducted interviews with 10 people with intellectual disabilities and 10 caregivers who later participated in the four focus groups. The people with intellectual disabilities and caregivers who participated in this study were not related or recruited as dyads. All interviews took place in the participants' homes and lasted an hour on average. A five-minute break was included halfway through interviews because the RAs found one-hour interviews to be lengthy. Several participants with intellectual disabilities required support from their guardians to participate in this study due to their physical mobility and communication needs. Each RA asked three questions they memorized from the interview guides, while the primary investigator asked the remainder of the questions. After the interviews were complete, the primary investigator did a preliminary analysis of the interviews and presented the themes to the RAs.

This research team worked together to identify and develop three common themes from the interviews, which were used to develop focus group questions. Two focus groups were then conducted with people with intellectual disabilities (five participants per group) and two focus groups with caregivers (also five participants per group). The focus groups took, on average, two hours. Breaks were taken as needed. The RAs were included in all aspects of the focus groups, including by asking questions and facilitating discussion. The primary investigator supported the RAs to co-facilitate by providing prompts and follow-up questions as needed. Participants received a stipend for transportation costs as well as refreshments during the interviews and focus groups. The RAs were essential to the successful completion of the focus groups. This was especially visible in the focus groups, where the RAs were viewed as insiders, which encouraged free and open dialogue. This helped address the power dynamic between the researchers and research and was one of the benefits of the design of this inclusive research study, similar to others reported in other studies (Purcal et al. 2019; Walmsley et al. 2018).

The presence of RAs with intellectual disabilities also sparked interest, especially among caregivers who did not think it was possible to involve people with intellectual disabilities as researchers. In some instances, the caregivers interrogated the RAs about their experience as researchers. Although well intended, sometimes the interrogation came off as if doubting the capabilities of the RAs as researchers. This was evidenced in the caregivers' tone and attitudes when they spoke to the RAs in a belittling manner. In such instances, the primary investigator stepped in to affirm that the RAs were trained and were continuing to learn through the process.

2.4. Findings and Dissemination

The dissemination of this research was a key component of this study, as the aim of inclusive research is to leave sustainable change on the issues being addressed in research (Walmsley et al. 2018). There were initial plans to hold a town hall with the key stakeholders in disability services. The host disability organization asked for stipends to be provided to prospective attendees of the town hall. This request presented a clear gatekeeping challenge, both practically in terms of the unavailable study budget and philosophically in that this study results should be freely distributed and received as part of a commitment to further understanding of the issues facing people with intellectual disabilities. It did not seem ethical to pay people to listen to the findings because it would attract attendance for the sake of pay, but not because the stakeholders were interested in or cared about the issues affecting people with intellectual disabilities.

Instead of hosting a town hall, findings were disseminated to the host organization and through outreach activities that were already planned by organization staff, such as a parents' fundraising meeting and a teachers' training. Accessible handouts were provided to all attendees at these events. The host organization was in the process of developing a new strategic plan, and so the findings of this research were welcomed to help inform this process. Attendees at the events welcomed this research findings, which they found to be informative and empowering for families and people with intellectual disabilities.

3. Working with Research Assistants

As noted above, there are a multitude of complexities in developing, practicing, and promoting inclusive research in Kenya. Barriers to the implementation of inclusive research in Kenya have resulted in a lack of opportunities for Kenyans with intellectual disabilities to participate in research training or to do research. Scholars in the field of inclusive research have attempted to bridge the gap of exclusion of people with intellectual disabilities from research by developing research trainings, implementing research together with people with intellectual disabilities, drawing lessons from their experiences, and sharing them with other inclusive researchers (Di Lorito et al. 2018; García Iriarte et al. 2014; Nind et al. 2016; O'Brien et al. 2014; Tuffrey-Wijne et al. 2020; Strnadová et al. 2020; Walmsley et al. 2018). However, this work is typically limited to Western countries and has not been conducted in Africa. This next section describes the processes that were involved in recruiting and training RAs with intellectual disabilities in Kenya. The training consisted of ethics and research methods using the training materials available at the time of this study.

3.1. Recruitment of Research Assistants

Inclusive research teams experience challenges in recruiting and training RAs with intellectual disabilities and receiving approval from ethics committees to include them in research projects (Ghaderi et al. 2023; McDonald and Kidney 2012). The U.S. IRB considered people with intellectual disabilities a "vulnerable population", and additional approval measures and caution were required to avoid coercion and ensure the voluntary participation of the RAs. The primary investigator worked closely with the disability organization staff, who recruited two suitable candidates to fill the RA positions. The demographics of the RAs included one male, 25 years old, and a female, 28 years old, and they had been attending day programs at the host organization for more than three years. The RAs were required to meet the following criteria to be part of this research team: be willing to be an RA and represent other people with intellectual disabilities; be able to communicate verbally; concentrate on a task for at least 15 min; work collaboratively; and learn how to do research. Once two RAs were selected, the organization's staff provided ongoing logistical support to the RAs, such as by providing reminders during trainings and fieldwork activities, by communicating and coordinating schedules with guardians, and by explaining unfamiliar words used during training to the RAs.

During initial training, it became evident that one RA was unable to complete foundational tasks to co-lead this research. This RA had difficulties understanding and retaining the training content, despite the primary investigator and support person using familiar words, phrases, and figures of speech. This RA also had a hard time remembering what to say to introduce herself, recall questions, or comprehend sentences with more than three words. Although she completed this research training with the support of the primary investigator and support person, the RA expressed that she felt she was unable to ask questions during data collection. The primary investigator requested that the disability service organization recruit an additional RA who also received training. The new RA was female and 24 years old. She had been attending day programs at the host organization for two years. Training the third RA followed a similar process and curriculum used during the onboarding of the first two RAs (described in detail below).

The two RAs who conducted fieldwork each received USD 50 per month for the eight months they were involved in this study engaging in training and fieldwork ($50 is an equivalent of 5000 Kenya shillings, which is a competitive local rate for part-time employment). The RA who did not participate in fieldwork received pay for the time spent on ethics and research training. Additionally, all three RAs were included as presenters for an online international webinar on inclusive research where they shared their experiences with this study.

Given the extended time spent on training, it would have been better for the primary investigator to request for an additional RA as soon as they noticed that one of the RAs was struggling with training.

3.2. Training of This Research Assistants

3.2.1. Ethics Training

When working at a university, anyone who engages in research requires training and awareness about ethical considerations during research. Ethics training is conducted with researchers with intellectual disabilities as well, so they understand the necessary protections of human subjects during research (Nind et al. 2016). The absence of accessible ethics training for researchers with intellectual disabilities approved by the U.S. IRB revealed power dynamics that exist between researchers with and without intellectual disabilities. Researchers without intellectual disabilities have the upper hand in understanding ethical considerations in research and then informing researchers with intellectual disabilities about them. It is not yet clear how balancing power regarding ethical considerations in research could impact how inclusive research is implemented. For now, researchers with intellectual disabilities need ethics training that they can understand, access, and possibly interrogate (Wolbring 2003; Milner and Frawley 2019; Ouellette 2011).

For this study, the primary investigator used an IRB-approved training developed by the Johns Hopkins School of Public Health (JHSPH) (2010), the Human Subjects Research Ethics Field Guide. This training is designed to be used in rural and community contexts and consists of written modules. The training does not include audiovisual materials, as this format cannot always be supported locally. The training is not tailored for people with intellectual disabilities, but it had a Swahili translation conducted by Mohammed and Kitali (2011) (Johns Hopkins School of Public Health (JHSPH) (2010)), the language spoken by this research assistants. For accessibility, pictures were added to the training handouts to facilitate the understanding of the material by the RAs.

The ethics training covered topics related to data integrity and ethical interactions with human subjects. To account for fatigue and information access, the training took place virtually in two-hour sessions daily for five days. This consistency helped retain and build on the information from the previous day. Each day, the RAs engaged in a review, a discussion, a Q&A, and an opportunity for practice. For example, one RA explained that she did not discuss with anyone what her friend had shared with her and that this was an example of keeping confidentiality. The other RA reported that instead of having everyone speak up at the same time in a meeting he had attended, he suggested that people wait for their turn to speak. At the end of the training, the RAs were provided with certificates. Modifications to the training in terms of delivery modes, formats, time, and practical skill building were necessary to ensure this study remained inclusive. However, systemic barriers to inclusive research remain. IRB-approved ethics trainings need to be developed that are accessible to researchers with intellectual disabilities and available in languages other than English (McDonald and Kidney 2012; McDonald et al. 2022).

3.2.2. Research Training

Research shows that developing congeniality and trust can promote success in inclusive research and communities of practice (O'Brien et al. 2014; Strnadová et al. 2020). This research training of the RAs was extensive and required consistent in-person engagement with an initial focus on team building. The RAs joined for research training from 10 a.m. to 1 p.m. each day for two weeks and shared lunch together, which was provided by the primary investigator. Having a meal together was an opportunity to build relationships and cohesion within the team. It also ensured that the RAs had a meal since the support person informed the primary researcher that the RAs may not always have access to food.

Trainings for inclusive research have mostly been developed by adapting conventional research methods to make them easy to read and understand (Strnadová et al. 2020; Tuffrey-Wijne and Lam 2019). This has been conducted using pictures, plain language, easy-to-read formats, and pre-written scripts (Nygren 2022). Given that inclusive research has not been practiced in Africa with the intentionality it has received in Western countries and that no locally created research training exists, this research study adapted an existing research training course for people with intellectual disabilities developed by Kingston University and St. George's University of London (Tuffrey-Wijne and Lam 2019). The training was adapted for the Kenyan context and local people with intellectual disabilities. The adaptations consisted of adding Swahili translations and making the pictures and examples used more relatable, fitting, and culturally applicable to the Kenyan setting.

The training covered topics related to both qualitative and quantitative research, along with practical interviewing activities. This research assistants did not read or write. Using a traditional classroom set-up where we sat in a semi-circle holding conversations and projected the topics of discussion on the wall did not elicit the anticipated level of engagement. One of the RAs was unable to concentrate for more than five minutes. It became evident that holding conversations about research was not empowering the RAs in the same way as practicing research activities. The primary investigator then decided to adapt much of the training further into short activities. During these activities, RAs learned how to introduce themselves to participants, how to explain accessible information and interview guides to participants, how to gain informed consent, how to record interviews, how to ask questions, how to listen actively, how to facilitate group discussions, and how to respond to questions others would ask about this study. On each training day, the RAs took home a practice activity and discussed their feedback with the team the following day. Practicing these skills paid off during the implementation of fieldwork when the RAs demonstrated they were well prepared. As part of their preparation for fieldwork, the RAs were introduced to the actual interview guides used in this study. Each RA memorized three interview questions to ask participants during the fieldwork.

The lessons learned are in line with previous inclusive research process findings that there is a need to allow sufficient time for RAs to understand and practice for them to grow confident as researchers (Johnson et al. 2014; Walmsley et al. 2018). Team building helped the RAs, the support person, and the primary investigator get to know each other and learn how to work together (Fudge Schormans et al. 2019; O'Brien et al. 2014). The presence of a support person who knew the RAs well during training was instrumental because they sometimes helped to organize practice sessions and offered phrases and examples that the RAs were familiar with (Conroy et al. 2021; García Iriarte et al. 2023).

It was necessary to adapt training materials beyond increasing accessibility by using familiar language and cultural teaching tools (Mikulak et al. 2022).

3.2.3. Piloting the Interview Guides

To give the RAs an opportunity to practice the skills they had learned, pilot interviews were incorporated into this research training. The RAs conducted interviews with one parent and one individual with intellectual disabilities in collaboration with the primary investigator. During each interview, the RAs practiced asking the questions they had memorized, while all other questions were asked by the primary investigator. The RAs found asking follow-up questions challenging, so the primary investigator took care of this task.

The interview with the parent lasted an hour, while the interview with the person with an intellectual disability lasted forty-five minutes. Both participants were satisfied with the length of the interviews and provided feedback that the questions and pictures in the interview guides helped them speak about their experiences. The parent who participated in the pilot interview expressed joy to see people with intellectual disabilities interviewing her and participating in research. The participant with an intellectual disability expressed gratitude for being asked to share their experiences and needs. Both interviewees received a transport refund.

The RAs practiced recording the interviews with the support of the primary investigator. After the interviews, this research team listened to the recordings to ensure that they were saved correctly and captured clearly. The primary investigator determined that the questions were effective in eliciting responses from the participants. The RAs received feedback that they had asked their questions well and in the right order, according to the interview guide. They were reminded to always introduce themselves to participants. The RAs commented that the pilot interviews were a good learning experience for them since they learned it is important to listen to participants actively to be able to ask appropriate follow-up questions. The RAs told the primary investigator that they needed time to observe the primary investigator asking follow-up questions during interviews before they would feel comfortable doing so themselves. To complete the training, the primary investigator explained this study's research procedures for the interviews and focus groups to the RAs in detail while awaiting IRB approval for this study.

RAs articulated feeling proud and accomplished for completing the training and for being researchers. Although the RAs found research to be complicated, they were happy to be included in it and hoped they would continue to learn through practice. One RA asked if they could be celebrated for having completed the training. This research team agreed to recognize the accomplishments of the RAs at the end of fieldwork. The celebration consisted of a small party at the disability service organization and a meal out.

The challenges in including people with intellectual disabilities as RAs in this study were the result of both systemic barriers and practical and study-specific barriers. Systemic barriers included challenges to securing IRB approval and a lack of formal education for the RAs. Practical barriers included the RAs being unfamiliar with research in general and needing extended time to complete training. Study-specific barriers included challenges in identifying suitable RAs and the lack of culturally adapted research training. Despite these barriers, this study was successful in recruiting, training, and involving RAs with intellectual disabilities in inclusive research in Kenya.

4. Discussion—Pushing Boundaries When Conducting Inclusive Research in Kenya

Inclusive research is scarce, if present at all, in Kenya. This study employed a novel approach to conducting inclusive research with RAs with intellectual disabilities, local people with intellectual disabilities, and their family members. Conducting an inclusive research study in Kenya and supporting people with intellectual disabilities to serve as RAs was a new endeavor. People with intellectual disabilities, their parents and caregivers, the host disability service organization, and the local IRB did not expect people with intellectual disabilities to complete training and conduct research. Numerous interrelated complexities were present throughout the development and implementation of this inclusive research study, which impacted the participation of people with intellectual disabilities in this research process. Two primary barriers experienced in this study included: (1) internalized oppression of the RAs due to stigma stemming from superstitious beliefs, medicalization, systemic discrimination, and a negative perception of intellectual disabilities; and (2) research processes and training methods were not adequately adapted to the context. These barriers and their implications are discussed in detail below.

4.1. Effects of Stigma and Negative Perceptions of Intellectual Disabilities in Inclusive Research in Kenya

Kenyans with intellectual disabilities are excluded from much of public life and are denied equal access to formal education and work opportunities (Chomba et al. 2014). This is mainly caused by negative perceptions and the medicalization of intellectual disability (Gona et al. 2018), which gives rise to stigma, low self-esteem, and internalized oppression (Bunning et al. 2017). Low self-esteem and internalized oppression become barriers for people with intellectual disabilities to participate in research studies, either as researchers or participants.

People with intellectual disabilities are already an excluded and invisible group in Kenya (Bunning et al. 2017; Gona et al. 2018). The lack of services and policy frameworks that ensure that people with intellectual disabilities are participating in the same way as their non-disabled counterparts is discriminatory (Kahonde 2023). The involvement of people with intellectual disabilities as participants and as researchers in this study was an opportunity to improve their visibility. Additionally, it created a platform for people with intellectual disabilities to express their voice and shape knowledge about intellectual disability in Kenya. During this study, people in positions of authority at times acted in ways that were disempowering to people with intellectual disabilities. For example, the suggestion by the Kenyan IRB to remove researchers with intellectual disabilities from this study was removing power from them. In such instances, authority contributes to the exclusion, silencing, and oppression of people with intellectual disabilities in Kenya.

The exclusion of people with intellectual disabilities from knowledge production contributes to the misconceptions around intellectual disabilities in Kenya. These misconceptions form the basis of decisions such as the exclusion proposed by the Kenyan IRB. This further silences people with intellectual disabilities in Kenya, who have a handful of platforms where they can be seen and heard. This ultimately causes barriers to improving their lives through services and supports.

4.1.1. Medicalization of Intellectual Disabilities

Medicalization of disability situates the ‘problem’ of disability within the individual (Patsavas 2018). The dominant view in Kenya is that intellectual disability is a medical problem. This view was upheld by the Kenyan IRB members, who were of the opinion that people with intellectual disabilities should not hold active roles in conducting research and that the etiology of intellectual disability should be described in this research study plan. Including medical causes of intellectual disabilities in this inclusive research study would shift the focus away from societal barriers (Barnes 2019; Oliver 2013) that negatively impact the lives of Kenyans with intellectual disabilities and hinder the implementation of inclusive research. The primary investigator was keen to have individuals self-identify as people with intellectual disabilities because it shifts power to the individuals to decide how they are represented and cultivates self-determination (Siebers 2017).

Medicalizing intellectual disability paves the way for people who do not have lived experience with intellectual disability to develop biased knowledge about intellectual disability. This detracts from opportunities to develop an intellectual disability epistemology from the perspective of those with an embodied experience of living with an intellectual disability. It was therefore necessary to refuse to adhere to the requests of the Kenyan IRB, since the purpose of this research was to dismantle ideologies that are harmful to the intellectual disability community (Wilson 2022). In the future, the Kenyan IRBs would benefit from information regarding the usefulness of including people with intellectual disabilities in research.

4.1.2. Internalized Oppression Due to Stigma

Internalized oppression is a common challenge for people with intellectual disabilities (Watermeyer and Görgens 2013). In this study, stigma seemed to perpetuate the internalized oppression of people with intellectual disabilities, which hindered their ability to advocate for themselves. As a consequence, they often looked up to their caregivers and staff for approval.

Empowering the RAs through extensive training and support did not materialize into instant advocacy because years of keeping people with intellectual disabilities subjugated impacted their self-esteem. Collegiality did not seem sufficient to dismantle years of internalized negative rhetoric and low self-esteem within the short research period. For example, one RA believed that they were possessed by evil spirits because their parents had told them these spirits caused their disability. This RA shared that their parents had taken them to church on several occasions to be prayed over for deliverance. Other researchers have also reported that intellectual disability is commonly seen as a result of witchcraft or a curse in Kenya (Bunning et al. 2017; Gona et al. 2018; Munyi 2012). The negative beliefs about intellectual disabilities had a negative impact on the RAs development of the confidence required to carry out research tasks. This played out during fieldwork, where the RAs barely spoke unless it was necessary, such as when asking their interview questions or when asked to do something by someone else.

RAs and participants with intellectual disabilities had a number of "learned responses" to adhere to how they thought people without intellectual disabilities wanted or expected things to be. Because people with intellectual disabilities were perceived as people who lacked agency, they were infantilized by caregivers and by staff in the organization where they received services. For example, the primary investigator observed during field trips that the support person told the RAs where to sit inside the car and when to eat their snacks. The RAs always obliged without questioning the reasons behind the instructions they received. It was common to see the RA pause and wait for approval to take action or say something. On the other hand, the RAs were quite vocal when they were around their peers. Internalized oppression seemed to result in fear and a lack of trust in anyone besides those with whom they shared an insider-embodied experience.

Self-advocacy laid the foundation for inclusive research in Western countries (Bigby et al. 2014; Bigby and Frawley 2015; Walmsley and Johnson 2003), but there is no self-advocacy movement in Kenya as of yet. There is also a need to build trust in people with intellectual disabilities in Kenya for self-advocacy to develop. Building trust will require changes about how Kenyans think about and treat people with intellectual disabilities at individual and systemic levels. Before communities of trust come to be, there is a need to change narratives into rhetoric that affirms Kenyans with intellectual disabilities' place and belonging in Kenyan society.

4.1.3. Systemic Barriers in Education

Although it is not a must for researchers with intellectual disabilities to have reading and writing skills (Nind et al. 2016), the lack of literacy skills by the RAs in Kenya was a result of discriminatory systems. Kenya has not yet put in place a legal mandate to educate people with intellectual disabilities, and the reasons for it are not clear (Chomba et al. 2014). Research shows that given the opportunities, some people with intellectual disabilities can gain literacy skills if supports, resources, and accommodations are provided (Luckasson and Schalock 2013; Thompson et al. 2009). The lack of a system that supports the education of people with intellectual disabilities in Kenya demonstrates that issues that matter to people with intellectual disabilities do not receive sufficient attention (Mercier et al. 2008). This makes it even harder for people with intellectual disabilities to advocate for their rights because of a lack of tools and support to do so. There is a great need to empower Kenyans with intellectual disabilities with the tools they need to advocate for their issues, including the right to receive formal education.

4.2. Indigenizing Training and Research Together with People with Intellectual Disabilities

Inclusive research methods and practices have mostly been developed in Western contexts. The methods may therefore lack the nuances necessary for the practice to work for populations in the global south that have not been exposed to research. This research was new to the RAs, the disability service organization, and the participants. The primary investigator relied highly on written communication during training and fieldwork. The RAs found this approach challenging, especially because of their limitations in reading and writing. The presence of a support person with insider knowledge proved to be very useful because they were using phrases, figures of speech, and experiences that RAs were familiar with and that have been seen to work elsewhere (Carnemolla et al. 2022). In contexts such as Kenya, it will be useful for inclusive researchers to consider working with support people who have worked with or lived closely with the involved researchers with intellectual disabilities to facilitate their understanding of research. Support personnel need to be people who are keen to empower people with intellectual disabilities. Because of the level of engagement of the support person, it will be prudent to consider remunerating them for their time, work, and contribution towards making inclusive research possible.

Inclusive researchers in global South contexts will need to develop research trainings in collaboration with people with intellectual disabilities. Indigenizing research practice and training by embedding meaningful culturally appropriate approaches such as metaphors, songs, proverbs, and storytelling might be more relatable to local people with intellectual disabilities (Caxaj 2015). For example, the support person in our research team used this African proverb to help the RAs understand the concept of keeping confidentiality: "*Cia mucii ti como*", which translates to "*what is discussed at home stays within the home*". The phrase was catchy and easy to understand, and even months later, this research assistants reminded themselves of keeping confidentiality by just saying this proverb.

Developing research curricula for RAs with intellectual disabilities in global South contexts requires setting aside significant time to collect as many cultural and traditional tools as possible to adapt training. Additionally, it will be important to reflect on the meanings and harmony of the tools when applied to research methods of data collection and analysis (Geia et al. 2013; Somerville et al. 2021). Further research is indicated to determine methods of training and implementation of inclusive research procedures that can be easily understood by people with intellectual disabilities in contexts such as Kenya.

5. Conclusions

In continental Africa, inclusive research still lags because of misconceptions about the agency of people with intellectual disabilities and a lack of expertise around inclusive research. In this first known attempt to conduct inclusive research in Kenya, it was evident that the abilities of people with intellectual disabilities to participate as researchers and participants were stifled by internalized oppressions and external barriers such as limitations by IRBs. Additionally, research training was less adapted to the Kenyan context, which affected the effectiveness of implementing fieldwork. This was in part due to RAs lacking some form of formal education. As a result, the RAs lacked the tools to advocate for themselves. To achieve the level of advocacy where people with intellectual disabilities are actively engaged in inclusive research, they need to feel empowered and develop self-determination skills. The reflections in this paper are from non-disabled researchers only. Future research needs to include reflections on the RAs.

Historically, research methods have not favored the participation of people with intellectual disabilities as researchers (Lester and Nusbaum 2018). Adapting the research methods for use by people with intellectual disabilities in different cultures seems counterintuitive. Since people with intellectual disabilities are most attuned to their local contexts and cultures, research methodologies that embed positive cultural aspects of their context might make better sense to them. For example, the use of materials written in plain and local language accompanied by pictures did not seem sufficient to help RAs in Kenya understand research. It is necessary for inclusive researchers in contexts such as Kenya to develop culturally competent, inclusive research materials. Reimagining inclusive research from a global south perspective will require the attention of researchers from a variety of disciplines, since the lives of people with intellectual disabilities span all aspects of epistemic and ontological imagination.

Upcoming inclusive researchers in Kenya have the arduous task of advocating for Kenyans with intellectual disabilities to take up their rightful place in society and shape their own futures. Junior and upcoming researchers need to reimagine research methods and procedures so they are a good fit for people with intellectual disabilities. Most importantly, they need to push back on patronizing attitudes and medicalization, which stand in the way of affording people with intellectual disabilities the justice they have been denied. As more people get involved in inclusive research in Kenya, narratives around intellectual disabilities and perceptions in academia are bound to change. People with intellectual disabilities may reconsider their beliefs about research participation and perceive different realities once they are able to successfully participate in knowledge production. Inclusive research will contribute to changing narratives around intellectual disabilities through evidence and advocacy.

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social sciences

Article

'The Ball of Cooperation Rolls on': Some Personal Reflections on My Experiences as a Researcher

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Abstract: People with disabilities are increasingly actively involved within research projects. For many of them this is a temporary role, but some work on longer-term projects and even build a career out of it. This is the case for the first author of this paper. He has worked as a researcher for almost six years. He is involved in various projects, all highly diverse in terms of subject, design, scope and collaboration with fellow researchers. In this paper, he looks back on his experiences in recent years. Together with colleagues, he reflects on his contribution to the various projects, his own development as a researcher and the impact of the work on his personal life. He finds that the essence of the motto 'Nothing about us, without us' has become increasingly intertwined with his life and identity through his work.

Keywords: inclusive research; participatory research; intellectual disabilities; collaboration; lived experience

1. Introduction

Inclusive research has come more and more to the fore over the last 20 years. This form of research made it possible to switch from research 'into' people with disabilities to research 'with' people with disabilities. The idea was to involve people in designing as well as conducting research, to better understand their lived experience, and above all to respect their practical knowledge. Much of this research is intended to represent the interests of people with disabilities, and address issues of importance to them. It must be possible to use the research results to help people with disabilities lead better lives.

From the first inclusive studies, lessons were learned and solutions were explored for problems that arose. For example, training programmes were developed in which both co-researchers and professional researchers could participate. These training programmes came in for criticism, as they risked molding the co-researchers too much in the image of an academic researcher (Nind et al. 2016; Sergeant et al. 2020). Within subsequent stages of inclusive research, many co-researchers have become involved in committees set up to evaluate research projects (Bigby et al. 2014; O'Brien et al. 2022). In addition, many were also members of self-advocacy groups that helped ensure that inclusive research was increasingly on the agenda and taken seriously, both locally and internationally (Strnadová and Cumming 2014; Walmsley et al. 2018).

Many lessons have been learned from these initial years of inclusive research, but at the same time, problems sometimes persist. For example, based on their systematic review on the involvement and experiences of co-researchers, Hewitt et al. (2023) emphasize the complexity of inclusive research. This complexity involves, amongst other issues, challenges in organizing appropriate support and training for co-researchers (Bigby et al. 2014; Montgomery et al. 2022) and the experience that funding for inclusive research is not always dependable. In addition, O'Brien et al. (2014) indicate that lack of time often remains a problem for co-researchers. Guidance from a job coach[1] is not always a given, and many co-researchers only remain involved in specific areas of a research agenda (they conduct interviews, for example, but do not subsequently process them).

This paper presents a unique story, focusing on the position, accumulated expertise and experience of the first author. It details a long, continuous and varied research career, which has taken the first author into various research environments and roles. This paper presents his personal reflections on this experience. The co-authors contributed to the reflections in this regard and offered suggestions at various moments in terms of getting thoughts down on paper.

2. Context

2.1. This Is Me

My name is Mark. I was born prematurely, 48 years ago now. Compared to the people around me, I had a somewhat slower start in life. This had repercussions in the first jobs I worked at through the mediation of an employment agency, where I always realised that I was not a good fit. In 2005, I was diagnosed with PDD-NOS, a form of autism. This led me to the Philadelphia Care Foundation (a care organisation for people with intellectual disabilities in The Netherlands) for support. This opened up opportunities for me, as I could work on my talents in a partially sheltered setting. I was able to develop myself, also because for a long time I served on various client[2] participation councils[3] and even served as chairman of the national council.

My home situation for a long time was living in a residential community where I was supported by professional support workers. I lived with seven other residents and was able to lead my own life. In 2013, my life was enriched when I re-found my faith. I had been raised Christian all my life by my parents, but in 2013 this became a conscious choice. New friendships were forged in the church and my drive to do something for my fellow human beings grew. There were also situations in the church and society where I could help, both practically with my hands and by having something to say. I also began to immerse myself in the church on a spiritual level. In recent years, I have completed studies in the church, at a part-time Bible college. This allowed me to develop even more as a person. Not only in terms of knowledge of the Bible and principles that apply to Christian life, but also in terms of reflecting and describing experiences in personal life. I also met my partner at the church, and we have been married for a few years now, and live together in our own home. I still get support from support workers, but it is different now, being once a week near where I live.

2.2. This Is My Work

Via the participation council of the Philadelphia Care Foundation, I came across a job vacancy for a co-researcher. This seemed like a great opportunity, because it would allow me to observe and advise on policy. Instead of being a hobby, this could become my job. At the end of 2017, I was really a part of Philadelphia. For the first few years, I worked on a large project with one other researcher, the second author in this paper (Miriam Zaagsma). This was her PhD thesis. We wrote a paper together about our experiences in working together on this project (Zaagsma et al. 2022). In this current paper, I discuss the personal experiences I had during the projects that came after that. The first part of its title (‘The ball of cooperation rolls on’) is a reference to our previous paper (the title of which ended with ‘. . .and then the ball of cooperation started rolling’) and emphasizes the fact that we now focus on my continued work efforts and experiences. Table 1 lists the various projects I have worked on in recent years. You can see that these projects had different subjects and that the composition of the teams varied from project to project.

Table 1. Overview of [Name first author]'s projects.

	Type	Topic	Organisation	Collaboration	Period
1	Research (PhD)	Digital support service	PCF [a]	1 researcher	2017–2022
2	Research	Financial respresentation services	PCF	2 professionals (not researchers)	2020–2021
3	Development and research	Serious game on mental resilience	PCF	8–9 professionals (not researchers), multiple disciplines	2021
4	Development and research	Instrument for screening on health issues	PCF	1 researcher	2021
5	Research (PhD)	Integrated emotion-oriented care	PCF	1 researcher	2022
6	Research	Socially assistive robot	PCF	1 researcher	2023–now
7	Research	Relationships, intimacy and sexuality	DsiN [b]	1 researcher and a larger project group	2022–2023
8	Preparation European research proposal	Stigma and representation in film	DSiN	10 researchers (international)	2022–2023
9	Training	Collaboration in inclusive research teams	DSiN	1 researcher	2022–now
10	Development and research	Socially assistive robots in families headed by parents with ID/D	DSiN	3 researchers and larger project group (multiple disciplines)	2022–now

[a] Philadelphia Care Foundation; [b] Disability Studies in the Netherlands Foundation.

After Miriam's PhD thesis was completed, a lot of things changed for me. I was still employed by Philadelphia, and I started collaborating on various smaller studies for 20 h a week. I was also working 8 h a week as a project officer in a department that fostered the use of innovation in care and support settings. Since mid-2022, I have been seconded to the Disability Studies in Nederland Foundation (DSiN)[4] for 15 of the 20 h I spend on research. This foundation works to raise awareness of disability in society by means of research and education, and aims to contribute to the empowerment of people with disabilities. The foundation is affiliated with a university: the University of Humanistic Studies in Utrecht, The Netherlands. One of the co-authors of this article (Alice Schippers) is both working for DSiN and as a professor at this university. This means that we are affiliated with both educational institutions and care organisations.

3. Materials and Methods

To write this article, I did not want to reflect on my work on my own. I wanted to involve the people I worked with. I started by approaching six people with whom I had worked closely over the past year and a half. These were five researcher colleagues and my supervisor. I put three questions to them by email: (1) What helped us work well together? (2) How did we make decisions? Did we make decisions together or did I give advice and someone else made the decision? (3) What were the pros and cons of conducting research together?

I received responses from all six of them via email. Based on their responses, I started thinking more about this and writing down my thoughts. I had various conversations with my co-authors (sometimes individually and sometimes all together). Based on these conversations, I started working further with them, drafting this article in several sessions.

4. Reflections

In this section, I describe some of my reflections. I selected those reflections that I think are important to share and will be valuable to other researchers as well. I organised my reflections into three parts. In the first part (Section 4.1), I describe how the projects in which I am (or have been) involved have complexity as the common feature. Three things stand out in this regard: the subjects on which I conduct research (Section 4.1.1), working (simultaneously) on many different projects (Section 4.1.2) and working in different environments (Section 4.1.3). In the second part (Section 4.2), I go into more detail on the collaborations I have (or have had) with colleagues. I focus on what I consider to be important ingredients to ensure successful collaboration (Section 4.2.1) and what I see as my contribution to the projects as a co-researcher (Section 4.2.2). In the third part (Section 4.3), I analyse the development I have undergone in recent years, both as a researcher (Section 4.3.1) and how my work and my personal life have influenced and interacted with each other (Section 4.3.2).

4.1. Working in a Complex Environment

4.1.1. Complicated Topics

A recent important project looked into the use of robots in families headed by parents with intellectual disabilities. There are various taboos and stigmas associated with this project. It also deals with technology, and involves researchers from different backgrounds, such as researchers from the technological domain. I find this very interesting and enriching, but it also comes with a lot of confusing terminology. The researchers sometimes talk in great detail, and quickly, about technical facets that I am hardly aware of. What also made it complicated for me is that a colleague I worked with a lot did not speak Dutch. My English was better than her Dutch, so we spoke in English. But that did sometimes made communicating and working on the subject complicated.

Another research project also addressed a taboo subject, namely sexuality when living in a care facility. My researcher colleague and I noticed that a number of respondents with mild intellectual disabilities approached us directly to talk about this topic. They told us they wanted to talk directly with us, preferably online, and that they did not want their support workers from the care organisation to know about it. It turned out to be an advantage that I was not affiliated with their care organisation (I worked at a university), since this offered them extra reassurance of confidentiality. Because I had already been involved in several research projects as a co-researcher and hands-on expert, I could also ask more focused questions. I lived in a residential community for over 10 years, together with other clients. At first, I only had my own bedroom, and later my own apartment. I learned a lot during this time, in terms of taking others into consideration and looking for positive sexuality in long-term care settings.

4.1.2. Many Different Projects

In the projects I work on and have worked on, the teams have a highly diverse make-up. In the project on sexuality, I work closely with one colleague, and in another project with three other colleagues. What is more, each of the projects has a structure in which more organisations and people are involved.

I was used to working with just one researcher. In current projects, however, I usually work with several people in a team, or in consortiums. A consortium is a team made up from different organisations, all working together. This complicates things, because not everyone can make the same amount of time available. If you want to optimise the collaboration, it is useful to get to know each other to a certain extent. That way you can show understanding for each other when something becomes a challenge in terms of work and/or time.

Different research methods are used in the various projects, varying from desk research in one project to action- and design-based research in another. I found design-based research a bit more challenging because nothing is fixed in advance and I have to constantly adapt to changes and new plans.

Working on various research projects gives me a lot of freedom. I can arrange the work so that I can give the best of myself. If I am in a positive collaboration with people, in which everyone's talents are utilised, I get a lot of energy. At the same time, switching between projects is energy-draining. This makes it important to have good time management. For example, through my job coach I learned to organise my work by using colours in my calendar. For each day, I marked the hours I was going to work on a given project with a specific colour. That way, I could see exactly what I was going to work on, and not spend more time on a project than agreed on. For me, it is a good idea not to switch too much between projects during a day. That way, I keep the balance of work and energy positive.

4.1.3. Different Environments

Within the university, I work with my colleagues from DSiN at the Care Ethics department. We primarily conduct research there. We share knowledge from literature several times a year, and I once contributed to the draft of a research proposal on loneliness.

My colleagues at DSiN mostly work part-time because (like me) they have other work on the side, are still studying, or are trainees. Many of them are ambitious junior researchers. I have found that working on many different projects at the same time is the norm. I have also noticed that people in academia set high goals, especially when they are juniors. Because of their inexperience, they often want to organise meetings at the last minute. There is no guarantee with junior researchers that you will have access to all the information. I noticed, for example, that I was not being put in the cc. of emails. This means that I can get less done, partly because I am less prepared than I would like to be. I have found that if I am included in email exchanges, I can see certain actions coming up, and I can work more efficiently.

There are clearly advantages to working in a small independent team as well, because, as a small organisation, DSiN is affiliated with various educational consortiums and interest groups in care settings, and I have the opportunity to go to various meetings, to follow courses and even to teach myself. This means I can take on board all kinds of additional information, and pick and choose the most interesting for myself, and then continue to share my knowledge again.

I generally experience a lot of mutual commitment. One advantage of working in a small team is that I can be involved in more work. Precisely because I am so eager to learn, this is a nice aspect for me. However, I then need to be flexible in my time, and have the necessary space and time available. It is also important to have colleagues with whom I can work together well and feel a connection with so that everyone can play to their talents. One of my talents is talking. I gave a guest lecture in a seminar at the university in the Disability Studies course. I talked about my research work. I really enjoy teaching; I can introduce students to co-research. This gives me a lot of energy and reminds me that I am in a privileged situation, and that you need to seize the opportunities that come along.

4.2. Working Together with Colleagues

4.2.1. Ingredients for Successful Collaboration

(Get to) know each other really well. The collaborations I have been part of were generally pleasant and easy-going. I learned a lot along the way and, more importantly, also gained personal insight. Taking an interest in each other is also important, that you are curious about the other person, also as an individual, outside of work. One of my colleagues agreed, and she wrote to me: "*It helps if you can share some things with each other on a personal level. It doesn't have to be the case, but to me it makes the collaboration better. When you know each other better, you can know and use each other's strengths*". I especially enjoy working with people who, like me, undertake a lot of initiatives and are interested in others. It is important to take the time to get to know each other. Everyone has his or her own way of looking at something. When you know this, there is less chance of having to break down prejudices towards each other. Getting to know each other does not always come naturally. You both have to be willing to be vulnerable and open. When you are getting to know someone and finding common ground, you also need to invest quite a lot of time if you want to get to know each other well. Sometimes, the circumstances make it more difficult to get to

know each other. For example, on one of my projects, we mainly communicated via video calls. Although conversations online are faster, I noticed that it takes longer to get to know each other. When you eventually meet in person, after dozens of online meetings, it does feel familiar.

Equality. I noticed that although some colleagues tried to shape our collaboration in a very equitable way, this was less the case for others. With the colleagues who felt an equal footing was important, I had regular and pleasant contacts. We looked together at what actions needed to be taken, and worked out who would do what based on who was suitable for it and who had time. This was not only a very practical way of collaborating, but also took into account everyone's talents and abilities. A colleague wrote to me: "*In our collaboration, we look at capabilities and talents. For example, some people are good at writing, others at asking questions. I'm sometimes impatient and hasty, but Mark is good at going into detail. We give each other the possibility to do what we are good at. As a result, we work nicely together*". For me personally, time has always been the most important factor in making decisions whether to do things or not. After all, there are a lot of things I like doing. Over the years, I did notice that I can make better and faster choices in what I do and do not do: I say yes or no more consciously. In the collaborations with some colleagues, I noticed that we communicated less with each other. For example, they kept me less informed of developments in their work. They did not involve me in certain decisions they made for themselves. I do not think this was always consciously or on purpose, but it is not pleasant. I noticed that I then had to find out things myself, for example, to ask if an appointment was already planned, if that was necessary for the project. It was more difficult to work like that than being an equal partner in the project/research. And it takes up more communication and energy, which, in my opinion, is a waste of time. For me, the main thing is involving each other and not making decisions on your own. Of course, it is also fine that the other person sometimes makes decisions without me. It is not about ignoring the principle of equality; it is mainly about respecting each other, and involving people where necessary. If we discuss together and agree that the other person makes decisions in a certain period or situation, that is also good. The following quote from my colleague is a good example: "*During the 'train the trainer' session, I took more of the decisions. We did this by mutual agreement because Mark had a little less time to prepare for it properly*".

Consciously looking at the collaboration together. I think it has been very worthwhile to sit with colleagues and look at our collaboration together, to see what is going well and what could be done better. You can plan a separate meeting for this, or you can do it during the work. In the various projects, this was not always done at the same level of detail. If it did not happen, I always thought it was a pity, and above all a missed opportunity. Sometimes, I felt like I had to take the initiative each time. This was more often the case when I worked with junior researchers. They did not seem to be as interested in reflecting on the collaboration. In contrast, colleagues who (also) had a background in care seemed to consider it more often than colleagues with only a research background.

4.2.2. Not More of the Same, but Something New

Each person has his or her own ideas, and sees the world in their own way. Similarly, I have my own ideas about how the world works. And what makes me extra special compared to my researcher colleagues is that I am more familiar with the experiences of people with intellectual disabilities than they are. That is my strength as a researcher, and I can add this to the knowledge of my colleagues. For example, during interviews, I can ask questions that are more relevant to the lived experience of the interviewee. One of my colleagues said: "*A lot depends on conducting research in practice; in our case, how people with intellectual disabilities are represented. Working with Mark brings the practice and experiential knowledge that is so desperately needed. For example, Mark asks different questions during interviews than I might come up with, because he shares that lived experience with many of the respondents*". If you think of a research study as a chessboard, I am a different chess piece than my colleagues. Another colleague put it like this: "*Mark can empathise well with the* *world of people with disabilities, which gives him a 'knowledge privilege' in the field of experiential knowledge*".

In addition, I like to get to the bottom of things, and I think that is a quality as well. Where colleagues often settle for a short answer, I keep asking questions. I may not always be relevant, as I sometimes go off on a tangent with my questions because it may be something in my own interest. And it has also happened that I mix up questions from different studies running at the same time. My persistent questions are not only useful during interviews, but also for colleagues when I keep asking them about the research process.

4.3. My Development and Lessons Learned

4.3.1. I as a Researcher

More nuanced. Being able to process information more deeply and hear opinions and points of view from others means that I have a broader perspective. This provides me with an opinion that is more nuanced than the label I used to give to that information. I have found that looking at things in more detail gives your opinion and conversation more context and meaning. And your opinion becomes more nuanced due to the amount of information. I can also more easily put myself in the shoes of others and show understanding for others. I also feel more easily understood myself.

More philosophical. Continuing to ask questions helps me gain wisdom. As a researcher, I have the opportunity to gather information in many ways, and to ruminate on that information. I have found that I have become more philosophical as a result. I notice this in the way I speak. I think I understand and speak the same language as someone who calls himself a philosopher. On Wikipedia, a philosopher is described as a sage.

More confidence. Even though it is still important for me with colleagues to get to know each other well (see Section 4.2.1), I do notice that this has changed. When I was just starting out as a researcher, it was much more important to feel completely comfortable in a team than it is now. I needed a personal click with a colleague. This is less important now. I think this has to do with my self-confidence as a researcher. I now get my self-confidence more from myself and from experiences at work. I do not need the affirmation of others as much now.

4.3.2. How My Personal Life and My Work Are Intertwined

My private life has changed in recent years, because I got married a few years ago. My living situation, for example, has changed, as mentioned in Section 2.1. Whereas making compromises proved to be a bit of an issue for me before, this is vital when you are married. Because I now find it easier to put myself in others' shoes in my work, it filters down into my private life. Asking questions, analysing and informing is something that has become interwoven into my life as a whole.

In addition, I have found that my Christian conviction of gratitude influences my work. At Bible college, I reflected on my past and realised that enjoyment has always been an important value in my life. I used to chase it, and now I find it in Biblical values that I embody. For example, the Bible says, "*Rejoice always and delight in your faith, be unceasing and persistent in prayer, in every situation [no matter what the circumstances] be thankful*".[5] (Life Church 2024). At work, I find that I do not think in terms of problems, and do not see many hurdles. Having gratitude in my life means that my faith is set free. Gratitude makes big challenges smaller. For me, research is a task where the process is perhaps even more important than the result.

Meditation gives me focus, also in my work. A good example is a research project where I was supposed to collaborate with an English-speaking colleague. I wondered whether I could actually handle it. Meditating and thinking long and hard about it gave me the belief that I could do it, and that my involvement would actually be beneficial for the participating Dutch families. I also believed that it could make me more confident, with the prospect of contributing to a European research proposal. In the end, I did actually become more confident in terms of the English language. That makes me grateful, to realise I can face a challenge but remain steadfast. Meditation was also valuable in another project. At first, I had reservations when being asked to take part in a research study on sexuality. I consider sexuality and intimacy a private subject that I only talk about with my wife, or possibly very close friends. Meditation made things much less complex, as I realised that I could participate in my role as a researcher rather than as a hands-on expert. As a result, I could commit to that project and I proved to be a complementary asset to my colleague.

The examples above show that my work is strongly interwoven with my personal situation. The Bible says, "*Whatever your hand finds to do, do it with all your might*"[6] (Life Church 2024). In other words, if you cannot do as you should do, you should do as you can do. So, I do what I can do. And my colleague does what he or she can do. When you understand each other and know what each other wants, and everyone does what they can, there is more space and mutual understanding and you get the best results. Each research study has its own flow, and I have come to the conclusion that any collaboration works best when you 'go with the flow'. Let me be 'co(-researcher) with the flow'.

5. Discussion

In this discussion, I go over various issues that have struck me in my various research experiences in recent years.

Trust. As a researcher with experiential knowledge, I was able to create trust, which made people (respondents) willing to share sensitive topics with us. I described this in Section 4.1.1. with regard to a specific study on (positive) experiences with sexuality within care and support settings. I think my involvement helped to create trust in several ways. First, the respondents appeared to find it important that they could approach the researchers directly. Contact via supervisors often meant that an interview did not take place. We therefore announced the study via a flyer that was distributed within the researchers' networks and through social media channels. This meant that people could approach us themselves, directly, and so we got in touch with respondents who were generally motivated to talk about the topic. Second, before and during the interviews, my colleagues and I invested in getting to know each other and creating a safe setting. Specifically, this meant that in all interviews, we took ample time to get acquainted with the respondents and made a conscious decision regarding which topics we would ask about first, and which we were going to come back to later or even omit. Third, I think my own experience of living within a care organisation and wanting to represent people's interests by standing up for my opinion also made a difference, because it often created recognition and acknowledgement. Reflecting on this with the research team, we noted that trust was created because I am one of them, and can empathise with the ethical dilemma the respondents were in. At the same time, I think it was also nice for the respondents that I had sufficient distance from their day-to-day lives. For example, we also did the interviews online, so there was literally physical distance, while we were talking about physicality. All this created trust.

Partnerships. In the research teams, I was given the opportunity to participate as a full partner in research. With my colleagues, we recognised in this the concept of 'relational autonomy' (Mackenzie 2014). This concept implies that you are always dependent on each other, or interdependent. That is the case in general, but especially within research teams that divide the work among themselves, and complement each other in terms of skills. For example, I have experiential knowledge that other colleagues do not have, while they have more experience with, for example, writing. This is also how this article came about, by discussing with my co-authors together and sometimes literally handing over the computer while I dictated and a colleague typed. I definitely experienced autonomy. I experienced it precisely because we were equal partners. For me, autonomy is about giving each other space, and respecting each other.

Interwoven with personal life. Thanks to my experience with receiving care and support services, and thanks to my role on the participation council, I have seen changes that take place in care settings over time. One of the most important changes is the shift from people with disabilities as 'objects' of research, to people with disabilities as 'subjects' in research, and involving them in ambassador roles. Through my more than six years of experience as a researcher, I have increasingly had the opportunity to determine and explore various research themes, topics and questions. I could do this from my (shared) interests and experiences: it is actually my personal life. The common thread was: what do we, people with disabilities, think is important to research? For me personally, this in particular took the form of contributing to a European research proposal on the topic of stigma among people with intellectual disabilities. Through my experiential knowledge, prejudices of colleagues on that subject were visible and recognizable. But it also broadened my own view on the subject. The definition of stigma therefore became clearer to me, namely, that a lack of knowledge is a reason to label something, and that this label can stigmatise. As such, it became clear that not only researchers, but also I myself—and perhaps other people with disabilities—stigmatize.

As a conclusion, it is clear to see in this article that I endeavoured in many ways—together with colleagues—to add real value to research. This was partly by ensuring that my role and tasks as co-researcher were worked out and included in such varied ways as to avoid the risk of stigmatising (in this case: locking someone into a pre-described and unchangeable role of co-researcher). As my colleague (Geert van Hove.) puts it: [Mark] becomes a Houdini figure whenever a role is too rigidly defined. In addition, my involvement in the various studies offered added value because through the process I became more confident and 'relationally autonomous', and therefore a veritable partner in the various networks. Finally, the strong connection to my own life also provided additional opportunities to grow, as I experienced it, from 'object' (Mark Koning) the co-researcher) to 'subject' ([Mark Koning] the colleague).

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Informed Consent Statement: Informed consent was obtained from all subjects involved.

Data Availability Statement: The data presented in this study are available on request from the corresponding author due to privacy concerns.

Conflicts of Interest: The authors declare no conflict of interest.

Notes

[1] A job coach is a professional who helps people (temporarily) to perform their work; for example, helping them with overcoming barriers in the workplace and/or obtaining and keeping an overview of the work.

[2] Clients are people who procure care and/or support services from a care organisation (such as the Philadelphia Care Foundation).

[3] A participation council is a group of people (in this case clients) who meet regularly to jointly advise and decide on policy in discussion with the care organisation.

[4] Disability Studies in Nederland (DSIN) fosters research and education in the field of disability studies. For more information, see https://disabilitystudies.nl/ (accessed on 11 January 2024).

[5] 1 Thessalonians 5:16–18.

[6] Ecclesiastes 9:10a.

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social sciences

Article

The Role of Trust, Respect, and Relationships in Maintaining Lived Experience and Indigenous Authority in Co-Designed Research with People Living with Disability [†]

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[†] The authors would like to respectfully dedicate this paper to Aunty Maria Robinson who was a member of both the team that conceptualised this research and the Indigenous Advisory Group for its 5 year duration. Her wisdom and input has ongoing impact.

Abstract: Co-design of research can evolve organically when the questions to be asked have their roots deep1 in the soil of partnerships based on trust, respect, and a common vision for equity and inclusion. White Questions—Black Answers, a PhD thesis research project focusing on the inclusion of Indigenous students with disability in the Australian Higher Education Sector, demonstrates this premise. Founded on Indigenous Standpoint Theory, the methodology of this research foregrounds the central role of Indigenous people with lived experience of disability—in the study design, its implementation, and in the validation of the results. This paper shares the conceptual framework and relationship hierarchy for the research, ensuring that the authority of those with lived experience was maintained and central to all research activities. It showcases a way forward for other fields of co-designed research, delivering both academic rigour and leadership by those with lived experience.

Keywords: decolonisation; disability; Indigenous; Indigenous standpoint

1. Introduction

This study, undertaken in the Australian Higher Education sector, produced a blueprint for the co-design of research by non-Indigenous researchers with Indigenous people living with disability. It evolved out of the organic leadership of Indigenous supervision in this research and the desire of the lead researcher (i.e., the PhD candidate—herein referred to as the researcher) to acknowledge the authority of Indigenous advisors living with disability. A conceptual framework was developed and applied throughout this research. This conceptual framework reallocated power in the research relationship away from the PhD researcher to the owners of the knowledge being researched. As such, this provides a way in for non-Indigenous researchers to contribute to the research goals of Indigenous populations who live with disability.

Alvesson and Sandberg (2013) prescribed innovative and imaginative research methods and introduced the path-up scholarship methodology. Path-up scholarship proposes challenging existing frameworks and the use of alternative methodologies. It refers to a process of immersion for the researcher, who questions themselves, their values, their biases, and the applicability of standard research methods, rather than following research conventions to secure acceptance. They state that as researchers, we should be: Committed to . . . ideas we care about rather than focusing on what our publications will do for our image, our compensation, or our careers. That is, we need less instrumental gap-spotting and publication-prioritising sub-specialists working for a long time only within one area, and more researchers with a broader outlook, curious, reflective, willing and able to question their own frameworks and consider alternative positions, and eager to produce new insights at the risk of some short-term instrumental sacrifices, that is, a more critical and path-(up)setting scholarship mode (p. 143).

Similar to decolonisation methodologies, including universal design of learning, cultural safety, person-centredness, and social inclusion, the research focus of path-up scholarship is on those whom it serves rather than the system. Charbonneau-Dahlen (2020), an Indigenous American researcher, developed Symbiotic Allegory as an Innovative Indigenous Research Methodology that combines traditional Indigenous storytelling with Western research methods. Charbonneau-Dahlen (2020, p. 35) affirmed the 'importance of creating methodologies that incorporate the ways of knowing of the group being studied', facilitated by 'a member of the group being studied who is able to collect data in a respectful and culturally harmonious way for the purpose of disseminating the research'. Careful, supportive, creative, purposeful, and responsive are descriptors for these methods of innovative research. It is with this approach that Kerr (2021) embarked upon her PhD research, White Questions, Black Answers, as a non-Aboriginal woman, from which this paper is drawn. The research did not commence with an established methodology to guide research activities; instead, it responded iteratively with methods compatible with the conceptual framework (Figure 1), which evolved in partnership with the Indigenous leadership of those with an Indigenous standpoint on disability: John Gilroy, Roslyn Sackley, Maria Robinson, and Naomi Carolin.

Involvement of those with lived experience of being an Indigenous Australian living with a disability in this research through supervision, advice, or participation constituted the beating heart of the research and drove its purpose, lens, and activities. It was through deep mutual respect that the non-Indigenous researcher was entrusted to undertake the research and supported through the five-year duration of the research journey. Those with lived experience were not chosen by the researcher as contributors to support her research intentions; rather, the researcher was chosen by those with lived experience to serve and undertake research that they deemed necessary and valuable. This resulted in a collaborative research relationship with leadership by those with an Indigenous standpoint on disability. The research questions that they wanted answered were:

1. What are universities doing concerning supporting Indigenous students with disability?
2. What lessons can be learned from listening to the stories of Indigenous people with disability who have lived experience navigating the Australian Higher Education Sector?

The researcher was known to those with an Indigenous Standpoint through previous collaborations regarding the support of Indigenous students with disability. They had been colleagues while working with Macquarie University Accessibility Services, a national service that provided accessible learning materials for the Australian Higher Education Sector between 2004 and 2014. Relationships and trust were further enhanced through open and frequent communication between the researcher and the team throughout the entirety of the project. Their counsel was sought with regard to the Indigenous perspective of disability and gender-specific ways of doing and knowing. As women with leadership roles in their communities, they each contributed wisdom and insight that would not have been possible without their central role in the project encompassing the ongoing development of mutual trust between the Indigenous Advisory Group and the researcher.

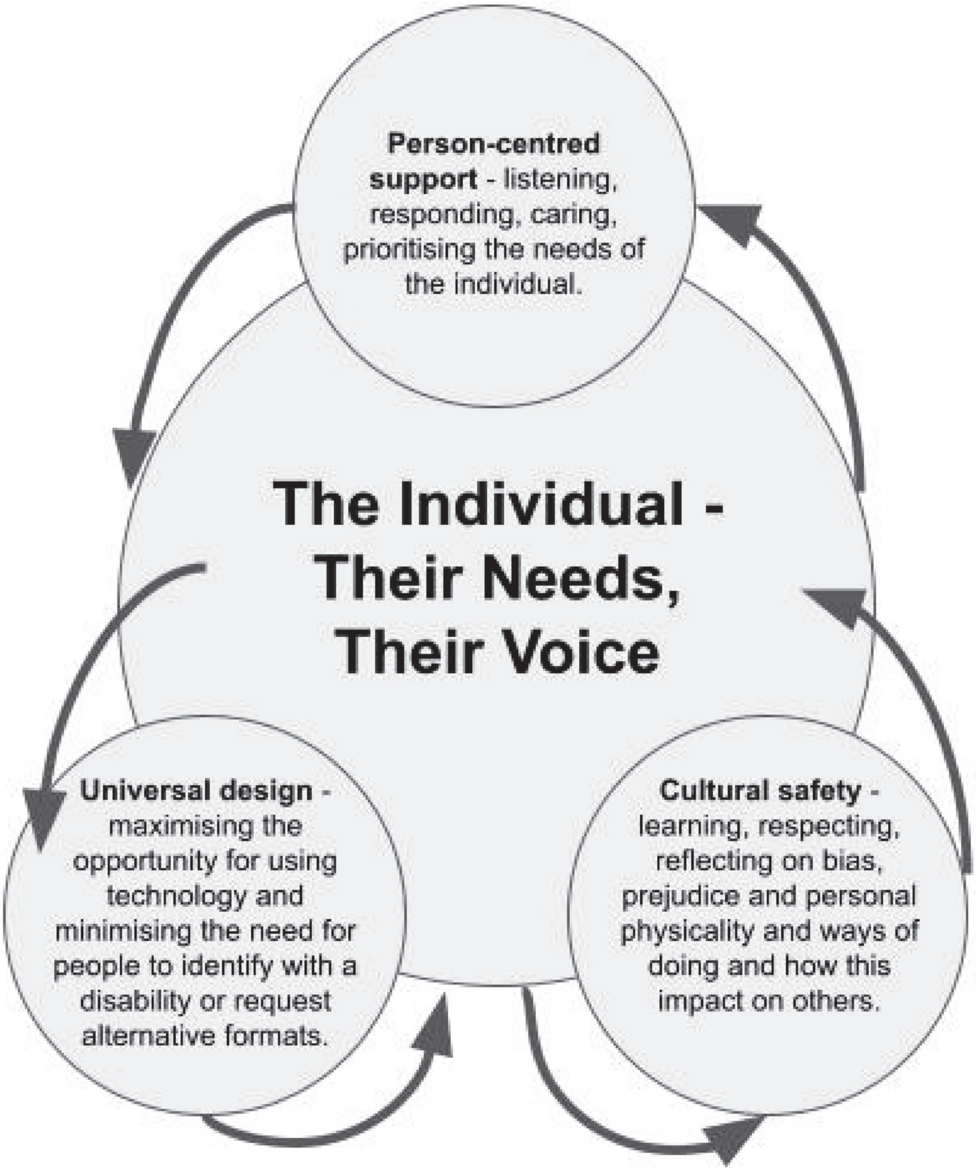

Figure 1. Framework for All. Note. From "White Questions—Black Answers: Effective Inclusion of Indigenous Students with a Disability into Higher Education in Australia" Kerr (2021, p. 155).

2. Method

Founded on Indigenous Standpoint Theory, as presented by Gilroy (2009a), the methodology of this research foregrounds the central role of Indigenous people with lived experience of disability—in the study design, its implementation, and in the validation of the results. This research applied a mixed methods convergent parallel design. As described by Creswell and Plano Clark (2011), the study involved collecting and analysing two distinct datasets and provided a solid methodology for validation of the quantitative and qualitative data collected in this study. The Quantitative Track comprised an audit of Australian university websites and a review of Disability Action Plans to ascertain the nature of service delivery. The Qualitative Track comprised listening to the stories and truth-telling of five Indigenous people with disability who had undertaken higher education in Australia. Truth-telling in the context of this research involved sessions going on for as long as participants needed and being conducted in the manner they requested. Following the collection and analysis of the unique datasets, a process of comparison and identifying relationships between the two Tracks was undertaken.

This research was:

- Supervised and led by an Australian Indigenous scholar who is recognised nationally for his work in Indigenous health and disability, thereby ensuring that research activities undertaken have been mindful of and informed by someone with an Indigenous standpoint.
- Informed, guided, and validated by an Indigenous Advisory Group, and
- Supported by an Indigenous cultural broker, who attended all interviews.

The Advisory Group comprised three Aboriginal people with lived experience of disability. Their role in this research was as supportive peers guiding the embedding of Indigenous standpoint throughout this research. The Advisory Group's involvement was crucial in securing the participation of Indigenous people with disability who had undertaken higher education and in laying the foundation for trust and open, honest communications. The Advisory Group also played a crucial role in validating the research findings.

Roslyn Sackley was employed in the role of cultural broker and was present for all interviews. Roslyn is a Nyiampaa and Wiradjuri woman with total vision loss due to meningitis as an infant. Roslyn has taught in the Australian Capital Territory and New South Wales primary, senior secondary, TAFE, and university sectors. As a cultural broker, she did not ask any research questions, comment on responses, or participate in data collation or analysis. The purpose of her role was to:

- Ensure the embedding of cultural safety into the data collection process.
- Improve the power balance in the interview process in favour of the interviewee.
- Provide: (i) empathy and cultural support to the interviewee, (ii) feedback for better ways of conducting the research to the researcher, and (iii) reassurance of the efficacy and purpose of the research for the participants.

Figure 2 represents how the conceptual framework was applied to the interviews and illustrates the power relationship between the researcher, a non-Indigenous woman without disability, and the Indigenous Australian participants living with disability. The image shows three concentric circles—the researcher is represented as the smallest inner circle. The next circle represents the participant and the cultural broker together (i.e., the cultural broker is there to support the participant, not the researcher), with a two-way line leading to the researcher representing sharing. The outer circle represents cultural safety. Participants were given the option of where and how they wanted to participate in the study. Participants lived in various states and territories while undertaking their studies; however, at the time of participation, they were residing in Sydney (one female), North Coast New South Wales (one male), South Coast New South Wales (one male), Canberra (one female), and Adelaide (previously Darwin; one female). Due to the commitment made to the participants to preserve anonymity and avoid plausible or accidental disclosure, we are not in the position to provide further demographic data, other than to say that they were between the ages of 26 and 70, all were Indigenous, and all had disabilities, which included sight impairment, deafness, intellectual, psychosocial, and physical disabilities.

A time limit was not set for the interviews—each participant set the duration and content of their session. Each session was also attended by the cultural broker, who helped participants feel relaxed and empowered during the research process. The cultural broker would introduce themselves and the researcher, talk about their family, and reflect back comments when participants mentioned their own families and communities. To avoid rushing participants, interviews commenced when the cultural broker indicated that it was the right time to proceed. The entire focus of this methodology was to empower the participants and help them both relax and gain an understanding of the respect that the researcher had for them and their knowledge. Five participants were invited to tell their personal stories of engagement with higher education, and the researcher listened. Sessions were recorded and interviews were transcribed and analysed. However, during the interviews, no notes were taken; instead, the researcher and the cultural broker listened and engaged with what was being said by the participant, considering the impact of their experiences on their lives.

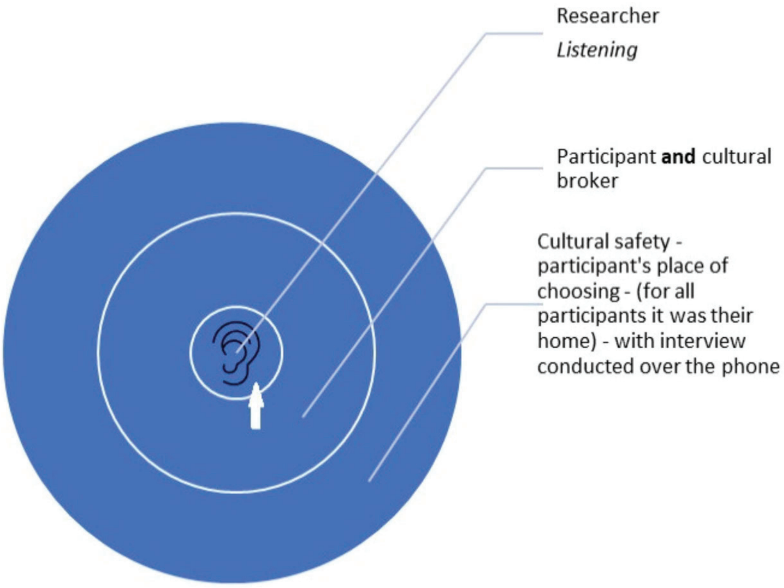

Figure 2. Power in the interview relationship. Note. From "White Questions—Black Answers: Effective Inclusion of Indigenous Students with a Disability into Higher Education in Australia", Kerr (2021, p. 75).

Three studies, consisting of two quantitative and one qualitative study and a final validation meeting with the Indigenous Advisory Group, provided insights into the experience of Indigenous students with disability engaging with the Australian Higher Education Sector. The first study that was undertaken in 2016 involved 40 Australian universities, identifying what services and supports they were providing to students with disability, Indigenous students, and Indigenous students with disability. The second quantitative study that was undertaken in 2020 examined the disability action plans of the same 40 Australian universities to capture strategic planning with regard to supporting the same student cohorts. The qualitative study focused on capturing the lived experience of Indigenous people with disability undertaking higher education. These insights were validated at the conclusion of the research through a triangulation process of all collected data.

The triangulation method adopted was drawn from López López (2015) as a method to verify and facilitate:

> the comparison of information obtained from the application of different techniques … and triangulation of information sources, whose value consists of verifying the inferences extracted from an information source by means of another information source. (p. 180)

The data and findings from the final verification meeting with the Indigenous Advisory Group also contributed to the verification of the findings. This provided the researcher with greater confidence in the findings, as Oleinik (2017) stated:

> triangulation in content analysis increases the validity and reliability of the outcomes. (p. 176)

This process is illustrated in Figure 3 (Kerr 2021).

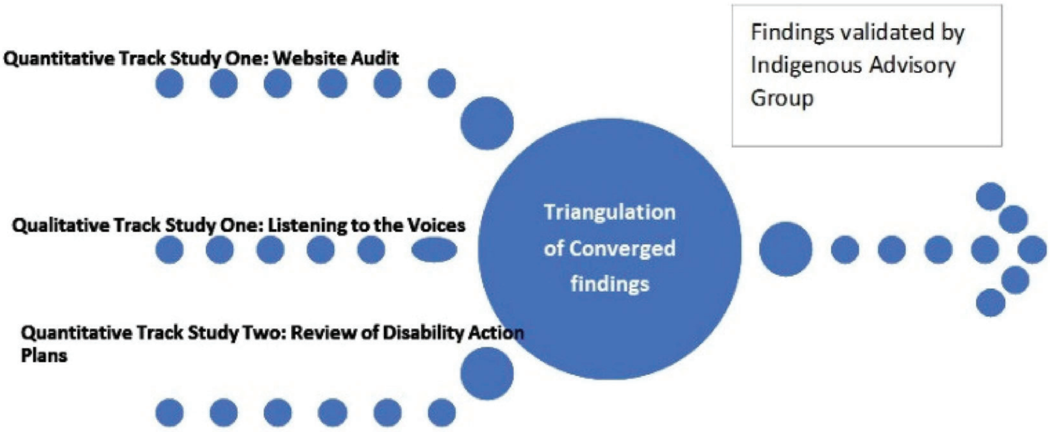

Figure 3. Tracks for the research. Note. From "White Questions —Black Answers: Effective Inclusion of Indigenous Students with a Disability into Higher Education in Australia", Kerr (2021, p. 65).

The approach taken as a non-Indigenous researcher was designed to ensure cultural safety and empowerment for all participants who contributed their Indigenous standpoint to the research. This approach is in line with what Daniels-Mayes (2023) calls BlakAbility, where research addressing the intersectionality of Aboriginality and disability is led by those with lived experience and an Indigenous standpoint on disability. She states:

> Indigenous people living with disability battle with issues related to racism, ableism and colonisation, impacting well-being and life outcomes throughout the life course. Yet, the intersection of Aboriginality and disability remains vastly under-researched. Research using intersectionality embedded with decolonising knowledges and practices and Indigenous standpoints on disability, which is informed and led by those with lived experience (BlakAbility), is urgently needed. Failing to do so serves only to perpetuate inequity and oppression borne out of two centuries of colonisation and will allow disability researchers to continue theorising about Indigenous people without recognising and embedding their understandings and lived experiences that are shaped by their personal, cultural and historical contexts. (p. 4)

Key to this methodology was the desire to ensure that participants did not feel coerced into sharing their stories, knowledge, and wisdom and, at all times, felt respected, listened to, and revered as lived experience specialists. The goal was to increase each study's rigour and ensure the data's validity, resulting in the production of outputs that have utility throughout the higher education sector for the benefit of Indigenous students with disability. Following the completion of data collection and analysis of findings from both Tracks, in line with the mixed methods convergent parallel design methodology, the studies' findings were brought together, as described by Creswell and Plano Clark (2011):

> the researcher collects and analyses both quantitative and qualitative data during the same phase of the research process and then merges the two sets of results into an overall interpretation. (p. 77)

After aligning the validated findings and analysing the answers to the research questions, the Framework for All was developed, as seen in Figure 1.

3. Results

As a result of the approach taken within this research, both the PhD researcher and two of the supervisors, who did not have Indigenous heritage nor live with disability, were able to play their respective supervisory roles and see this study through to its completion in a culturally safe manner. Those with lived experience, who were the initiators of the research, saw their interests being served and their knowledge and professionalism trusted and respected. Throughout the five-year period of the research, the advisory group met regularly with the PhD researcher, both formally and informally, building trust. Conference phone calls were the main mode of communication due to two of the advisers being blind, making video conferencing unsuitable. Face-to-face lunchtime catch-ups were also arranged. When conference presentations were made, the names of the advisory group were mentioned and acknowledged. Additionally, the leader of the advisory group co-presented at both local and international conferences alongside the PhD researcher and was successfully nominated for a national award for Excellence in the category of 'Lifetime Achievement Advocacy'. Relationships and trust built throughout this research, in turn, led to the outputs of the PhD being used as one of the foundation stones of a major five-year project funded by the Australian Research Council, commencing in 2024. It was and continues to be an emancipatory framework, as described by Barnes (2003):

> [which] is controlled and run by disabled people that devise and control the research agenda and, equally important, to whom and how the research findings should be disseminated. Advocates of this perspective recognize [that] research outcomes in themselves will not bring about meaningful political and social transformation, but that they must reinforce and help stimulate further the demand for change. (p. 13)

With regard to the PhD research project itself, in summary, the study revealed the following six key findings:

1. Systemic barriers for Indigenous students with disability were created by variable and bureaucratic institutional processes. Examples include the widespread requirement for medical diagnosis of a disability before the provision of assistance and a lack of flexibility in course design, delivery, and assessment.
2. The Indigenous perspective of disability was found to be a dual consideration, with Indigenous students not presenting for disability support and Indigenous staff not accessing disability services and supports for their students.
3. Institutional supports for Indigenous students and students with disability were siloed into different areas, creating a lack of clarity for Indigenous students regarding where to go for help and placing them at risk of missing out on services and supports available to non-Indigenous students.
4. Systems were not cognisant of the additional barriers faced by students who were both Indigenous and had disability.
5. The ineffective transition from higher education to employment was a major frustration. Participants found themselves in a continuous loop of attempting further qualifications to improve their life opportunities.
6. There was a desire for and appreciation of supportive and respectful communications from support services. Further, a spirit of resilience, determination, and the desire to succeed was observed in participants. For all, the experience of undertaking higher education had a lasting impact on their lives. For some, it introduced generational change within their families.

4. Discussion

Indigenous Standpoint Theory (IST) and decolonisation formed the foundational layer for the theoretical context. As a non-Aboriginal researcher undertaking this PhD research, the first question that needed to be answered was whether or not it should be undertaken at all. Should research such as this, which affects Indigenous people's lives, only be conducted by Indigenous researchers? In addressing this question, Dew et al. (2019) used the insider/outsider approach, whereby non-Indigenous researchers (the outsiders) walk side-by-side with Indigenous researchers (the insiders) towards a shared goal of improving the lives of the Indigenous people and their communities being researched.

Foley (2003) raised the subject of Indigenous Epistemology and IST in the context of wanting to provide an alternative research methodology and framework for Indigenous researchers. In undertaking his PhD, his concern was Indigenous researchers whose research activities were being frustrated and thwarted by being forced to accept Western, ethnocentric research methodology. He wanted to provide a meaningful alternative that would both scaffold and enable Indigenous scholars' research activities. IST was intended to be an Indigenous framework designed by an Indigenous scholar for Indigenous scholars. Foley (2003) provided four criteria for practitioners to form the discussion basis for determining Indigenous standpoint. He stated that the practitioner must:

> Be Indigenous, well versed in social theory, critical sociology, post structuralism and post modernism . . . Indigenous research must be for the benefit of the researchers community or wider Indigenous community and/or Indigenous research community . . . wherever possible the traditional language should be the first form of recording. (p. 50)

The work of Smith (2012) concurs with Foley (2003)'s assertion that Indigenous research should only be conducted by Indigenous researchers. Historically, those termed 'white settler researchers' by Smith have approached research with Indigenous communities from a deficit perspective, misrepresenting findings, and using them to reinforce colonising agendas. Smith (2012) stated that:

> From an indigenous perspective Western research is more than just research that is located in a positivist tradition. It is research which brings to bear, on any study of indigenous peoples, a cultural orientation, a set of values, a different conceptualisation of such things as time, space and subjectivity, different and competing theories of knowledge, highly specialised forms of language, and structures of power. (p. 92)

Understandably, many Indigenous communities and Indigenous academics see no place for the white researcher in this space. However, this stance does not consider the impact already made by Indigenous researchers on decolonising academic perspectives. Due to the decolonising actions and research conducted by Indigenous scholars using Indigenous methodologies, white researchers are coming into this research field with the desire to contribute to the decolonising agenda rather than reinforce colonising norms. If, as stated by Foley (2003) and Smith et al. (2019), Indigenous research is to be considered research conducted by Indigenous people, about Indigenous people, and for the benefit of Indigenous people, then it could be concluded that the research that has been shared in this article is not Indigenous research. It is agreed that no amount of reading or empathetic listening could provide the appropriate foundation for assuming that the researcher is accurately applying the lens of Indigenous experience to claim an Indigenous standpoint on their own merit. However, this PhD study focused on the interface of the higher education system with Indigenous students with disability and was conducted by a non-Aboriginal Australian with experience in the higher education sector. It sought to learn what the system could do to better support Indigenous students with disability—it was not seeking change or action from the students. Thus, the title: White Questions—Black Answers.

In his PhD thesis, Gilroy (2009a), also an Indigenous scholar, developed a conceptual framework for research and policy development regarding Aboriginal people with disability; in doing so, he merged IST with the International Classification of Functioning, Disability and Health (World Health Organization 2001). In presenting his framework, Gilroy (2009a) attempted to provide a way for non-Indigenous scholars to adopt IST with the involvement and leadership of Indigenous people in the research process. He stated that 'non-Aboriginal researchers can adopt IST in their research regarding Aboriginal people only if Indigenous people were involved in the research process' (p. 129).

In developing his framework, Gilroy (2009b) embedded six criteria in the IST component, which speak directly to the non-Indigenous researcher. They are the need for Aboriginal Community inclusion in the research; for researchers to be well-versed in the influence and impact of European colonisation and dispossession of Aboriginal communities' traditional lands and cultures; for researchers to be part of the struggle for Aboriginal communities to be self-determining; to acknowledge the cultural interface that they bring to the research; the similarities and differences between communities; and to use, wherever possible, local Indigenous languages (Gilroy 2009b, p. 132).

Gilroy's (2009a) framework provides a way for non-Indigenous researchers to examine systems and make them more responsive and effective for Indigenous students, clients, and patients. Global research on education and government systems is increasingly being undertaken by private consultancy firms (Gunter et al. 2014; KPMG 2020). Without a framework that can be readily adopted, Indigenous standpoint risks being excluded from the process, in which case the colonisation agenda will prevail. Therefore, a framework within which white researchers can operate is crucial so that the research they conduct is culturally safe and overseen by Indigenous stakeholders. Safeguards must be in place to ensure that power remains with Indigenous stakeholders. If Indigenous stakeholders oversee interpretations and outputs, the research remains set to benefit Indigenous individuals, families, and communities.

Therefore, this study used Gilroy's (2009a) IST, embracing the leadership and guidance of those with an Indigenous standpoint. This research was initiated after a request made to the researcher from two Indigenous people with disability who subsequently joined the Indigenous Advisory Group for this study's duration. Activities were conducted under the guidance of an Indigenous scholar (nominated by one of the people who requested the research) and the Indigenous Advisory Group. The researcher did not assume the mantle of having an Indigenous standpoint; however, as a non-Aboriginal researcher, respectfully embraced oversight and guidance from those with an Indigenous standpoint, thus securing the benefit of the Indigenous standpoint for the research, its execution, analysis, findings, and recommendations.

Key to the methods developed and adopted for this research was empowering those with lived experience of the subject matter being researched. In essence, the research model had built-in checks to ensure that the researcher was not unwittingly reinforcing colonising norms. The relationship between the researcher, the Indigenous Advisory Group, and the cultural broker was and continues to be one of respect and walking together towards a common goal. It was not one of hierarchy fueled by the researcher's personal goals and ambitions, but one where the Indigenous Advisory Group entrusted the researcher with the responsibility of discovery and dissemination of the findings from the research. For five years, the group worked with the researcher, and at its conclusion, bore witness to the final viva voce examination of the thesis.

The methodology used within the thesis bears relevance to the paradigm of inclusive research (O'Brien 2023), where ownership over the research process is in the hands of researchers with lived experience of intellectual disability. Grace et al. (2022) have referred to the process, not unlike that of indigenous methodology, as one of decolonising the way research has been done in the past to people with profound intellectual disabilities and demanding respect for wider ways of knowing, doing research, and being human. The learnings from this study for inclusive research also lie in the relevance of the Framework for All (see Figure 1). Much of the reporting of inclusive research focuses on how people with intellectual impairments are involved as co-researchers and the accessible methods used to collect and analyse data (O'Brien 2023), whereas the Framework for All holds a message for all co-researchers both with and without disability on how to interact beyond considerations of accessibility with participants who live with disability. It reminds those involved in inclusive research that a core aspect of their role is to be person-centred, listening deeply to those they interview/observe; using technology/multimedia to involve participants previously overlooked due to communication issues; as well as giving due consideration to cultural safety to circumvent prior cultural bias and prejudice. It challenges the traditional power balance of the research relationship and transforms the research beyond participatory to emancipatory. Stone and Priestley (1996), when addressing the related question of who should undertake disability research, identified that:

> the emancipatory model requires . . . full ownership of the means of research production—ownership by the research participants not the researcher. (p. 702)

Kerr (2021), focused on ensuring the empowerment of participants during the interview process, with a cultural broker present during each interview (see Figure 2). This approach is worthy of further discussion and research to explore its application to inclusive research involving participants with different disabilities. For example, when undertaking research with participants living with intellectual impairments, would the individual participants benefit from having another person in the interview who also lived with an intellectual impairment?

5. Conclusions

This research has produced the Framework for All to assist higher education institutions of any size in supporting Indigenous students with disability. In the process, it has developed and utilised a methodology and conceptual framework that non-Indigenous researchers can use to secure answers to their White Questions. This conceptual framework ensures oversight by those with an Indigenous standpoint, as defined by Gilroy (2009a), subordinating all research activities to the cultural safety and human rights of the Indigenous people who will be affected by the research. It provides a way for non-Indigenous researchers to become agents of decolonisation, identifying and remedying exclusion and suppression practices throughout Australian institutional systems. It goes beyond inclusion of disempowered participants to securing their authority and oversight over the entire project.

This approach has potential for all co-designed research projects when researching with and for disempowered groups. At its core is the relationship and the desire to facilitate and advance the agendas of those who are the focus of the research, building and maintaining a relationship of service and collaboration, not exploitation.

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Article

Our Recipe for Good Inclusive Research

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Abstract: Co-researchers with intellectual disabilities and a Ph.D. student formed an inclusive research team. The co-researchers joined the inclusive research team so they could learn more about research and have control over the research. Our team have held regular research skills meetings. The focus of these meetings was getting to know each other and learning what each person brought to the team, as well as learning what inclusive research is and how to conduct research together. Learning these things has helped to design and undertake an inclusive research project about pets for people with intellectual disabilities. In this article, our team shares our experience of conducting inclusive research. We have learnt that each team member brings their own strengths to the team and we have connected and formed friendships. We completed an inclusive research project and found there were some challenges our team had to overcome. We conclude that people with intellectual disabilities are capable of leading research. Being part of an inclusive research team enables co-researchers to show others what they can do. Sharing what our team has found out can help others to conduct inclusive research.

Keywords: inclusive research; co-research; research with people with intellectual disability

1. Introduction

1.1. What This Article Is about

Our inclusive research team worked together to write this article. There were four people in our inclusive research team: a Ph.D. student and three co-researchers with intellectual disabilities. We also had support from the Ph.D. student's supervisor, who has a Ph.D. and works as an academic at the university.

This article reflects on our experience as an inclusive research team learning about inclusive research and conducting inclusive research together. The focus of the inclusive research study our team chose was people with intellectual disabilities' experience of having pets or wanting pets.

Inclusive research is when people with and without intellectual disabilities conduct research together (Johnson and Walmsley 2003). Our inclusive research team was involved in all parts of the research process. Co-researchers with intellectual disabilities had control over the research instead of others controlling it. The co-researchers performed all parts of the research with some support. The co-researchers choose the direction our research went in and the topics we wanted to research. They set the pace of the work, took their time, and moved on when they were ready. All of these ways of working inclusively align with the definition of inclusive research that our team followed (Johnson and Walmsley 2003; Walmsley et al. 2018).

1.2. Why We Completed This Project

Our team completed this project because one of the researchers (first author) was conducting a Ph.D. focussing on the experiences of inclusive researchers when they are part of a research project from start to finish. Our team would not exist otherwise. This is what each of our team members had say about why they wanted to be involved in the research team:

Fourth Author: “The research group was something different to do so I’m not stuck at home. I also wanted to meet new people and make new friends”.

Second Author: “I wanted to learn about research from the other side after being a guinea pig in lots of other research”.

Third Author: “I wanted to be part of the inclusive research team because it’s something I always believed in”.

First Author: “I wanted to give people with intellectual disability another way to have a voice about things that are important to them. So, I started an inclusive research group. I wanted to know what the experience is like for the inclusive research team”.

Last Author: “It is very important to have people with lived experience contributing to every part of the research project if possible, to make sure the project is relevant and accessible”.

Other people with intellectual disabilities were involved as co-researchers in our team along the way as well. The team started with seven co-researchers with intellectual disability, but four of them stopped attending because of personal reasons such as moving where they lived or changing their choice to participate in other activities. They told our team that they had initially become involved because they wanted to show that people with intellectual disabilities are capable of being researchers.

1.3. How We Wrote This Article

“Normally I use Easy Read so putting it into academic speak was hard for me, that’s where (first author) came in.”—Second Author

The Ph.D. student (first author) initiated a discussion about our research outputs, one of which was a journal article, and the team agreed to write the article. It was important to all members of our inclusive research team that they were all involved in writing this journal article together. Our team started the process by having a discussion and brainstorming our responses to each section of the article. The section headings are based on some Easy Read author guidelines from a journal. The Ph.D. student (first author) and one of the co-researchers (second author) who had an interest in being more involved in the article performed some more brainstorming together to expand on the responses. They had several meetings to discuss the findings and the sections of the article. The second author dictated commentary while the first author typed it up. The first author then translated some of the information into a more academic format, with support from the university supervisor (last author).

Once the article had been written, the Ph.D. student (first author) met with each of the co-researchers individually to read the article to ensure it still reflected their experience correctly. They performed this again when revisions were made to the article during the publication process.

This article will now explain what our team achieved, how it was performed, and what was found.

2. Our Background and How We Grew While Working as a Research Team

“Research training was fun.”—Fourth Author

Our team was started by the Ph.D. student (first author). Her Ph.D. looks into the experience of our inclusive research team. She invited each of the co-researchers to join the inclusive research team to learn all about research and undertake an inclusive research project. While conducting this work together, the first author looked at our experience of being part of an inclusive research team and what the research process was like for all members of our inclusive research team. The research question this study aimed to answer was as follows: what are the experiences of an inclusive research team when co-researchers with intellectual disabilities are involved in an inclusive research project from start to finish?

Our team worked together over five years. We had some long breaks in between because the Ph.D. student had a baby and then COVID-19 interrupted our research. The Ph.D. student (first author) recruited co-researchers through sharing recruitment information with disability service providers. Some of these disability service providers invited her to run information sessions so people could decide if they were interested in joining the research team, others passed the recruitment information on to individual people with intellectual disabilities they thought might be interested. Some of the co-researchers knew each other because they received support from the same disability service providers or went to some of the same activities, although some of the co-researchers did not know each other prior to joining the team.

> *"Visuals are the best way for me to learn because it helps me understand"—Third Author*

Our team had research meetings to get to know each other and to learn about research and what inclusive research is. Some of the ways our team learnt were through watching videos, talking about the topics, and brainstorming ideas. The first author (Ph.D. student) changed the information into an Easy Read format to help co-researchers to understand it better. The co-researchers gave the Ph.D. student advice at the end of each research meeting about things she could improve on for the next meeting. For example, some of the co-researchers said they were visual learners, so the Ph.D. student looked for opportunities to include videos and practical activities in the research meetings.

> *"It was fun playing games to get to know each other. I liked the game where we threw the ball and it had questions about ourselves we had to answer"—Second Author*

During the first few research meetings, the team spent time getting to know each other. The team wanted to make sure they were comfortable with each other. Games and one-page profiles were used to get to know each other. A one-page profile is a person-centred tool that uses three headings to capture important information about a person (Sanderson 2024). The three headings helped the team to learn what was important to each group member, what other people liked and admired about them, and how our team could support each other in the group.

> *"We worked to our strengths–like mine is speaking but don't quite have the words, that's where First Author comes in again. Whereas others like to have more background roles, while I love to do everything."—Second Author*

The team also spent time talking about each person's strengths. This helped us to think about who could perform each research task in the group. For example, one co-researcher was not comfortable interviewing participants, so they played a support role helping other co-researchers to role-play practising an interview. Some of the co-researchers have experience being in front of a camera, so they took the lead starring in videos developed to share our research findings in an accessible way. However, the team all worked together to write the scripts, so everyone still had a role and was part of deciding what to include in the videos.

The team learnt about qualitative and quantitative data by looking at journal articles with examples (Scorzato et al. 2017; Baum and Burns 2007). The co-researchers decided that quantitative data had too much mathematics and that they preferred working with words, because it gave more information about people's experiences.

The co-researchers agreed that learning what information could be trusted was very difficult. They had not heard of "peer-reviewed" before, nor had they searched for journal articles. The Ph.D. student showed the co-researchers how to search a database; it was important to the co-researchers to attempt this and learn how it was conducted. The co-researchers decided it was hard to understand many of the articles, so they asked the Ph.D. student to conduct further searches of the literature and create Easy Read summaries about the research topics they were interested in. The Ph.D. student was already experienced at Easy Read translations, having undertaken training in this area and developed these skills working in another role.

The team spent a lot of time learning about research. They completed some training in research and the co-researchers led the planning of their own research study. The purpose of the training was to ensure all researchers (with and without intellectual disabilities) understood research methods.

> *"Research training was interesting, I liked the PowerPoints First Author made because they were easy to understand. The journal articles however were not."—Second Author*

Initially, the training began with team building and providing an overview of research. This allowed the inclusive research team to choose the topic of their inclusive research study and begin to design their study. The training continued throughout the course of the inclusive research study and the training provided was specific to the skills and knowledge needed to carry out each aspect of the study. For example, an overview of possible research methods the inclusive research team could choose to use was provided so they could then be supported to choose their research methods. Once the team had chosen their data collection method of semi-structured interviews, specific training was provided about how to conduct interviews. Further details about the research skills training will be published separately.

2.1. Deciding on a Research Topic

> *"I have friends with pets so that topic was of interest to me, seeing their connection with the animal."—Third Author*

To decide the direction of the research, the team came up with a few broad research topics that were of interest:

- Parents with intellectual disabilities;
- National Disability Insurance Scheme (NDIS);
- Therapy animals.

These topics were of interest to the co-researchers because they were relevant to their own lives and those of their peers with intellectual disabilities. The team looked at what research had already been conducted on these topics and found there was already a lot of research on all of these topics. Since there was already some research about therapy animals, the team had the idea to look at pets and people with intellectual disabilities. The team could not find much research on this. Pets were a topic of interest because some of the co-researchers had pets and really valued them, and others in the group really wanted pets but could not have them. They wanted to know what the experiences of other people with intellectual disabilities and pets were.

The team also talked about parents with intellectual disabilities being a sensitive topic because some team member had experiences of having their children being taken away from them. Some of the group found it upsetting to talk about this topic and others were worried that if this was the research topic it would be hard to find people to participate in the research because they might not want to talk about it. The team had to find a research topic the co-researchers were comfortable with. They narrowed it down to a choice between NDIS or pets for people with intellectual disabilities. They found another inclusive research team was already conducting a research project about the NDIS and did not want to risk repeating their work. The group settled on pets to ensure their research project was unique.

> *"It was difficult to find a topic because there were so many to choose from, we didn't want to double up on other research and we wanted to make sure it was a topic people would be interested in."—Second Author*

It was interesting that all of the topics the co-researchers came up with were things that impact their lives. They could have chosen to research anything, but they were all very interested in the topics, and felt strongly that the topic would be of interest to other people with intellectual disability and those that support them. They also thought that their research findings could help with recommendations for people with intellectual disabilities who have or want pets.

The overall purpose of this inclusive research project was to look at the experiences of people with intellectual disabilities who have a pet or would like a pet. This research explored the benefits of having a pet and the barriers to having a pet.

2.2. Who Participated?

The team talked about who would participate in the study. They wanted to keep the focus narrow so they did not become overwhelmed with data and have to conduct many interviews. The team talked about whether they would interview families, support workers, or people with intellectual disabilities. The co-researchers decided on people with intellectual disabilities because they all have an intellectual disability and they think it is important to hear from people with intellectual disabilities.

2.3. Learning about Ethics

The team had to learn about ethics, so they asked the Ph.D. supervisor (last author), who is an experienced researcher, to come and talk to them about it. The Ph.D. supervisor taught the team about the principles of ethics. The team then started on their own ethics application to the university's ethics committee. The application had to be carried out online. The Ph.D. student (first author) broke down the questions for the co-researchers and, as a team, they discussed the answers. The questions that were asked on the ethics application were not in plain English and were more suited to academics. The Ph.D. student then went away and wrote up the application based on what was discussed. An important ethical consideration for the project was ensuring people with intellectual disabilities had information presented to them in a way they could understand so they could make an informed decision about their participation and how the information they shared would be used.

Another challenge of obtaining ethics approval was having to complete a working-with-vulnerable-persons check. This meant all team members had to have identification documents and fill in a long and complicated government form. The ethics committee became slightly confused between our ethics application and another similar one at the time from another research group, so the team had to correct the committee on that. The team were relieved when they finally obtained ethics approval (project number HEG2441-1).

Once the team had ethics approval, they began to undertake their research study about pets for people with intellectual disabilities. The findings of their inclusive research study will be reported in another paper.

3. What We Found Out about Inclusive Research

There were many good things about being part of the inclusive research team. The good things and the challenges will now be explained and discussed.

3.1. Getting Paid

> *"I like the fact that we got paid, it made me feel like my time was valuable"—Second Author*
>
> *"The pay helped me with bills, your supposed to be paid when you do something like this, to keep going in life"—Third Author*
>
> *"It was good to be paid to learn new things"—Fourth Author*

The co-researchers were all paid for being part of the inclusive research team. The Ph.D. student (first author) did not, since she was completing this as part of her Ph.D. studies and her supervisor was completing this as part of her usual academic research work. The co-researchers thought they were volunteering to complete the research project at first (without expecting any payment); however, the Ph.D. student was successful with an Endeavour Foundation grant, which meant the co-researchers received a monthly voucher for the time they put into the group. The co-researchers all agree that being paid for doing the research project was a positive. For some co-researchers, if they had not been paid, they may not have continued to be involved in the team, because everyone needs money to get by in life. Being paid also made the co-researchers feel they had accomplished something and that what they were doing was worthwhile. This is consistent with other inclusive research teams who found payments for co-researchers were an important way of making them feel their contribution was valued (Butler et al. 2012).

3.2. Learning

The co-researchers all learnt new things:

- What research is about and why research is conducted.
- Different ways research can be carried out, like interviews, focus groups, and surveys.
- There are lots of steps in the research process, like deciding what research to conduct and how to conduct it, collecting information, looking at the information, and sharing the research finding.
- It is important to know what information can be trusted when conducting research. It can be hard to know what information can be trusted. For example, the co-researchers learnt that websites like Wikipedia are not trustworthy because anyone can write what they want on there.
- How to use Zoom so the team could continue their research during COVID-19.

3.3. Further Opportunities

> *"Because of this research I got a job at a university which I love and get paid award wages."—Second Author*

Two of the co-researchers were able to secure a job because of the research skills they learnt. They both now work at a university as research assistants, contributing lived experience perspectives to inclusive research teams.

3.4. Social Aspects

> *"Coming to the research meetings helped me in a social aspect because if I wasn't coming to the meetings I would be doing absolutely nothing or watching Netflix."—Second Author*

> *"I enjoyed learning about different things and meeting Second Author"—Fourth Author*

The co-researchers were able to get to know each other and meet new people. Some even see each other outside of the research group meetings. Participating in inclusive research gave the co-researchers the opportunity to come together as a group. They all agreed that the social aspect of the group and making new friends was a positive of the research. Having a friendly group and taking the opportunity to get to know each other helped the group work together as a team.

3.5. Personal Development

> *"This research project gave me the opportunity to do public speaking. I have improved a lot. I used to get massive stage fright but now that's improved"—Second Author*

Participating in inclusive research developed the co-researcher's self-confidence. They had the opportunity to try new things like public speaking. For some, it was the first time they had achieved something like this and having the opportunity to take part showed them they could achieve it.

3.6. Challenges

There were challenges for the inclusive research team. One of the most difficult parts of the research process was deciding on a research topic. The team had many ideas, but all members had to agree on just one. They also wanted to make sure the research project did not repeat research that had already been conducted.

Many parts of the research process were difficult or confusing; for example, understanding journal articles and applying for ethics approval. The co-researchers all agreed about the importance of having someone to break things down and putting things into Easy Read to make the research process accessible.

> *"The biggest challenge was that pesky virus that turned up in 2020. It meant we couldn't meet in person, we had to meet online"—Second Author*

COVID-19 was challenging and meant that sometimes the team had to find different ways of working together. When the team could not meet in person they would meet on Zoom. This was something completely new for the co-researchers. When the team was able to meet again in person, they had to learn new rules like social distancing. COVID-19 was also challenging as it slowed the research down significantly because people with intellectual disabilities, disability service providers, and families were busy focussing on keeping safe from COVID-19. There were also times when the team had planned to meet as a research group or with participants that had to be cancelled because of COVID-19 diagnosis or symptoms.

4. What It Meant to Us to Conducted Inclusive Research

> *"People with intellectual disability should be given the same opportunities to do research as everyone else. We might need help with things, but we're just as capable as everyone else"—Second Author*

From the team's experience of learning about and conducting inclusive research, they learnt about good inclusive research. Taking their time, getting to know each other, and believing they are capable were all important ingredients in their recipe for good inclusive research.

The team know that good inclusive research takes time, especially when co-researchers with intellectual disabilities are part of every step of the research process, from determining the research topic right through to dissemination of the findings. There is a lot to learn about conducting research and a lot to plan to carry out the chosen research. It is important that there is time and support to break things down.

Our inclusive research team's experience is similar to what other studies have reported. Hewitt et al. (2023) conducted a systematic review looking at the experiences of inclusive research teams. All studies in the review identified the importance of making the research methodology and presentation of research findings accessible. Many of the strategies to achieve this align with those our team used, as described earlier in this paper, such as verbal discussions (brainstorming), presenting data in multiple formats (Easy Read summaries), and controlling the pace of meetings (we worked at our pace, we took our time, and we moved on when we were ready). This is an important consideration for university researchers when deciding to use inclusive research methods, as funding and academic deadlines are often barriers to allowing sufficient time (Bigby and Frawley 2010; Bjornsdottir and Svensdottir 2008).

Getting to know each other was important. It helped the team to work well as a group and feel comfortable with each other. Other inclusive research teams have also reported getting to know each other and being able to work as a team as important (Grayson et al. 2013; Haigh et al. 2013; Hewitt et al. 2023).

The team's experience learning and conducting inclusive research has shown people with intellectual disabilities are capable of being part of a research team for the whole project and contributing to every part of the research process. Being involved in the inclusive research team gave them the opportunity to show other people what they can achieve. This project adds to other studies, because it is one of the only ones that describes co-researchers being involved from the beginning, participating in all parts of the research process, and making decisions about what was researched and how it was carried out. The co-researcher's involvement in the inclusive research team was not just about conducting research; it was also about what can be achieved with that research. The co-researchers believe their inclusive research study about pets for people with intellectual disability will provide the following:

- Give a better understanding of why pets are important to people with intellectual disabilities.
- Help to learn about barriers to having a pet, so this can be addressed.
- Educate NDIS, the government, service providers, and families about pets for people with intellectual disabilities.
- Check people with intellectual disabilities' understanding of the responsibilities of having a pet. This will help to teach them what they need to know to become a pet owner.

Other inclusive research teams have also reported their research having a larger impact, such as giving a voice to people with intellectual disabilities (e.g., Williams and Simons 2005; Money and Tilly 2012; Grayson et al. 2013; Rogers and Tuckwell 2016; Riches and O'Brien 2020) and creating change in programmes, society, and policy (e.g., Hreinsdottir and Stefansdottir 2010; Stanley et al. 2019).

5. Final Words

The team's experiences as an inclusive research team reflect the experiences of other inclusive researchers. The team's experiences learning about and conducting inclusive research led them to all agree that including people with intellectual disabilities in conducting the research is important and should always happen. Conducting research enabled the team to learn new skills, show others what people with intellectual disabilities are capable of, and have a greater voice about a topic of importance to them and others with intellectual disabilities. In the words of one of the co-researchers (third author):

> *"It is our society and our world, so we should be involved".*

The inclusive research team hope that other people can learn from them and that they will become involved in inclusive research too.

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social sciences

Article

Examining People's Experiences of Working in Collaborative Relationships While Conducting Inclusive Research Involving Persons with Intellectual Disabilities

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Abstract: This study examined the experiences of working in collaborative relationships while conducting inclusive research involving persons with intellectual disabilities. More specifically, the study explored work relationships, social relationships, and factors that influence collaboration within inclusive research teams. Interviews were conducted with nine researchers with intellectual disabilities, eight academic researchers, and nine principal investigators who were all involved in six inclusive research projects together. The analysis of the interviews produced four themes: (1) the diverse nature of the involvement of researchers with intellectual disabilities; (2) the significance of involving researchers with intellectual disabilities within academic research; (3) shaping equity in research projects; and (4) stereotyping hindering collaborations with researchers with intellectual disabilities. These findings have implications for research and practice, both in terms of promoting inclusive research and facilitating the meaningful participation of persons with intellectual disabilities within various aspects of society, including education, employment, healthcare, and social activities.

Keywords: intellectual disabilities; collaborative relationships; inclusive research; intergroup contact theory

1. Introduction

The importance of full participation and social inclusion for people with intellectual disabilities is widely acknowledged and anchored in the United Nations Convention on the Rights of Persons with Disabilities (United Nations 2006). Alongside this, inclusive research, which involves people with intellectual disabilities being empowered to actively collaborate as co-researchers rather than merely serving as the subjects of research, has emerged as an effective strategy through which to ensure that the perspectives of people with intellectual disabilities are represented within policy, implementation, and research (Walmsley et al. 2018; O'Brien et al. 2014; O'Brien 2022; Strnadová and Walmsley 2018). Aligned with Walmsley et al.'s (2018) updated definition of inclusive research, we position collaborative researchers in research projects as researchers, whereby some researchers bring experiential knowledge from living with an intellectual disability, while others have received formal training as academic researchers.

Inclusive approaches foster an environment of equitable knowledge production and sharing between academic researchers and researchers with lived experience (Bigby et al. 2014; Milner and Frawley 2019; Nind and Vinha 2014). Built upon participatory and emancipatory research methodologies derived from the constructivist research paradigm, inclusive research is a specific branch of participatory and emancipatory research within the realm of intellectual disabilities. This approach advocates for the comprehensive involvement of persons with intellectual disabilities throughout all phases of the research process, adhering to the principle of "Nothing about us, without us". Inclusive research, a concept that gained prominence in the 1990s, aligns itself with broader inclusion-focused developments, such as Social Role Valorization (Wolfensberger 2000). In 2003, Walsmley introduced a foundational strand of inclusive research specific to the field of intellectual disabilities, contributing significantly to the evolution of inclusive research methodologies in this domain.

The focus on reciprocal relationships within collaborative teams is crucial for understanding the shared benefits of collaborating within inclusive research for both academic researchers and persons with intellectual disabilities (Embregts and Frielink 2023). Reciprocal relationships, which are characterized by trust, respect, and mutuality, form the foundation of successful collaboration (Embregts et al. 2018; Sergeant et al. 2022). As such, persons with intellectual disabilities gain increased self-confidence, self-esteem, and a sense of control through actively participating, which, in turn, yields opportunities for skill development and capacity building within the context of inclusive research (Bigby and Frawley 2010; High and Robinson 2021; Sergeant et al. 2022). Researchers with intellectual disabilities have underscored the significance of experiencing full participation, which extends far beyond carrying out core research tasks to instead encompassing the collaborative dynamics of a research team, thus fostering a sense of value and belonging that is constitutive of social inclusion (Fulton et al. 2021). While the competencies and skills that facilitate optimal collaboration have been outlined previously (Embregts et al. 2018), a deeper exploration is required in order to understand both the nuanced experiences of academic researchers and persons with intellectual disabilities and how they navigate such collaborative relationships within real-world research contexts (Chalachanová et al. 2020; Hewitt et al. 2023). This shift in focus emphasizes the pivotal role of reciprocal relationships in driving successful collaboration within inclusive research.

Inclusive research brings together academic researchers and researchers with intellectual disabilities to cooperatively work toward the common goal of conducting research on issues relevant to enhancing quality of life (Walmsley et al. 2018). Within these collaborations, inclusive institutional support from principal investigators, funders, and the broader research community affirms valuing and equally recognizing the diverse contributions of both academic researchers and researchers with intellectual disabilities. Moreover, consciously incorporating and maximizing the key conditions that underpin this approach—frequent and extended contact, equality, cooperation, and institutional support—may serve to further enrich the collaborative relationships and degree of mutual understanding within inclusive research teams (Novak et al. 2011). With this in mind, the present study explores the first-hand experiences of academic researchers, researchers with intellectual disabilities, and principal investigators engaged in collaborative partnerships.

2. Method

2.1. Setting and Participants

The "Gewoon Bijzonder" national program for persons with disabilities in the Netherlands secured funding from the Netherlands Organization for Health Research and Development (ZonMw) for an initial grant call, which would support six research projects. A key requirement of this funding was the active engagement of people with intellectual disabilities as co-researchers. The present study forms part of the seventh research project funded by the "Gewoon Bijzonder" national program, exploring the collaborative relationships between researchers with intellectual disabilities, academic researchers, and principal investigators who worked together on the other six projects. The focal areas of these six research projects encompassed topics such as social relations and technology, living in an ethnically diverse city, healthy lifestyles, self-determination, and participation. These projects took place over a four-year period, commencing sometime between October 2016 and January 2017, and they all had the common objective of generating, disseminating, and applying knowledge that would enhance the quality of life and support for persons with intellectual disabilities. Within each research project, which encompassed multiple studies, researchers with intellectual disabilities and academic researchers collaborated closely on at least one of these studies.

The present study involved the active participation of at least one researcher with an intellectual disability, one academic researcher, and the principal investigator from each of the six research projects. Given that most of the research projects comprised multiple academic researchers, researchers with intellectual disabilities, and/or principal investigators, a total of 26 participants took part in the present study. Specifically, nine researchers with intellectual disabilities participated (three females; six males) with an average age of 40.6 years (SD = 12.9, range 23–63), eight academic researchers (seven females; one male) with an average age of 30.8 (SD = 6.2; range 26–43), and nine principal investigators (eight females; one male) with a mean age of 47.8 (SD = 7.8; range 32–54). Demographic information was collected through a concise questionnaire that was administered during the interview process.

2.2. Procedure

Subsequent to receiving approval from the Ethics Review Board of [name of university removed for blind peer review purposes] (EC-2017.68), the first author initiated contact with the principal investigators on each project to set up an introductory meeting. This meeting was also attended by two additional researchers who were part of this seventh overall project but not directly involved in the present study. During the meeting, each of the principal investigators explained the objectives and research designs of their respective projects, while the first author clarified the purpose and design of the present study. Following these meetings, all principal investigators received a detailed informational letter describing the data collection process. The first author also sent an email inviting them to participate, which they all accepted. The meetings were then scheduled at their earliest convenience in order to discuss the involvement of their academic researchers and researchers with intellectual disabilities, including the best way to approach them. The potential participants (i.e., the researcher with intellectual disabilities and the academic researcher working together on a project) were then informed about the project and invited to participate, but only one of the academic researchers declined due to their workload. Those participants who were willing to participate were then scheduled for interviews at a time that was convenient for them, which led to a total of 26 interviews being held at either the participants' workplaces or homes.

These interviews, which were transcribed verbatim by a professional service, were conducted between December 2017 and July 2018, approximately one to one and a half years after the start of the research projects. To protect participants' identities, no names were used in the results. All the participants provided their written consent prior to the interview, with the consent form being explained to the researchers with intellectual disabilities using accessible language. No incentives were offered as participation was seen as forming part of their roles in the six included research projects.

All interviews were conducted and analyzed in Dutch, with the findings subsequently being translated into English by the authors and reviewed by a native English speaker. An independent translation of the quotations was performed by a native English speaker who was not involved in the study.

2.3. Interview Guide

A semi-structured interview guide was developed to explore the first-hand experiences of academic researchers, researchers with intellectual disabilities, and the principal investigators engaged in collaborative partnerships. The guide drew upon an existing study by Novak et al. 2011, which was translated into Dutch and adapted to fit the specific circumstances of this study, that is, inclusive research collaborations. Notably, customized versions of the guide were created for each of the three key participant groups: researchers with intellectual disabilities, academic researchers, and principal investigators. This allowed the interview questions to be tailored to the respective roles and experiences of each type of research partner. The guides primarily focused on illuminating the relationships between researchers with intellectual disabilities and academic researchers, as it is these two groups who most frequently interact in day-to-day collaborative work.

The semi-structured interview guides contained open-ended questions designed to elicit detailed, descriptive responses without introducing bias. The questions probed for various details pertaining to the participants' research relationships and experiences of the collaboration, such as, for example, "How many other colleagues work in the direct environment of the researcher with a disability?" and "Where and with whom does the researcher with a disability have their lunch break?". By adapting a previously validated interview protocol for exploring intergroup contact within the workplace to fit the context of inclusive research, the guide developed here was able to provide a relevant framework through which to explore the on-the-ground experiences of collaborative dynamics and social inclusion from the perspectives of the different research partners. The open-ended question format allowed the respondents to share their perspectives in their own words, thus yielding richer qualitative insights that can help inform the future optimization of inclusive research practices.

2.4. Analysis

A six-step thematic analysis approach (Terry et al. 2017) was used to analyze the interviews. First, two members of the research team thoroughly read through all the transcripts to familiarize themselves comprehensively with the data. In the second step, the first author coded salient phrases within the transcripts to identify key concepts emerging from the data, a process that was subsequently reviewed by a second researcher. Any disagreements over coding were resolved through in-depth discussion and consultation with two additional team members. In the third analytic phase, the coded data fragments were systematically grouped based on their shared similarities in order to begin forming overarching themes. Fourth, the coherence and consistency of these themes were evaluated both internally (within each theme) and externally (between different themes) by all members of the research team. This process, in turn, allowed for the refinement of the thematic structure so as to ensure that the themes were distinct, robust, and grounded in the dataset. Fifth, the emerging themes were defined, named, and discussed with a researcher with intellectual disabilities to gain additional insights. Finally, a comprehensive report was prepared by the authors, including the selection of evocative quotations from the participants to enrich the manuscript.

2.5. Rigor of the Methodology

The methodology of our study incorporates multiple measures to enhance trustworthiness and credibility. First, comprehensive discussions on codes and proposed (sub)themes were conducted among the authors and three additional researchers. This collaborative process aimed to ensure the richness of emerging themes, taking into account a diverse range of perspectives. Furthermore, to validate the consistency and clarity of our coding, a second coder performed coding checks. Triangulation, a key aspect of our approach, was achieved by interviewing various stakeholder groups, researchers with intellectual disabilities, academic researchers, and principal investigators. This methodological strategy not only strengthens the reliability of our findings but also ensures a holistic understanding by considering multiple viewpoints within the studied context.

3. Results

After analyzing the interviews, four themes were identified as follows: (1) the diverse nature of the involvement of researchers with intellectual disabilities; (2) the significance of involving researchers with intellectual disabilities within academic research; (3) shaping equity within research projects; and (4) stereotyping hindering collaborations with researchers with intellectual disabilities.

3.1. Theme 1: The Diverse Nature of the Involvement of Researchers with Intellectual Disabilities

The diverse nature of the involvement of researchers with intellectual disabilities was evident across the various collaborative research projects. While some researchers with intellectual disabilities spent an average of only two hours per week working on projects, others contributed a much more significant amount of time, sometimes dedicating, on average, two to three full days each week. This was in contrast to academic researchers, who typically worked four to five days per week on related research projects. In addition, researchers with intellectual disabilities often did not have a designated workplace or consistent work location within their organization. Next, researchers with intellectual disabilities carried out a wide range of activities and tasks, which were tailored to each project's specific research requirements. For instance, one researcher with intellectual disabilities indicated that they contributed to developing suitable interview questions, while others described participating in data collection through interviews, focus groups, or workshops, along with actively contributing to the writing process and playing a role in shaping the project during the design phase, offering valuable insights and perspectives that enhanced the overall research framework.

On days when the researcher with intellectual disabilities was working, the academic researcher and the researcher with intellectual disabilities most commonly had lunch together. Other colleagues frequently joined them, which, according to researchers with intellectual disabilities, helped to strengthen their sense of belonging with the team of researchers. The mealtimes also provided opportunities for the academic researcher and researcher with intellectual disabilities to casually connect, updating each other on the project as well as their personal lives outside of work. They believed that engaging in discussions about both work and personal matters positively contributed to a greater sense of belonging.

> *"I bring my own lunch, but I always have lunch with the researcher. But sometimes I have lunch with other people, I don't mind, but I always have lunch with others, which is nice. It adds to a sense of belonging for me. It is also a way to have a pleasant moment, filled with humor. We do that on days I work. We don't see each other outside work."*

Besides frequent face-to-face meetings, the researchers with intellectual disabilities stayed connected through regular phone calls, emails, and text messages in order to both communicate about the project and schedule upcoming tasks. However, outside of work hours, the academic researchers and researchers with intellectual disabilities rarely interacted socially.

While some principal investigators tended to remain distant from the day-to-day collaboration, others made an effort to actively engage with the researchers with intellectual disabilities. For instance, one principal investigator scheduled frequent meetings with a researcher with intellectual disabilities to discuss progress, challenges, and goals, both with respect to the project and their own personal development. However, other principal investigators openly admitted to having very minimal interaction with and knowledge about the co-researcher's specific work schedule and contributions. Hence, although not all principal investigators had frequent direct contact with the researchers with intellectual disabilities they worked with, they nevertheless played a crucial role in promoting collaboration and equal treatment within the research project. For instance, according to all parties, most principal investigators actively facilitated the involvement of researchers with intellectual disabilities within both formal and informal team activities and social gatherings, which, in turn, fostered an inclusive team environment. One principal investigator explained it in the following way:

> *"In an effort to include researchers with intellectual disabilities in daily work activities, I took steps like consulting with academic researchers when we received invitations to give presentations at events. I proposed, 'Hey, I think it would be beneficial for us to participate in this. I believe X [name of researcher with intellectual disabilities] should be involved as well. They are our researchers with intellectual disabilities, so I would*

> *appreciate their participation.' I would bring attention to it by suggesting that they bring along the researchers with intellectual disabilities, without being coercive, but rather by asking."*

Within several projects, researchers with intellectual disabilities underscored the pivotal role played by the principal investigator's commitment to ensuring the project's success. They valued the principal investigator's genuine concern for and involvement with all of the team members. Moreover, these researchers saw the principal investigators and academic researchers they worked with not as their superiors but rather as their direct colleagues. In addition, according to the academic researchers, the principal investigators they worked with played a crucial role in terms of both ensuring that they started out from a position of equality and enabling joint decision-making. For example, several principal investigators actively facilitated the cultivation of egalitarian partnerships by taking measures such as translating complex texts into more understandable language, fully incorporating input from researchers with intellectual disabilities, and investing time in relationship-building activities that promoted a sense of belonging between all the collaborators. However, it may not always be flawless, as one academic researcher asserted: *"I believe we approach the collaboration and relationship-building activities with utmost seriousness, and there's a strong commitment from each of us. We are dedicated to it, and we acknowledge that, yes, mistakes happen. Learning is a continuous process for all of us."*

3.2. Theme 2: The Significance of Involving Researchers with Intellectual Disabilities within Academic Research

Overall, principal investigators, academic researchers, and researchers with intellectual disabilities broadly recognized the significance of involving researchers with intellectual disabilities within academic research projects. Specifically, as noted by several principal investigators and academic researchers, they offer a unique viewpoint that can enhance the research process. One academic researcher explained in what ways their perspective was valuable.

> *"You especially learn how the perspective can also be different. What the average other person's perspective is, you just don't know. You can't assume that if you've learned how it works with one person with an intellectual disability, then it works like this for everyone. Utilising that experiential knowledge in your project expands, as it were, multiplies that experiential knowledge amongst researchers who do not have an intellectual disability."*

In addition, both academic researchers and principal investigators greatly acknowledged and appreciated the active engagement of researchers with intellectual disabilities within their respective research projects. This active engagement was observed to significantly enhance the level of collaboration within the team. Several principal investigators recognized the value of involving researchers with intellectual disabilities within research and, moreover, demonstrated their support for the collaboration by dedicating time to engaging in in-depth discussions about project developments with researchers with intellectual disabilities. As one principal investigator stressed:

> *"What I find most annoying is when I get the feeling of 'oh, are we doing this for the content or just for appearances?'. You simply don't want that. You really want them [researchers with intellectual disabilities] to have a substantive contribution, and I do feel that we have followed that. It gives you a good feeling. People really put a lot of effort into it. Everyone does. Not only the researchers with intellectual disabilities, but also the academic researchers."*

Furthermore, both principal investigators and academic researchers underscored the importance of the input from researchers with intellectual disabilities, who were able to directly draw upon their lived experiences, particularly during the foundational phases of research projects, including the design and implementation stages. For example, academic researchers argued that the process of collaborating with a researcher with intellectual disabilities added an extra dimension of diversity and creativity to the research approach and outcomes, explaining how the partnership allowed for the combining of complementary strengths and perspectives. Several principal investigators emphasized that the contribution of researchers with intellectual disabilities led to research that was more inclusive, pragmatic, and reflective of the priorities of the target population.

Moreover, the principal investigators recognized the potential for researchers with intellectual disabilities to play an important role in the wider dissemination and distribution of research findings to key audiences. Academic researchers highly valued the unique perspectives and experiential insights that were shared by the researchers with intellectual disabilities, deeming them to be profoundly informative contributions that significantly enhanced the practical implications of their study results. Researchers with intellectual disabilities also asserted that they could serve as a direct link to practice, insofar as they are easily able to connect with the target group. However, it is worth noting that some researchers with intellectual disabilities did not feel responsible for the project as a whole; rather, this responsibility was seen as laying with the academic researcher. Indeed, they even went so far as to state that they felt the project could be completed without their involvement.

> *"Well look, X [name academic researchers] is the academic researcher, and I am the co-researcher. She handles the broad contacts with the projects, something I'm not involved in. Nevertheless, I do receive emails from her, keeping me updated on the projects and what is expected. I collaborate on vlogs, create reports, read, and contribute to trainings. Our tasks are different and not equally important. The academic researcher has the final responsibility for the entire research, as she oversees everything. She does a lot of writing, and although I'll also co-author an article with her, if I'm not there, the article will probably still be written."*

3.3. Theme 3: Shaping Equity within Research Projects

Both academic researchers and researchers with intellectual disabilities shared the goal of promoting equity in their collaborative relationships within research projects. As part of the pursuit of equity within research projects, they underscored the critical importance of building robust relationships, facilitating open dialogue that encompasses both work-related and personal information, fostering a profound sense of belonging, and demonstrating unwavering commitment. The principal investigators, who were leading the research initiatives, also recognized the importance of promoting equal and harmonious team dynamics. However, according to insights from both academic researchers and researchers with intellectual disabilities, the specific ways in which equity sometimes manifested in practice differed across the teams. For instance, some academic researchers place great importance on establishing an equal foundation right from the outset of a project. For them, equity was rooted in co-ownership over the research and collective responsibility being shared between all team members. Several researchers with intellectual disabilities shared this perspective and felt collectively responsible for the project as well. As one researcher with intellectual disabilities stated:

> *Yes, ... Just to be clear, I'm referring to my fellow researcher, I'm not talking about the secretary or anything, but you all think about how you will carry out all phases of the research, that the involvement will be the same.*

Academic researchers and researchers with intellectual disabilities understood equity within the context of inclusive research projects as referring to appropriately recognizing persons' inherent strengths and talents, which then naturally leads to a division of tasks based on complementary areas of expertise. The academic researchers emphasized that researchers with intellectual disabilities were deliberately included within the present research teams, specifically because of the unique personal experiences and perspectives they contributed. According to this view, it is important to actively create conditions that allow researchers with intellectual disabilities to provide input equitably based on their knowledge and capabilities. For example, one academic researcher referred to topics like advanced statistical analyses, in which they made the decisions, and then subsequently informed the researcher with intellectual disabilities about this afterwards.

> *"When it comes to complex statistical analysis, connecting it to theory, and engaging in higher-level academic reflection, those tasks are a bit beyond the co-researcher's expertise. Thus, I do handle different responsibilities in those areas. However, I always make sure to inform the co-researcher afterward and explain our actions to ensure a clear understanding of the work. This communication is crucial."*

Some researchers with intellectual disabilities also acknowledged that there were clear distinctions between the roles of academic researchers and researchers with intellectual disabilities, viewing academic researchers, for example, as being responsible for the foundational study design while positioning themselves primarily as serving in an advisory capacity based on their experiential knowledge. Both parties openly acknowledged and valued these different skills and abilities within their collaboration, which was also reflected in the number of hours dedicated to the project. In the words of an academic researcher:

> *"Well, in that regard, I think that... yes, we [academic researchers] contribute much more to the project, just realistically speaking, but it's also logical. For my PhD trajectory, including writing articles, I work four days a week, and we estimate an average of half a day to one full day for the project. And that doesn't just include preparing for meetings but also writing documents and, yes, everything else that is involved."*

3.4. Theme 4: Stereotyping Hindering Collaboration with Researchers with Intellectual Disabilities

Academic researchers, researchers with intellectual disabilities, and principal investigators all underscored the significance of discarding stereotypical thinking when collaborating within inclusive research. One principal investigator emphasized the significance of involving researchers with intellectual disabilities, insofar as it served as a catalyst for profound self-reflection regarding their own preconceptions of collaborative engagement within inclusive research initiatives. Similarly, some principal investigators and academic researchers indicated that other researchers may sometimes hold unfounded stereotypes toward researchers with intellectual disabilities, including, among other things, assumptions regarding their hesitancy to seek assistance and the misunderstanding that they lack the ability to conduct research, which, for example, is attributed to a perceived difficulty in understanding complex statistical analyses.

According to several academic researchers, holding onto such stereotypes can create a work environment that hinders inclusive collaboration. Researchers with intellectual disabilities themselves shared varying experiences related to stereotyping in the workplace. While some experienced being approached in a childish way, others felt that the academic researchers did not view them through the lens of their disability. Furthermore, they underscored that it was important for both researchers and the broader research community to be mindful that well-intentioned attempts to make persons feel comfortable can potentially be perceived as patronizing, thereby undermining their independence and capabilities.

> *"Most people in the research world, especially scientists, find it difficult to be honest with people with disabilities. So, they just act all nice and friendly because they think that's what those people prefer. They do it to avoid hurting them, but in doing so, they don't take me seriously as a researcher. I wish they would just be honest, even though it's hard. Not everything is feasible, and it's okay to say that. When they do that, trust is built, and the atmosphere between me, my colleagues, and the researchers I work with becomes very positive. Being honest, open, and trustworthy makes a big difference."*

4. Discussion

This study explored the first-hand experiences of researchers with intellectual disabilities, academic researchers, and principal investigators who were actively engaged in collaborative partnerships. These insights, derived from participants involved in six inclusive research projects funded by ZonMw, which involved people with intellectual disabilities actively contributing as researchers with experiential knowledge, may serve to contribute to the continued optimization of inclusive research practices. Conducting a thematic analysis of the interview data generated four overarching themes: (1) the diverse nature of the involvement of researchers with intellectual disabilities; (2) the significance of involving researchers with intellectual disabilities within academic research; (3) shaping equity within research projects; and (4) stereotyping hindering collaboration with researchers with intellectual disabilities. These themes encompass several important findings that will be discussed in turn below.

First of all, the present study underscores the diverse nature of the involvement of researchers with intellectual disabilities within collaborative research projects, encompassing varied time commitments and a broad spectrum of tailored activities. Notably, while researchers with intellectual disabilities were involved in the project design phase in some cases, in the majority of cases, they were not, which is in line with findings from previous studies by Nind (2014) and Walmsley et al. (2018). Drawing on their findings, Nind (2014) and Walmsley et al. (2018) noted that this lack of involvement in agenda setting hinders a comprehensive understanding of their potential contributions. Thus, these authors stress the importance of incorporating researchers with intellectual disabilities into all research phases, including the project design phase. Additionally, it is crucial to recognize the distinct challenges, namely in terms of both time and energy dynamics, that researchers with intellectual disabilities face compared to their “typical” researcher counterparts (Molina Roldán et al. 2021). Addressing these challenges, as highlighted by Sergeant et al. (2022) and Molina Roldán et al. (2021), is essential for both optimizing their contributions and fostering a supportive and inclusive research environment that values diverse capacities and needs.

Secondly, according to the participants within the present study, inclusive research projects benefit from the involvement of the unique perspectives and experiential knowledge of researchers with intellectual disabilities, insofar as they enhance the research process and findings. Prior research has demonstrated numerous benefits associated with collaborating with persons with intellectual disabilities within their capacity as experts by experience, whether in a researcher role or other positions, such as being an advisor (Bigby et al. 2014; Embregts and Frielink 2023). Specifically, according to earlier research (Bell and Mortimer 2013; Nind and Vinha 2014; van den Bogaard et al. 2023), experts with experience with intellectual disabilities reported an enhanced sense of value and empowerment. Similarly, people with intellectual disabilities working as experts by experience in non-research roles, such as trainers, also reported experiencing increased self-esteem, confidence, a greater sense of belonging, and enhanced reciprocity (Den Boer et al. 2024; Embregts and Frielink 2023; Flood et al. 2013; García Iriarte et al. 2014). These insights are in accordance with the comprehensive synthesis conducted by Walmsley et al. (2018), who analyzed 52 articles focusing on inclusive research projects. Their findings identify three primary areas in which inclusive research generates added value compared to conventional research-led endeavors. First, they drew attention to the distinct contributions made by co-researchers with intellectual disabilities as a result of their insider perspective. Second, their comprehensive synthesis explicitly recognizes these contributions through published accounts. Lastly, inclusive research was shown to enhance the lives of a broader population by addressing their specific needs and challenges. In light of these areas of added value, Walmsley et al. (2018) underscore the significance of inclusive approaches that actively involve researchers with intellectual disabilities throughout the entire research process. Such approaches ensure the accessibility and real-world applicability of research outcomes, with the amount of time allocated to the project being of secondary importance to the depth of their active participation, which, in turn, significantly enriches the authenticity and effectiveness of the research.

Thirdly, the goal of equity within research collaborations is shared by academic researchers and researchers with intellectual disabilities, with an emphasis on co-ownership, shared responsibility, and equitable decision-making from the very inception of projects.

According to our participants, building robust relationships, engaging in open dialogue related to both work-related and personal matters, and fostering a profound sense of belonging and commitment all have a pivotal role to play in terms of establishing an equitable starting point within research teams. To cultivate successful collaborative relationships between researchers with intellectual disabilities and academic researchers within inclusive research teams, Embregts et al. (2018) also found that the unwavering commitment of all stakeholders is of paramount importance. In addition, effective communication, honesty, and respect are shown to be essential for establishing trust, fostering a positive atmosphere among researchers, minimizing patronizing behavior, and cultivating an environment of trust and professionalism (Embregts et al. 2018; Sergeant et al. 2022). Moreover, both the development and maintenance of collaborative relationships are contingent upon a variety of factors, including, among other things, the contextual setting, resource availability, the extent to which the inclusive ideology is integrated within the research institution, and the underlying motivations driving the research collaboration between team members (Frankena et al. 2016; O'Brien et al. 2022).

Finally, the academic researchers and researchers with intellectual disabilities involved in this study emphasize the pivotal role of principal investigators in both championing collaboration and cultivating an inclusive team environment that places significant value on everyone's contributions. Consequently, they play a pivotal role in shaping and sustaining positive contact and interactions within research teams. In this context, the application of Allport's intergroup contact theory (Allport et al. 1954) offers a highly pertinent framework through which to make sense of the interactions within inclusive research teams. The theory postulates that positive contact and interactions among members of different groups, whether majority or minority groups, privileged or marginalized, can mitigate prejudice and enhance intergroup attitudes. However, the realization of these benefits necessitates several optimal conditions: firstly, frequent and extended interpersonal contact to facilitate the development of meaningful relationships; secondly, the establishment of equal status relations amongst group members; thirdly, cooperative efforts toward shared goals that foster interdependency; and finally, explicit endorsement of collaboration and equity by authorities and institutions (Pettigrew and Tropp 1998). The significant role of the principal investigator with respect to the latter is evident. Decades of extensive research have consistently provided robust evidence for the validity of intergroup contact theory across a wide array of social groups and real-world contexts (Davies et al. 2011; Pettigrew and Tropp 2006; Zhou et al. 2019). Given this substantial evidence base, employing the intergroup contact theory as a theoretical framework for future research on inclusive research projects holds considerable promise, insofar as it may help to elucidate the dynamics of inclusive interactions and prejudice reduction.

However, the results of this study should be interpreted in light of some limitations. Firstly, the fact that the funder required collaboration with researchers with intellectual disabilities within inclusive research projects may have discouraged academic researchers and principal investigators from openly sharing their thoughts, such as, for example, feeling compelled to collaborate. In an effort to address this bias, researchers ensured the confidentiality of the interviewees by decoupling participant identities and project affiliations. Secondly, across the six research projects, variations existed in the levels of interaction that the principal investigators had with the researchers with intellectual disabilities. While researchers with intellectual disabilities and academic researchers affirmed the significant role of even those principal investigators with limited interaction in promoting collaboration and equal treatment, a potential study limitation lies in the limited scrutiny of persons' roles within the projects and the extent to which these roles were equitable and rooted in inclusion. We encourage future research to systematically evaluate and address this aspect to enhance our understanding of the dynamics of inclusion in research settings. Thirdly, the present study did not include a researcher with intellectual disabilities from the outset, although one was involved at various stages to aid data collection preparation and result interpretation. Fourthly, this research adheres to traditional structures in that the principal investigator was in a leadership role. As such, it is important that future research engage with Jones et al.'s (2020) call for researchers with intellectual disabilities to assume leadership positions within inclusive research. Hence, we underscore the importance of future research exploring more inclusive role boundaries, wherein researchers with intellectual disabilities actively lead rather than primarily supporting projects led by researchers without intellectual disabilities.

For research to genuinely embrace inclusion for people with intellectual disabilities, approaches such as conducting inaccessible statistical analyses or engaging in exclusionary everyday research tasks may not be suitable. Therefore, a critical call to action is for principal investigators and academic researchers to engage in closer collaboration with researchers with intellectual disabilities, aiming to entirely reshape the research process and integrate inclusion at every level. To further this aim, in a sister project of this study, training for inclusive research teams was developed (Sergeant et al. 2021). Furthermore, it is crucial to investigate the specific phases of a project in which persons with intellectual disabilities can provide valuable contributions, especially when addressing questions that may require handling larger datasets. For these situations, the Academic Collaborative Center [name removed for blind peer review purposes] has designed a training course titled "Experts by experience in research". This course introduces persons with intellectual disabilities to the process of conducting scientific research. Beyond direct involvement as researchers, another common avenue for contributions from persons with intellectual disabilities is through advisory roles (Bigby et al. 2014). In alignment with this advisory approach, the Academic Collaborative Center has established a scientific research advisory board comprising individuals with intellectual disabilities. Selected for their experiential expertise, these board members provide guidance on research design, recruitment strategies, and data collection methods (Embregts and Beenhakker 2023).

5. Conclusions

In conclusion, despite the acknowledged limitations of the study, our findings nevertheless indicate a clear imperative for targeted initiatives within inclusive research. This emphasizes the critical need for sustained efforts that are specifically aimed at fostering inclusivity and ensuring the meaningful involvement of persons with intellectual disabilities within the field of academic research. By addressing these challenges within the research context, we strive to contribute toward the realization of a more equitable and inclusive research agenda that values the invaluable contributions and overall well-being of all parties involved in the process.

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Article

Peer Support Provided by People with Intellectual and Developmental Disabilities: A Rapid Scoping Review to Develop a Toolkit for Inclusive Research

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Abstract: Inclusive research teams actively engage people with intellectual and developmental disabilities at all stages of research development, implementation, and dissemination. There is a dearth of research that specifically addresses the use of peer support in research engagement, yet research using peer support may provide a useful framework for engagement in inclusive research teams. A rapid scoping review was completed following the reporting guidelines for PRISMA-SCR. The scoping review identified five peer support roles (communication, sharing experiences, helping peers to learn, peer development, and creating a welcoming environment) and two types of support and accommodation for peer supporters (individual and environmental). The findings of the rapid scoping review aided in developing key sections of a Peer Support Toolkit to help people with intellectual and developmental disabilities engage in research to create more inclusive research teams and research that is informed directly by the needs of people with lived experience. The scoping review and toolkit were completed by an inclusive team.

Keywords: intellectual and developmental disabilities; peer support; inclusive research; scoping review; rapid scoping review

1. Introduction

Partnering with people with intellectual and developmental disabilities in research (inclusive research) can ensure that research is important and meaningful. Inclusive research often leads to increased interest in participation and greater acceptance of results, as well as a process that is empowering to inclusive research team members (Domecq et al. 2014; Dudley et al. 2015; Harrison et al. 2019; Sheridan et al. 2017; Walmsley et al. 2018). In the last twenty years, leaders in inclusive research have established methodological best practices for decision-making processes, accessible data collection and analysis, and dissemination (Frankena et al. 2019). Yet, there is still a pressing need for quality approaches to training and building the capacity of research collaborators with intellectual and developmental disabilities that are aligned with the key tenets of inclusive research (Embregts et al. 2018; Garratt et al. 2022; Milner and Frawley 2019). Peer support can be a useful approach for facilitating engagement for people with intellectual and developmental disabilities in the research process in a way that is performed 'with' and 'by' people with disabilities (Kramer et al. 2013, 2023, 2018; Milner and Frawley 2019; Strnadová et al. 2014; Tavecchio et al. 2019).

The (Developmental Disabilities Assistance and Bill of Rights Act 2000) of the United States of America defines a developmental disability as a condition that is attributable to a mental and/or physical impairment, manifested before the age of 22 years, long-term, results in significant limitations in multiple areas of functioning, and requires specialized supports (Developmental Disabilities Assistance and Bill of Rights Act 2000). A broad range of specific diagnostic conditions are encompassed by the category of developmental disabilities, including Autism Spectrum Disorder, intellectual disability, and cerebral palsy (Boyle et al. 2011). The term developmental disability is often used interchangeably with other labels, like neurodevelopmental conditions. However, Intellectual Developmental Disorder is a more specific condition that falls under the umbrella of developmental disabilities. People with developmental disabilities and/or their families in the US use a variety of terms to describe their identity, such as self-advocate, autistic or neurodiverse, person with lived experience, and person with special needs. However, there is no clear consensus, and terminology may be regional- or diagnostic-specific, and it may vary depending on the context in which it is used (Autistica 2023; Self Advocates Becoming Empowered 2023; Self-Advocacy and Leadership 2023). Given that the population described above is a highly heterogeneous group, we use the term intellectual and developmental disabilities in this manuscript to reflect all of these individuals.

For people with intellectual and developmental disabilities, there is growing evidence that peer support improves outcomes in areas such as independent living, socialization and relationships, and employment (Brady et al. 2016; Causton-Theoharis 2010; Chan et al. 2009; Griffin et al. 2016). Peer support is an organized method of providing formal or informal support and is founded on the concept that a peer with lived experience is poised to better understand the unique perspective of another person with a similar experience (Bazzano et al. 2009; Frawley and Bigby 2014; Power et al. 2016; Schwartz et al. 2020; Pfeiffer et al. 2021). Similarly, engagement in research leads to transformative change for people with intellectual and developmental disabilities in their professional, personal, and community lives (Herer and Schwartz 2022; Hopkins et al. 2022; Zaagsma et al. 2022). Current literature on peer support focuses mainly on the effectiveness of a specific peer support intervention on a targeted outcome (Weidle et al. 2006); yet, there is a dearth of research that has systematically examined the use of peer support in research engagement. Still, existing peer support research, conducted outside of a specific inclusive research approach, may provide a useful framework for integrating peer support as a mechanism for engagement in inclusive research teams.

People with intellectual and developmental disabilities have multiple identities and characteristics that they can leverage as peer mentors. This may include their gender identity and expression, cultural and linguistic backgrounds, and nationality (Wehmeyer et al. 2017). In this paper, we specifically focus on peer support provided by people with intellectual and developmental disabilities. This is a purposeful challenge to the over-representation of non-disabled, same age "peers" in peer support literature that includes people with intellectual and developmental disabilities (Płatos and Wojaczek 2018; Travers and Carter 2022). Peer support builds on the theory that shared lived experience and reciprocal relationships provide a mechanism for change (Substance Abuse and Mental Health Services Administration (SAMHSA) (2015)). The use of peers who do not share the lived experience of disability in educational, vocational, and social interventions eliminates a significant component of the proposed mechanism of change and disregards the lived experience, expertise, and capacity of persons with intellectual and developmental disabilities (Bigby et al. 2014; Walmsley et al. 2018). Again, as aligned with the key tenets of inclusive research (Embregts et al. 2018; Garratt et al. 2022; Milner and Frawley 2019), conceptualizing peer support by experienced researchers with intellectual and developmental disabilities is an opportunity to further advance inclusive research methodology.

We conducted a rapid scoping review and developed a Peer Support Toolkit for collaborative research teams with the primary aim of identify strategies and expanding the use of peer support as an inclusive research method. The purpose of this rapid scoping review was to identify the key components of peer support including roles, strategies, and supports, provided by individuals with intellectual and developmental disabilities that could translate into methods for research engagement. The review included a range of different study designs and methods across the literature that used peer support strategies and interventions provided by and for people with intellectual and developmental disabilities. Results were integrated into a Peer Support Toolkit, with the collaboration of a team of researcher with intellectual and developmental disabilities, to support the engagement of people with lived experience in research (Pfeiffer et al. 2021).

2. Methods

The review followed the reporting guidelines for PRISMA-SCR (Tricco et al. 2018). A rapid scoping review is a recommended method when including a range of study designs and methods across the published and gray literature (Sucharew and Macaluso 2019). This method was suited to our study aim given the growing, but comparably limited, literature on the topic of peer support provided by individuals with intellectual and developmental disabilities. Further, a rapid review aligned with the overall study goal to quickly translate the existing knowledge into a toolkit. This allowed us to extract strategies and components across a variety of research literature specific to peer support by and for individuals with intellectual and developmental disabilities. The research team consisted of two project leads with extensive experience with inclusive research teams, a stakeholder, research staff with intellectual and developmental disabilities, and two additional research staff.

2.1. Search

To identify studies to include or consider for this rapid scoping review, the review team collaborated with a medical librarian to develop detailed and systematic search strategies for each database (Bramer et al. 2018). Details of the full search strategy are provided at http://hdl.handle.net/20.500.12613/4663 (accessed on 21 December 2023) (Roth et al. 2020), which is a freely available repository for sharing and archiving a range of scholarly works, including search processes for reviews. Specific search methods and terms for each database are available in metadata available at this site for replication purposes. Developed for PubMed (NLM) initially, the search was then translated to ERIC (EbscoHost), CINAHL (EbscoHost) and PsycInfo (EbscoHost) using a combination of keywords and subject headings. A gray literature search included dissertations and theses within Dissertations & Theses Global (Proquest). Included articles were written in English and published between 2005 and 2020. Given the relatively recent emergence of peer support in the field of intellectual and developmental disabilities, these dates were appropriate and helped to ensure the rapid pace of our review. The search excluded studies with children and only included articles with participants aged thirteen years and over. The age range was set at thirteen years and above to ensure the inclusion of articles focused on transition age youth and the young adult population with intellectual and developmental disabilities, as there is a subset of the literature that specifically focuses on peer support within this age range (Ryan et al. 2016; Weidle et al. 2006).This allowed the team to find literature that included information that could be translated into peer support strategies for adults with intellectual and developmental disabilities on inclusive research teams. Researchers completed the final search on 24 November 2020. The search resulted in 3154 studies. Endnote X.7 identified 267 duplicate studies and omitted these for the deduplication of records, and 2887 references were eligible to screen for inclusion (see Figure 1).

2.2. Screening and Review

The researchers used Covidence, a web-based collaboration software platform (Covidence Systematic Review Software 2020), to manage the screening and review process. The research team determined the inclusion and exclusion criteria prior to the review. The inclusion criteria were as follows: (1) a study population of people with intellectual and developmental disabilities aged 13 years or older (including intellectual disability, autism, cerebral palsy, and other developmental disabilities); (2) the description and use of intentional peer support interactions; (3) peer support provided by a person with an intellectual and developmental disability; and (4) articles published in English. The researchers excluded articles if (1) people without an intellectual and developmental disability provided peer support (e.g., no diagnosis, spinal cord injury, specific learning disabilities, ADHD) and/or (2) publications were conference presentations/abstracts, book chapters, or websites.

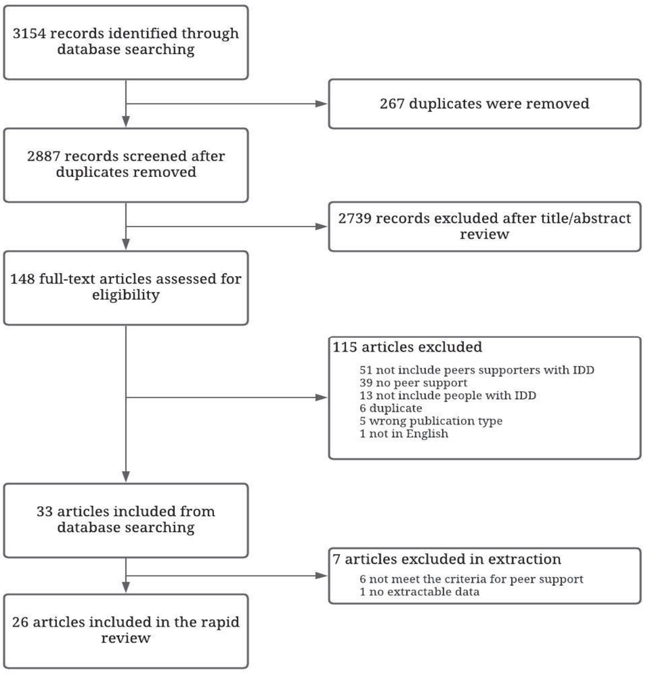

Figure 1. *PRISM* flow diagram. Note that this figure provides a *PRISM* flow diagram of the article's search and review process in each phase of the scoping review.

A total of five research team members were involved in the review process. One of the team members and authors was a person with an intellectual and developmental disability who identifies as an autistic adult. He was involved in the screening of abstracts and the full-text review of articles, as well as resolving conflicts between other reviewers. Two blinded and independent reviewers screened each study by title and abstract. If there was a conflict between reviewers, a third reviewer was involved in a consensus discussion with the two initial reviewers. Title and abstract screening resulted in the exclusion of 2739 records. The research team repeated this process for full-text article screening and article selection. The research team reviewed 148 full text articles and excluded 115 for the following reasons:

1. Did not include people with intellectual and developmental disabilities (n = 13). Articles were excluded that did not include people with intellectual and developmental disabilities over the age of 13 years. Reviewers excluded articles that focused on other non-intellectual and developmental disabilities (i.e., specific learning disabilities such as ADHD, dyslexia).
2. Did not include any identifiable peer support component (n = 39). Articles were excluded that did not identify peer support or any of its components in the full text, including those articles that referred only to naturally occurring peer relationships or friendships. Researchers also excluded articles that did not describe an intentional interaction between peers, such as those using pre-recorded videos of a peer modeling a target behavior or outcome.
3. Did not include peers with intellectual and developmental disabilities (n = 51). Articles were excluded that did not have a peer with an intellectual and developmental disability (e.g., a typically developing peer) delivering the peer support strategy or intervention.

4. Wrong publication type (n = 5). The research team excluded conference abstracts and presentations, book chapters, and websites.
5. Not in English (n = 1). Articles were excluded that were not written in English, as researchers did not have access to confirm accurate translation.
6. Duplicates (n = 6). Duplicate articles identified by reviewers were excluded.

Following a full-text review, 33 articles that described peer support for people with intellectual and developmental disabilities were retained. During the extraction process, researchers eliminated another seven articles, as one article did not have any extractable data (n = 1) and the remaining six did not meet the criteria for peer support (n = 6), as there was no *intentional* interaction between peers (e.g., those using pre-recorded videos of a peer modeling a target behavior or outcome). The final review included 26 full-text articles.

A thematic analysis process was used when extracting the data. Two research team members completed line-by-line coding of text initially from three randomly chosen articles to identify themes and categories to guide the extraction of information on peer support. Any new categories that emerged during data extraction were added after discussion and consensus from research team members. One person on the research team extracted all descriptions of peer support from each article. A second reviewer reviewed and validated the extracted information, revising or adding to the extracted data as needed. The full research team discussed questions about discrepancies in reaching consensus about the final content. Researchers categorized data extracted on peer support from each article as (1) terms used to describe peer supporters, (2) definitions of peer support, (3) descriptions of what peer supporters did, and (4) descriptions of assistance or training provided for peer supporters. The project leads then collaboratively coded these descriptions into key components of peer support, peer supporter roles and strategies, as well as supports and accommodations. These coded data were shared and discussed by an advisory board which included people who had lived experience with intellectual and developmental disabilities (n = 4), family and caregivers of people with intellectual and developmental disabilities (n = 3), and researchers with an intellectual and developmental disability (n = 3) to identify important themes and content for using peer support in inclusive research teams.

The aim of this review was to identify ways that peer support is provided by people with intellectual and developmental disabilities for the purposes of translating those methods into research engagement, not to evaluate the effectiveness of those strategies. The research team wanted to include a full range of study designs that incorporated peer support. Therefore, a critical appraisal of each article was not included.

3. Results

Three main themes were identified during the data extraction and analysis process including (1) key components of peer support; (2) peer supporter roles and strategies; and (3) supports and accommodations for peer supporters. The results provide descriptions of these themes, along with an overview of the article characteristics. Characteristics of the articles including the type of article, participants, design, and terminology used for peer support are identified to provide context for the interpretation and application of data.

3.1. Article Characteristics

We identified 26 articles that described peer support provided by people with intellectual and developmental disabilities. See the Table S1 for the article's details. Out of the 26 articles, eight focused on peer support provided by and for individuals with Autism Spectrum Disorders (ASD), ten on people with an intellectual and developmental disability other than ASD, and eight on a combination of a variety of developmental disabilities (including ASD and intellectual and developmental disabilities). The age range of peers with intellectual and developmental disabilities and those they supported across studies was from 13 to 71 years. Terms used to describe the peer supporter varied considerably across articles and included peer mentor (n = 8), peer tutor or educator (n = 5), peer facilitator (n = 3), and peer coach (n = 2). Ten articles used other terms to characterize peer support, such as coach, advocate, and ambassador (see Table S1). The various terms used to describe support provided by peers can guide research engagement and provide options for inclusive research teams for language that best aligns with their teams' preferences and philosophy.

The types of studies and articles varied and included twelve qualitative studies, eight single group intervention studies, three program evaluations, one case study, one editorial with included supporting data, and one two-group pre-test–post-test study using a randomized control design with a wait-list control group. A range of qualitative methods were used to elicit information about the peer support process including focus groups, interviews, observations, and self-reflections. The thematic coding was performed either solely by the research team or sometimes cooperatively with the participants.

3.2. Key Components of Peer Support

A primary theme that emerged from the results of the data extraction and analysis process was key components of peer support (see Table 1). These key components help to identify the common core characteristics of peer support, as conceptualized and reported in the literature. Establishing these key components reveals the hypothesized mediators that lead to the observed outcomes and benefits of peer support. In the context of inclusive research teams, peer support may need to incorporate these key components to ensure similar benefits.

The most commonly identified component of peer support was having a shared lived experience (n = 15) (Bazzano et al. 2009; Bertilsdotter Rosqvist 2019; Carley 2018; Crane et al. 2021; Dudley et al. 2015; Eisenman et al. 2014; Frawley and Bigby 2014; Kramer et al. 2018; Schwartz et al. 2020; Singh et al. 2011; Strnadová et al. 2014; Williams and Porter 2017). This was often described in the context of their diagnosis and the similar experiences that the peer and peer supporter shared. The second-most identified component was self-efficacy and self-advocacy (n = 11) (Bazzano et al. 2009; Borisov 2009; Eisenman et al. 2014; Frawley and Bigby 2014; Marks et al. 2019; Nind et al. 2021; Power et al. 2016; Strnadová et al. 2014; Weidle et al. 2006; Williams and Porter 2017; Wright et al. 2019). Self-efficacy refers to a person's belief in their own capacity, whereas self-advocacy is the ability to advocate for oneself or their views. These were described as constructs which a peer supporter facilitated in the peer support relationship. Reciprocity was identified as core characteristics of peer support in a number of the articles (n = 9) (Borisov 2009; Frawley and Bigby 2014; Kramer et al. 2018; Nind et al. 2021; Ryan et al. 2016; Strnadová et al. 2014; Williams 2015; Williams and Porter 2017; Wright et al. 2019). The construct of reciprocity was described as the mutual benefit of both the peer and peer supporter within the peer support relationship.

3.3. Peer Support Roles and Strategies

A related but different theme that was identified in the data extraction and analysis process was *peer support roles and strategies.* This theme describes the actual roles that peer supporters assume when providing peer support and the types of strategies they implement. Specifically, these are the actions taken by peer supporters to operationalize the key components that support the benefits and outcomes of peer support. This theme provides potential roles and strategies that peers with intellectual and developmental disabilities could use to support other people with intellectual and developmental disabilities to engage in inclusive research teams.

Table 1. Peer support key components, roles, and strategies.

Author(s)	**Key Components of Peer Support**				**Peer Support Roles and Strategies**					
	Shared Lived Experience	**Self-Efficacy/Self-Advocacy**	**Reciprocity**	**Friendship/Comradery**	**Role Modeling/Education**	**Support for Specific Tasks**	**Relationship Building**	**Creating a Safe Space**	**Positive Disability Identity/Normalization of Disability**	**Creating a Sense of Commonality**
(Bazzano et al. 2009)	x	x								
(Bertilsdotter Rosqvist 2019)	x							x	x	x
(Borisov 2009)		x	x		x	x				
(Brady et al. 2016)					x	x				
(Carley 2018)	x			x				x		
(Crane et al. 2021)	x							x		
(Davis et al. 2018)						x				
(Eisenman et al. 2014)	x	x								
(Frawley and Bigby 2014)	x	x	x		x					
(Hillier et al. 2007)							x			
(Kearney et al. 2018)				x		x		x		
(Kramer et al. 2018)	x		x	x		x	x			x
(Marks et al. 2019)		x		x	x	x			x	
(Nind et al. 2021)	x	x	x	x						
(Power et al. 2016)		x					x			
(Ryan et al. 2016)	x		x				x			
(Schwartz and Kramer 2018)	x			x			x	x		
(Schwartz et al. 2020)	x			x	x		x			
(Singh et al. 2011)	x									
(Strnadová et al. 2019)										
(Strnadová et al. 2014)	x	x	x		x				x	
(Weidle et al. 2006)		x								
(Williams 2015)	x		x							x
(Williams and Porter 2017)	x	x	x						x	
(Witton et al. 2017)				x	x	x			x	
(Wright et al. 2019)		x	x			x				

Descriptions of the roles of peer supporters in each article varied considerably, although there were a number of consistent themes across articles. Peer supporters were described as providing friendship/comradery (n = 8) (Carley 2018; Kearney et al. 2018; Kramer et al. 2018; Marks et al. 2019; Nind et al. 2021; Schwartz et al. 2020; Witton et al. 2017) and role modeling or education (n = 7) (Borisov 2009; Brady et al. 2016; Frawley and Bigby 2014; Marks et al. 2019; Schwartz et al. 2020; Strnadová et al. 2014; Witton et al. 2017). Others described peers as providing support for specific tasks (n = 8) (Borisov 2009; Brady et al. 2016; Davis et al. 2018; Kearney et al. 2018; Kramer et al. 2018; Marks et al. 2019; Witton et al. 2017; Wright et al. 2019), relationship building (n = 6) (Bazzano et al. 2009; Bertilsdotter Rosqvist 2019; Carley 2018; Crane et al. 2021; Dudley et al. 2015; Eisenman et al. 2014; Frawley and Bigby 2014; Hillier et al. 2007; Kramer et al. 2018; Schwartz et al. 2020; Singh et al. 2011; Strnadová et al. 2014; Williams and Porter 2017), creating a safe space for the peer (n = 5) (Bertilsdotter Rosqvist 2019; Carley 2018; Crane et al. 2021; Kearney et al. 2018; Schwartz and Kramer 2018), promoting the normalization of disabilities and positive disability identity (n = 5) (Bertilsdotter Rosqvist 2019; Marks et al. 2019; Strnadová et al. 2014; Williams and Porter 2017; Witton et al. 2017), and creating a sense of commonality (n = 3) (Brady et al. 2016; Schwartz and Kramer 2018; Williams 2015).

These actions were grouped during coding to identify five common roles that describe the function of the peer supporter in the peer support relationship. These roles included (1) facilitating communication, (2) sharing experiences, (3) helping peers to learn, (4) supporting peer development, and (5) creating a welcoming environment. Much of what researchers described could then be considered strategies to support each role. Strategies are the specific actions, activities, or tasks that a peer supporter can perform in their role to meet a goal. The peer supporter roles and strategies identified through the coding process are outlined in Table 2.

Table 2. Peer support roles and strategies.

Role	Strategies
Communication	• Setting up a regular meeting time and place • Communicating in ways that meet the peer's needs and preferences/choices • Role modeling how to be a good communicator • Advocating for the peer
Sharing Experiences	• Sharing stories about research and other experiences related to the intervention or targeted outcome • Noticing and talking about experiences the peer supporter and peer have in common
Helping Peers to Learn	• Sharing resources • Guiding the peer as they work to solve a problem or complete a new task
Peer Development	• Helping the peer set goals to grow as a researcher • Helping the peer set personal and professional life goals • Helping the peer keep track of their goals
Creating a Welcoming Environment	• Giving assurances to the peer • Validating their feelings and experiences • Noticing and celebrating success

(Pfeiffer et al. 2021, https://sites.temple.edu/reachlabtemple/peer-support-manual/ (accessed on 8 August 2023)).

3.4. Supports and Accommodations for the Peer Supporter

The final theme extracted and analyzed within the coding process was *supports and accommodations for the peer supporter*. This theme describes the types of assistance that researchers provided to peer supporters in their research studies. While most of the studies occurred outside the context of inclusive research, similar supports and accommodations may be helpful when implementing peer support on inclusive research teams. Coding across the articles identified two main types of assistance, including (1) individual supports and (2) environmental supports and accommodations.

Individual supports were provided by a designated person to help the peer supporter in their role (n = 12) (Borisov 2009; Davis et al. 2018; Eisenman et al. 2014; Frawley and Bigby 2014; Hillier et al. 2007; Marks et al. 2019; Ryan et al. 2016; Schwartz and Kramer 2018; Weidle et al. 2006; Williams 2015; Wright et al. 2019). This was often a more experienced person on the team who was identified as a peer mentor, co-facilitator or teacher, or group leader. This person would work alongside the peer or provide support and supervision to allow them to fulfill their role. Consistent supervision was repeatedly identified (n = 12) (Borisov 2009; Davis et al. 2018; Eisenman et al. 2014; Frawley and Bigby 2014; Hillier et al. 2007; Kramer et al. 2018; Marks et al. 2019; Ryan et al. 2016; Schwartz and Kramer 2018; Weidle et al. 2006; Williams 2015; Wright et al. 2019) as important to determine interest and comfort with their role, address problems, clarify expectations, and support self-efficacy. The peer supporter and peer often worked together to problem solve (n = 6) (Kramer et al. 2018; Marks et al. 2019; Ryan et al. 2016; Schwartz and Kramer 2018; Williams 2015; Wright et al. 2019). This included identifying any needed environmental supports.

Environmental supports and accommodations focused on aspects of the environment that are modifiable or enhanced to support engagement in research, including the environment of the research team (n = 10) (Davis et al. 2018; Kramer et al. 2018; Marks et al. 2019; Ryan et al. 2016; Schwartz et al. 2020; Schwartz and Kramer 2018; Weidle et al. 2006; Williams 2015; Witton et al. 2017; Wright et al. 2019). These supports and accommodations were provided by varying members of the research team members, including the investigators, research staff, or interventionists on the research team.

Researchers further coded individual and environmental supports and accommodations as process-oriented supports and tangible supports and accommodations. Process-oriented supports include non-physical supports, such as providing positive reinforcement or increasing the time needed to complete a task. Another example that aligns with the core components of peer support is to provide emotional supports and modeling. Tangible supports and accommodations include providing accessible materials, using visual supports, and having accessible technology. Table 3 provides a list of the specific types of processes and tangible supports extracted across articles during the coding process. This information provides lead researchers on inclusive teams with examples of possible supports and accommodations that were used in prior research for use within their own teams. Research leads can implement supports and accommodations preemptively or when needed to promote the success of peer supporters on their teams.

Table 3. Environmental supports and accommodations for peer supporters.

Non-Tangible, Process Oriented Support
Intentionally build opportunities for participation during all stages of the research process
Practice skills before applying them
Provide ongoing opportunities for practice/rehearsal, including refresher trainings
Modify concepts to increase the understandability
Use specific examples (e.g., provide concrete examples of abstract concepts; role plays of interpersonal skills; examples of tasks in action
Provide immediate feedback to the supporter about how they are doing
Slow the pace of instruction
Increase time for skills training when needed
Provide positive reinforcement
Fade assistance during interactions
Use communication cues (e.g., visual prompts for turn taking)
Provide specific education or training on different styles of communication
Provide reminders regarding how to positively approach peers and other coworkers
Provide emotional support

Table 3. *Cont.*

Tangible Supports and Accommodations
Intentionally build opportunities for participation during all stages of the research process Use technology to support communication (e.g., online discussion boards; synchronous typed/text messaging) Provide resources or handouts when available (e.g., peer mentoring handbook) Use tangible tools such as flowcharts, checklists, tip sheets for specific tasks, sample scripts, and worksheets
Provide accessible written materials including • Font and text size; • Color coding; • Individualized text; • Abbreviated versions of text; • Electronic versions of materials.
Use visual supports: • Picture schedule; • Create word clouds of key concepts; • Visual timelines; • Lists of rules; • Note cards.
Provide technical support for the use of technology: • Communications (i.e., email, videoconferencing); • Using devices or software.

(Pfeiffer et al. 2021, https://sites.temple.edu/reachlabtemple/peer-support-manual/ (accessed on 8 August 2023)).

Additionally, an understanding of the types of assistance used in prior research provides a foundation of individual and environmental supports for peer supporters that are engaging others with intellectual and developmental disabilities in research teams. This is important factor when building inclusive environments within research teams and optimizing the impact of peer support in that process.

4. Discussion

4.1. Translating Findings to a Peer Support Toolkit

This rapid scoping review identified the key components of peer support, roles, and strategies used by peer supporters and considerations for supports and accommodations that may be helpful when working with peer supporters with intellectual and developmental disabilities. The research team used these findings to identify ways that concepts like communication, peer assistance, sharing personal experiences, and creating a non-judgmental environment (e.g., Brady et al. 2016; Crane et al. 2021; Frawley and Bigby 2014; Schwartz et al. 2020) can be embedded in the research process. This movement toward more inclusive research teams can propel future research that is directly informed by people with intellectual and developmental disabilities. The application of peer support as a method for research engagement advances present engagement strategies that focus more on research participation by clearly identifying a central role for a person with lived experience as a member of the research team. We operationalized what we learned into the developmental of a Peer Support Toolkit (Pfeiffer et al. 2021, https://sites.temple.edu/reachlabtemple/peer-support-manual/ (accessed on 8 August 2023)).

The Peer Support Toolkit was developed in collaboration with a range of people with intellectual and developmental disabilities who worked on research teams at three institutions Temple University, University of Florida, and Boston University. Our team members had a range of experience conducting research. Team members at Temple University had 1–5 years of experience, while the team members at Temple University (who refer to themselves as the “Cool Cats”) had less than one year of experience, and almost all of their experience was asynchronous work conducted during the first year of the pandemic. One of the authors, an experienced peer supporter and autistic researcher from Temple University and the Cool Cats met weekly for several months to review the results from the rapid scoring review and identify and develop information that could be included in the toolkit. Team members at Boston University developed materials asynchronously, based on their identified interests and more limited availability during the project.

The first component of the toolkit, "For Peer Supporters", was developed with the intention to teach team members with intellectual and developmental disabilities how to serve as peer supporters on a research team. This component included two units: (1) what is peer support and (2) roles and strategies. In the sections for each unit, our collaborative team was responsible for translating key concepts into accessible language and identify images to support the meaning of the words. The team also worked on the development of interactive content to support learning, such as generating real-life examples of concepts, developing role plays, and creating videos. One of the authors created printable worksheets designed to support the use of the strategies based on worksheets and materials used by her inclusive teams, which were then trialed and refined by the Cool Cats. Table 4 includes a summary description of the materials developed by the team.

One of the most significant tasks completed by the collaborative team for this section of the toolkit was the creation of role play videos. Three videos demonstrate a peer supporter enacting three of the roles identified in the scoping review: (1) how to ask for accommodations during a research team meeting (role: help people communicate in a way that works for them); (2) coaching a new team member about how they handled a challenging situation while working with a research participant (role: help the peer mentor learn new research tasks); and (3) giving assurance to a new members of the team (role: create a welcoming environment). Videos may be more beneficial than words on paper, or adding an activity, for people with different learning needs and styles. Videos that show people with the lived experience of having intellectual and developmental disabilities engaging in research also facilitate the realization that "they are like me, and they are part of a research team, and that's something I want to be involved in" (as articulated by a member of our team). This could build self-efficacy, a key component of peer support (Bandura 2012; Burke et al. 2019; Dennis 2003)and change people's perspectives of what is possible for their career.

These video scripts were developed by the experienced peer supporter. He generated the content for the script by drawing upon his previous experience with working as a peer supporter, thinking of strategies he used as a person with a disability to participate in research, and reviewing the example roles and strategies identified during the scoping review. Table 5 includes an extended reflection from the peer supporter on the research team about the process of providing peer support to other members with intellectual and developmental disabilities on the team.

The creation of this Peer Support Toolkit was also an opportunity for the more experienced researcher to enact the roles and activate the key components identified in the peer review. The key component of reciprocity is apparent in the peer supporter's reflections, as he had the opportunity to support others and build capacity, while also being exposed to new things and building his skills and awareness (Thiele et al. 2019; Substance Abuse and Mental Health Services Administration (SAMHSA) (2015)). Working together on this project also created a sense of connection and community, and people's different disabilities and abilities were respected. The team's use of process-oriented and tangible supports and accommodations, as identified in the review, facilitated everyone's engagement in the development process, regardless of their years of research experience or communication style. These accommodations were especially crucial, since the team was working in a virtual environment (Kramer et al. 2023).

Table 4. Peer Support Toolkit units and materials developed to train peer supporters.

Unit and Section	Example Contribution of Team Members with Disabilities
Unit: What is peer support?	• Lived experience videos about being members of a research team. • Understanding the difference between formal and informal peer support, using pictures and examples
Unit: Roles and strategies for peer support	
Help people communicate in ways that work for them	• Provided examples of how to set up a regular meeting time and place. • Thought of accommodations that could support members of a research team (e.g., use chat on Zoom meetings, use plain language). • Gave examples of communication (body language, listening, telling others when you do not know, speaking up) that is “good” (e.g., ask people to slow down) and “needs improvement (e.g., yell at people). • Trialed a worksheet that peer supporters could use to help other team members plan ahead about what they want to share at a meeting. • Created a role play video showing a peer supporter helping a new member of a research team ask for accommodations.
Share your experiences	• Generated examples of things that are hard when working on a research team (e.g., lots of information is shared at a meeting) and the solutions they use to resolve the barriers (e.g., reviewing the agenda ahead of time). • Activities a peer supporter could do to get to know new people on the team (e.g., play icebreakers, go to the snack bar together).
Help the peer researcher learn new research tasks	• Links to videos our team used to learn about research • Created a role play video showing a peer supporter coaching a new member of the research team
Support personal and professional development	• Listed research skills that new team members may want to learn (e.g., learn how to use Excel, learn how to ask good questions during interviews) • Trialed a worksheet that peer supporters could use to help other team members set personal and professional goals and keep track of their goals.
Create a welcoming environment	• Things a peer supporter could say to help new researchers feel confident when learning new things (e.g., “Keep trying”, “I can help explain this to you”, and “You are trying new things”) • How a peer supporter could recognize the successes of new team members (e.g., say “good job”, send a text with a fun emoji) • Created a role play video showing a peer supporter providing assurance to a new member of the research team

The second component of the toolkit, “For Research Team Leads”, was developed to provide team leads, with or without disabilities, with practical resources to integrate peer support into their inclusive research team. The project leads were responsible for developing the content based on research and years of experience. The first unit, “Research Engagement and Peer Support”, integrates key concepts from peer support and inclusive research and provides links to external resources and publications about research collaborations with people with intellectual and developmental disabilities. It draws on supporting literature from inclusive research that identifies important concepts to make research engagement by people with lived experience more successful. These concepts include fair and equitable power between team members; trust between people with lived experience and researchers; education and regular communication for both researchers and team members with lived experience; and adequate compensation for the time and expertise of team members with lived experience (Bigby et al. 2014; Franke et al. 2019; Harrison et al. 2019; Nind and Vinha 2014). The key components of peer support overlap with these concepts, which enhances the roles of peer support in successful engagement in inclusive research teams. The second unit, “Peer Researchers in the Phases of Research”, maps the various roles of peer support to each phase of research, from choosing a research topic, to data collection, to dissemination. The third unit, “Recruiting and Hiring”, draws upon our own experience with recruiting, hiring, and onboarding team members with disabilities to provide exemplar job descriptions, accessible interview procedures, and other hiring considerations.

Table 5. A peer supporter’s reflections on providing support to an inclusive research team.

When making the scripts and videos for the tool kits, I used my personal experiences. I used to be in theater in high school, so I used my skills from theater. More importantly, our team talked about each script and made edits as a team. I like to be detailed, but not everyone is like that—so we wanted to make sure the story made sense for everyone on the team. We spent a lot of time practicing before the recording. We recorded different videos, and then picked one that we thought was the best.
One of the challenges doing this work was the distance between the two research teams. Temple University is almost 1000 miles away from the University of Florida. It would have been nice to come together in person and collaborate, but distance and the COVID-19 pandemic made this impossible. Differences in communication styles, and one team member’s use of an Augmentative and Alternative Communication (AAC) device, was not something I had a lot of experience with. Coordinating times we are all available for our meetings was also challenging.
Our team had to create a welcoming environment to deal with these challenges. Our team did a good job of balancing the responsibility of meeting the deadlines for the project and working together as a team in a way that is positive and enjoyable. We worked hard, but it did not feel like a lot of pressure, because we planned ahead and had a schedule.
When I first started working on this project, it was something as another part of my responsibilities. I didn’t realize the impact of what we did until later on. When I was no longer able to attend the meetings and started going into other spaces with very few people with disabilities, I realized the impact and uniqueness of our team. I am able to talk about my experience working with a research team that is inclusive of people with lived experience of disabilities with others. When I explain to people what we did, which is usually to neurotypical people, I try to teach other people that including peers on research team is really valuable for everyone. It provides employment to people with disabilities and it changes the perspectives of people who are not exposed to different disabilities—like autism, cerebral palsy, and other disabilities. We all have different perspectives about disabilities, and maybe they think people with disabilities can’t do anything. Working with people with different disabilities helps you understand what they can do and changes perspectives.
I learned that I had the ability to teach these skills and be a mentor for new researchers. Especially for people who are in the same stage of life and the same age as me. I hope in the future I can meet more people who are around the same age as me—and potentially all over the country—and we can share similar experiences.

An initial draft of the toolkit was reviewed by two researchers and two peer supporters with intellectual and developmental disabilities. All reviewers shared feedback to improve the overall layout and navigation of the toolkit pages, recommendations to improve the accessibility of the language, and the use of pictures and visual supports. Revisions based on these recommendations included a redesigned home page that described the toolkit’s audience. Overall, the reviewers felt that the toolkit was useful, and they liked the worksheets. The process of toolkit development was inclusive at all stages, which is a unique aspect of this work and one that significantly improves the quality of the toolkit created (Pfeiffer et al. 2021, https://sites.temple.edu/reachlabtemple/peer-support-manual/ (accessed on 8 August 2023)).

4.2. Limitations

This rapid scoping review was designed to quickly identify peer support strategies that could be leveraged to facilitate research engagement with people with intellectual and developmental disabilities. Many of the articles identified in the search did not include the demographic characteristics of participants, although some studies did identify the age range. Without descriptions of race, ethnicity, gender, and other demographic information, it is impossible to determine if the studies examined are collectively representative of the population. It is possible that different features of peer support may be more effective for different communities and populations. In addition, there was limited research that focused on including peer support within research teams, and these studies did not always focus on the effectiveness of peer support. This review included all types of study design in order to broadly identify the characteristics and roles of peer support.

5. Conclusions

This rapid scoping review identified the components of peer support, the roles and strategies used by peer supporters, and supports and accommodations for the peer supporter. The toolkit will help people with intellectual and developmental disabilities to engage in research, creating more inclusive research teams and research informed directly by the needs of people with lived experience. Ensuring those with intellectual and developmental disabilities are included in research in a supportive way will improve the effectiveness and equitable nature of future research.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/socsci13010047/s1, Table S1: Matrix of Rapid Scoping Review Articles.

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Data Availability Statement: Details of the full search strategy for the rapid scoping review are provided at http://hdl.handle.net/20.500.12613/4663 (accessed on 21 December 2023) (Roth et al. 2020), which is a freely available repository for sharing and archiving a range of scholarly works, including search processes for reviews. Specific search methods and terms for each database are available in metadata available at this site for replication purposes.

Conflicts of Interest: The authors declare no conflict of interests.

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Article

Using Inclusive Research Methods and the Housing Pathways Framework in Future Planning and Housing Research: A Pilot Study

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Abstract: Housing and future planning have been key areas of interest in intellectual and development disabilities research for a number of decades. However, the voices of adults with intellectual disabilities are underrepresented in this area of research. Furthermore, the use of inclusive research methods remains limited in the literature. This study sought to pilot the use of inclusive research approaches to investigate the viability of these methods and to begin to build an evidence base of inclusive research in this area of work. Inclusive data analysis and co-authorship approaches were used on a small qualitative dataset from a larger study investigating future planning and transitions out of the family home by adults with intellectual disabilities and their families in Australia. Three semi-structured interviews with adults with intellectual disabilities and family members regarding their housing preferences and planning were analysed using an inclusive data analysis approach following the principles of Interpretative Phenomenological Analysis. These were then further analysed using a plain language version of the housing pathways framework. The results of the pilot study will be used to inform the inclusive research methods used for the remainder of the project dataset. Overall, the use of inclusive methods to pilot a conceptual model to better understand qualitative data was found to be feasible. Small adjustments to the process and accessibility to better support engagement with the research process are recommended. Lastly, greater investigation into co-authorship approaches and options is suggested as a fruitful avenue of inquiry for future research.

Keywords: inclusive research; inclusive data analysis; co-authorship; future planning; intellectual disabilities; housing

1. Introduction

This paper discusses the process and outcomes of an inclusive pilot study. It was co-authored involving a co-researcher with an intellectual disability (third author) and university academic researchers (first, second, fourth, and fifth authors). It uses an inclusive data analysis process and tests the inclusive use of the housing pathways model (Clapham 2002) in relation to the housing preferences of adults with intellectual disabilities and their families when they are planning for the future. It is part of a larger research project investigating transitions out of the family home for adults with intellectual disabilities and their families.

Globally, as adults with intellectual disabilities and their family caregivers age, future planning can be a way of ensuring the family member with intellectual disability's needs continue to be met after family caregivers are no longer able to provide care (Brennan et al. 2020). Consequently, Lee and Burke (2020) suggested that future planning has become one of the most pressing issues in intellectual and developmental disabilities research. Housing is seen as an especially important part of future planning (Hole et al. 2013; Lindahl et al. 2019; Thakkar 2018). However, research shows that adults with intellectual disabilities tend not to participate in decision-making about where they live (Salmon et al. 2019). Not only are adults with intellectual disabilities often excluded from this process, but they are also underrepresented in research, particularly people with more complex support needs and/or who use alternative communication methods (Bibby 2012; Lee and Burke 2020; Walker and Hutchinson 2018). Furthermore, there is limited use of inclusive research practices in the areas of future planning (Hole et al. 2013, is a notable exception) and housing research for people with intellectual disabilities (Salmon et al. 2019). This is a significant limitation, given the centrality of the "nothing about us without us" principle of the disability rights movement (O'Brien et al. 2022). This pilot study sought to utilise inclusive research methods, also involving the inclusive use of the housing pathways framework to both investigate the viability of these approaches and to begin to address the lack of inclusive research practices in this area of research.

1.1. Housing Pathways Framework

Housing policy theorist David Clapham's (2002) housing pathways framework is recognised as integrating individual agency, housing policy, and social discourse around housing. According to Clapham (2002, p. 63), a housing pathway refers to "patterns of interaction (practices) concerning house and home, over time and space". An important feature of these interactions is how the household itself views them as opposed to the perspective of these interactions reflected in housing policies. This is deemed a more personalised view of housing. There are a number of key elements to a housing pathway. Firstly, a housing career is part of a housing pathway and refers to a household's mobility. This involves changes to a household's location, tenure, and/or physical characteristics. Often, mobility is triggered by life stages and events, such as marriage or retirement. In addition, the pathways approach considers the physical characteristics of the dwelling such as the layout and how these are viewed by the household. Thirdly, it considers the way in which the house is used by its occupants; for example, it may also be a place of work. Interactions with neighbours and experiences of the local area are also part of a housing pathway. Relationships connected to the dwelling as a result of the type of tenure of its occupants are also considered, for example tenant and landlord. Moreover, a household's life planning activities are important to understanding its housing consumption. Life planning and life stage events in this understanding are related to identity and a household's attempts at identity creation and self-fulfilment. Importantly, identity formation is a product of the household's actions as well as wider social norms, including discourses around housing related to particular groups in society, such as people with disabilities (Clapham 2002).

A key part of a housing pathway is a housing junction. These are the points at which a housing pathway changes, and these junctions provide valuable opportunities for evaluating and understanding housing policy (Clapham 2005). Such a junction is the topic of the interview data under examination where participants discussed their own or their family member's plans for moving out of the family home. The housing pathways model and related concepts have been adopted to a limited extent in disability studies (e.g., Chou and Kröger 2022; Mackie 2012), and, to our knowledge, they have never been used in an inclusive research study.

1.2. Inclusive Research Perspective

We use the term inclusive research to refer to research which "involves people who may otherwise be seen as subjects for the research as instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users" (Walmsley and Johnson 2003, p. 10). This definition aligns with the current co-researcher's description of inclusive research as being for people with disability and is how they interpret research and findings.

Furthermore, we acknowledge that terminology is important and that there is debate in relation to the use of the term "co-researcher". The current co-researcher preferred this terminology for his role and defined it as someone who finds out and collaborates information on different topics. It involves putting together reports, analysing data, and participating in online meetings. This aligns with the definition of co-researcher articulated by Walmsley et al. (2018), acknowledging the distinct contributions of the university researchers and co-researchers, while indicating that the process of inclusive research is collaborative.

There has been increasing discussion around whether inclusive research has reached a second generation, where it is appropriate for greater focus to be on research outcomes with less emphasis placed on process. We agree with Walmsley et al. (2018) that more information and insight is still needed into the process of inclusive research itself. Transparency remains important to determine good research practice (Tilley et al. 2021). Furthermore, data analysis and manuscript preparation are still mostly conducted by university researchers and not co-researchers. Additional discussion is necessary to establish and refine sound and quality inclusive research practices in these areas specifically (Nind 2017a; Riches et al. 2020; Rix et al. 2022; Seale et al. 2015; Stevenson 2014). Therefore, the aim of this study was to determine the feasibility of utilising inclusive research methods, particularly the inclusive use of a conceptual framework on a small dataset relating to housing preferences and future planning, with the aim of expanding this approach to a wider dataset.

The two research questions for this pilot study were as follows:

1. Is it feasible to use inclusive data analysis and co-authorship approaches in future planning and housing research?
2. Is it feasible to use the housing pathways framework for data analysis in an inclusive manner in relation to the housing preferences of adults with intellectual disabilities and their families when engaging in future planning?

2. Materials and Methods

2.1. The Wider Study

This pilot study forms part of a wider mixed-methods project with three stages of research and analysis involving adults with intellectual disabilities, family members, and disability service providers in Australia. The aims were (1) to determine what "successful" transitions out of the family home look like; (2) to ascertain the post-parental housing preferences and needs of adults with intellectual disabilities and family members; and (3) to develop evidence-based resources to facilitate decision-making about future care and housing. The project was underpinned by principles of inclusive co-design research and involved supporting and mentoring a person with intellectual disability as a paid co-researcher. The project received ethics approval by the Flinders University Human Research Ethics Committee (4635).

2.2. The Pilot Study

The pilot study used the data from three semi-structured interviews with adults with intellectual disabilities and family members regarding their post-parental care and housing preferences and needs from the second stage of the project. The interviews were all conducted by the first author in the same state in Australia between December 2021 and June 2022. Interviews lasted between a 40 and 70 min duration. They were audio-recorded and transcribed verbatim by a professional transcription service. Transcripts were deidentified and stored on university servers with password protection. Participants were asked about: their ideal housing and living arrangements, including support arrangements; whether different family members had different preferences and desires; the extent to which they had begun planning for a move out of the family home; whether moves out of the family home had been attempted before; their goals for moving out; and any concerns about the move. Participants were provided with an information sheet about the project and consent form prior to interview and were asked to sign and return the consent form before the interview. Easy-read versions of these forms were provided to participants with intellectual disability. It was emphasised that participation in the study was voluntary; participants could withdraw without penalty at any time; they could refuse to answer any questions; could raise concerns or complaints with Flinders University's Research ethics and compliance team; and were given the details of free mental health and disability support services if needed.

The specific steps of the pilot study were: identifying the housing pathways framework as an analytical tool; selecting an appropriate sub-set of the larger dataset to pilot; undertaking inclusive data analysis of three transcripts; applying the housing pathways framework to the themes generated from the data analysis; and co-authoring a manuscript. Its aims were to develop the skills of both the co-researcher and university researchers in inclusive research practices and to test whether the housing pathways framework could be used inclusively to better understand a qualitative dataset. The lessons learnt from the pilot regarding the inclusive research approaches used would subsequently inform the inclusive approach adopted for analysis of the remainder of the dataset.

Numerous studies have attempted to define steps for good quality inclusive research (Johnson et al. 2014; Nind and Vinha 2013; Walmsley et al. 2018). We have used modified recommendations about inclusive data analysis by Tilley et al. (2021) to inform our overall approach. Table 1 describes the co-researcher's and university researchers' perspectives of each recommendation. This information is presented in detail to also highlight the different strategies used to address the recommendations. In particular, it underscores the use of both simple interventions, such as creating an informal and relaxed atmosphere by going to the university café, as well as the more detailed and nuanced strategies necessary for successful inclusive data analysis.

Table 1. Inclusive research approach and steps (adapted from Tilley et al.'s (2021) recommendations).

Inclusive Research Steps	Co-Researcher (Third Author)	University Researchers (First and Second Authors)
1. Plan ahead.	We needed an office with computers in it, so we could type our information. We needed to work out how many hours to work and to organise cab vouchers for when I came on campus. We would call and email each other about this.	The project is mixed-methods inclusive, with a co-design. The co-researcher was employed early in the project. Initially, this involved the co-design of recruitment material, including creating easy-read information and recruitment videos. He was then involved in data analysis, piloting of the housing pathways framework, and manuscript preparation.
2. When collecting the data, remember that it will be analysed inclusively.	When the university researcher was collecting the data, we would talk about what we might do with it, like analyse it. We would discuss why we might do that.	Given that the co-researcher was part of the project from a very early stage, discussions about the research process, including data collection, occurred at the same time as the research activities were being undertaken.
3. Build trust and rapport between the researchers.	One of the university researchers (second author) who knew me before the project helped with the first couple of meetings with me and the university researcher (first author). Me and the first author introduced ourselves and said what we do. We started contacting each other through email, making appointments to catch up, and be on time and be reliable. Sometimes we would catch up at the university café.	From the outset, the co-researcher worked closely with the university researchers in a number of different ways. This helped to build rapport and trust. The co-researcher had previously attended the university and was already familiar with the campus. Building on this, several rooms conducive to group work were used for meetings and to work together. Mid-way through the sessions, the co-researcher and university researcher would take a break and often have a coffee together at the university café. The co-researcher would also attend the research team meetings, and this helped to build rapport and trust with the other team members as well.

Table 1. *Cont.*

Inclusive Research Steps	Co-Researcher (Third Author)	University Researchers (First and Second Authors)
4. Think of different ways to support the co-researcher's engagement.	When there was a lot of text, we would stop and break it down. When I did not understand something, we would work together to try and understand it, like asking questions and using examples. We would only look at one or two pages of transcript at a time, and I would highlight important parts.	Before beginning the data analysis, deidentified transcripts were printed out and the co-researcher and university researchers discussed what a transcript was, as well as the different parts to it, and the co-researcher read some of it. They discussed how they wanted to approach the analysis. The co-researcher was happy to use the original transcripts, rather than modified versions. They would work on one or two pages of transcript in each session. This was based on text density and amount because the co-researcher had indicated that too much text was difficult to understand.A plain language version of the housing pathways framework (Clapham 2002) was developed to help guide the discussion of the themes developed from the data analysis.
5. Carefully select the data to be used.	We only looked at three transcripts. Each transcript was about a different type of interview. One was with a parent and adult with intellectual disability, one was with just a parent, and another with just an adult with intellectual disability. We also looked at these transcripts because each interview had different answers.	Given that the study was a pilot of using the housing pathways framework for analysis, it was appropriate for only a sub-set of the data to be analysed.
6. Everyone has different expertise.	We would acknowledge each other's viewpoints.	The co-researcher and university researchers offered their opinions and thoughts. Where these diverged, they would discuss if it was necessary to come to a consensus and where it was, they would discuss the different aspects of their opinions and choose the one they believed best answered the question or was most illustrative of what they were trying to achieve.
7. Discuss the process periodically.	After every couple of sessions, we would talk about how we were feeling about the work and if we wanted to change anything.	At select points during the process, the co-researcher and university researcher would each discuss their thoughts and feelings about the process, including what was working and what was not. Notes were made of these conversations, and these reflections are found throughout the manuscript.

2.3. Inclusive Data Analysis Approach

Our way of conducting data analysis centred on what Nind et al. (2016) referred to as the apprenticeship model. This involved the co-researcher working alongside university researchers who acted as mentors and modelled research skills. Nind (2017a) argued that the loss of traditional academic complexity that can occur in inclusive data analysis is counterbalanced by the perspective gained from the co-researcher.

The analysis itself was undertaken using the principles of interpretative phenomenological analysis (IPA). The focus of exploring housing preferences was on lived experiences, and IPA supports this due to its grounding in phenomenology. It also recognises the interpretative process in data analysis (Eatough and Smith 2017). The approach allows analysis at the level of each individual interview, followed by an analysis of the dataset, identifying points of commonality and difference (Smith 2011). Lastly, it is appropriate for smaller datasets (Eatough and Smith 2017).

Three transcripts were chosen from the eight comprising the entire dataset at the time. One of the aims of the study was to pilot the housing pathways framework in an inclusive manner as an analytic tool and assess its feasibility; therefore, only a sub-set of the data was used for this part of the study. Depending on the outcomes of the pilot, these methods would then be considered for analysis of the remainder of the dataset. The co-researcher and university researcher discussed that three transcripts would be chosen, and the university researcher deliberated with the co-researcher regarding what the criteria for the included transcripts might be. It was important that the three transcripts were representative of the dataset in as many ways as possible. This included being representative of the methods employed to conduct the interviews; participants at different points in the future planning journey; participants considering different dwelling and tenure types; and different living arrangements. The co-researcher and university researcher went through all of the transcripts and discussed these aspects to choose the most representative sample. Details of the chosen transcripts are shown below. Pseudonyms have been used.

- John and Carol: a dyad interview with a family member and adult with intellectual disability; conducted via a videoconferencing platform; active planning for John to remain in the family home;
- Betty: an interview with just a family member; conducted in person; considering specialist disability accommodation (SDA)[1] with potential housemates;
- Jennifer: an interview with just an adult with intellectual disability; conducted in person; considering purchasing a home and potentially moving in with her boyfriend.

The specific steps taken to complete the inclusive data analysis using the three transcripts are outlined below.

1. The first reading of the transcript was for familiarization only. The co-researcher would read a section of the page and would then discuss it generally with the university researcher, including discussing sections that may be more difficult to understand.
2. In the second reading of the transcript, the co-researcher would highlight sections of the transcript he thought were interesting, important, and relevant to understanding the housing needs and preferences of adults with intellectual disabilities and their family members.
3. From this information, the co-researcher then wrote a summary of the transcript, and these were used as an easy reference point.
4. The co-researcher then used the highlighted sections of the transcript to develop themes highlighting the housing preferences and needs of adults with intellectual disabilities and their family members.
5. This process was repeated for the second transcript.
6. The next step involved analysing the separate themes from the first two transcripts together and generating themes for both.
7. The co-researcher presented these preliminary findings at a meeting of the entire research team to receive feedback on his analysis.
8. The same process for generating themes from the first two transcripts was followed for the third transcript and for generating themes between the first two transcripts and the third transcript.
9. The co-researcher and the university researcher discussed what they would call the themes, how they would describe them, and what participant quotes they would use to help illustrate them. This information is available in the results section.

2.4. Housing Pathways Approach

Once the data analysis had been completed and themes generated, the housing pathways framework was piloted. A simplified version of the housing pathways concepts presented in plain language was created by the researchers in this study and was used for the purpose of discussion of the framework with the co-researcher. This document is presented in Table 2. The concepts covered were mobility, including moving house; the physical features of a dwelling; how the dwelling is used by its occupants; neighbours and the wider geographical location and area; tenure; the role of housing in life planning; social discourses around housing which indicate expectations for housing, such as what dwellings are considered appropriate for older adulthood; and age and life stage of individuals and the household (Clapham 2002).

Table 2. Plain language wording of the housing pathways framework developed and used by the current researchers (based on Clapham's (2002) housing pathways framework).

Article Details and Housing Pathways Concepts	Answers and Explanations of Housing Pathways Concepts
Who is the author?	David Clapham
What is the name of the article?	Housing pathways: a postmodern analytical framework
What year was the article published?	2002
What is the name of the journal the article is in? (A journal is where different articles on similar topics are kept)	*Housing, Theory and Society*
What is the article about?	• The article is about an idea called "housing pathways". • You can use this idea to help you understand why people live where they do. • You can also use it to help you understand why people move.
What is a housing pathway?	• Over time, people can do many different things with where they live, like moving house, buying an apartment, or renting a townhouse. • These things are called a housing pathway. • There are many different parts to a housing pathway.
Mobility	• Mobility is one part of a housing pathway. • It means a person changes where they live. • There are many reasons a person might want to move. For example, they might have a new job. • They might also want to change the type of house they live in. For example, they might want a smaller or a bigger house.
Physical features of a property	• The physical features of a property can be important to people and are another part of the housing pathway. • These include if it is a house, townhouse, or apartment. • If it is old or new. • If is in good condition or bad condition. • If there is a lot of space or not much space.
How the property is used	• How people use the property is another part of the housing pathway. For example, it might be a house near the beach, and this means the people who live there can swim at the beach often.
Neighbours and the area	• What neighbours and the neighbourhood are like is another part of the housing pathway. • How people relate to their neighbours and the neighbourhood is also important.
Tenure	• Tenure is another part of the housing pathway. • This refers to whether the person has bought the property or is renting.

Table 2. *Cont.*

Article Details and Housing Pathways Concepts	Answers and Explanations of Housing Pathways Concepts
Life planning	• Life planning is another part of a housing pathway. • Life planning refers to all the other important things in a person's life, like family, a job, and education. • People's housing choices are often also influenced by these things. • For example, a person may decide to go to university and stay living with their parents until they finish their studies.
Other influences	• Other things can influence where a person lives, which they do not have choice over. For example, how much government funding they might be able to get to help them move out of their family home.
Time	• Time is another part of a housing pathway. • Time can be a person's age. A person might want to move out of home because they have turned a certain age. • Time can also be the ages of the people in someone's family. Parents may decide to move the family into a different home when they retire.

The process undertaken for this part of the study is outlined below.

1. A plain language version of the housing pathways framework (Clapham 2002) was created by the university researcher (first author) and is included in Table 2.
2. The university researchers (first and second authors) and co-researcher (third author) met to discuss the framework, including what piloting the framework would involve and how they might go about using it.
3. The co-researcher and university researchers decided they would discuss each theme individually in relation to each of the different housing pathways concepts contained in the plain language version.
4. The university researchers and co-researcher met at the university campus a number of times to do this, and each made notes of their discussions.
5. Once the process of analysis was finished, the notes were condensed into one set of notes which were shared.
6. From these notes, the co-researcher dictated to the university researcher how the discussion using the housing pathways framework should be written. The university researcher typed it up, and this information is included as part of the discussion section of this article.

2.5. Co-Authorship Approach

Co-authorship is not an uncontested space in inclusive research (Riches et al. 2020; Strnadová and Walmsley 2018). The approach for manuscript preparation was a combination of the apprenticeship model discussed for data analysis while also employing principles of the inclusive immersion model, where the co-researcher and university researchers work through the writing steps together and collaborate to solve problems (Nind et al. 2016). The process of writing a manuscript for publication in an academic journal was explained to the co-researcher. The co-researcher then decided whether he would be interested in being involved in writing a manuscript based on the data analysis he had undertaken and the use of the housing pathways framework. He reflected that he wanted to write a paper that others would read. He was interested in learning about other people's reactions and receiving feedback on his analysis. The co-researcher's main contributions to co-authorship are included as part of the steps outlined above for the data analysis and use of the housing pathways framework.

3. Results

The results are presented here to illustrate the outcomes of the inclusive data analysis process. Participants' demographic details as composed by the co-researcher are below.

Interview 1: John and Carol

> John is a 43-year-old male. He is single and was born in Australia. Carol is 76 years old, and she is John's mother. John has a brother, a sister-in-law, and a nephew and two nieces.

Interview 2: Betty

> Patricia is 26 years old. Warren and Betty are her parents. Robert is her older brother, and he is 28. Patricia has a younger sister Kathy, who is 21.

Interview 3: Jennifer

> Jennifer is 22 and she is ready to move out of home. Jennifer currently receives support through the National Disability Insurance Scheme (NDIS).[2]

Table 3 includes the themes identified and named by the co-researcher, including the participant quotes chosen to illustrate these themes. Four themes were generated: transport is important; finances are important; respite for Patricia; and people's ages.

Table 3. Themes, theme summaries, and illustrative quotes.

Themes	Theme Summaries	Quotes
Transport is important	For all three participants, transport needs were a significant determining factor in the choice of location. For John and Jennifer, access to public transport was vital in enabling them to meet their work and other commitments and in having access to amenities, like shops. Conversely, Patricia was unable to use public transport and finds car travel difficult. Consequently, a location which is both close to the family home and amentities is important.	"Definitely yeah. So, that's one of the main priorities was to get it [dwelling] in an area that was close to public transport" (Carol)
Finances are important	Individual and family finances similarly impacted housing and life-planning decisions. Jennifer was saving money for a house deposit, and this was contributing to her delaying moving out of the family home. John was planning on remaining in the family home but with more independence in his living arrangements. Keeping the family home was considered financially beneficial for all members of the family. It was anticipated that Patricia's move out of the family home would allow Betty and Warren to work more and save more money. Both Jennifer and Carol also expressed concerns around financial vulnerability and the potential for independence in living arrangements to heighten the risk of financial exploitation.	"Yeah, because I think I would be very sad or upset if you buy a house and you get, you know, your money gets stolen, or you know. You don't want to go through that" (Jennifer)
Respite for Patricia	For Betty and Patricia, the successful use of short-term accommodation heavily influenced housing preferences. Betty wanted Patricia to find long-term housing with the disability services provider responsible for her short-term accommodation.	"She's always been at [name of organisation]. She started at respite when she was six" (Betty)
People's ages	The ages of the adults with intellectual disabilities in combination with the ages of household members was a factor in the timing of the move out of home and was connected to broader life planning around housing. Significant milestones included reaching young adulthood; parents preparing for retirement; and, in Carol's case, a desire for a lifestyle change, which reflected her changing priorities as she was ageing.	"Because I feel like at a certain age, you know, when you're ready to move out that adult, teenage age, you know" (Jennifer)

4. Discussion

Both the experience of piloting the housing pathways framework to guide data analysis and the results of the analysis undertaken using the framework will be discussed. The results of the analysis are presented to highlight the outcomes of the inclusive use of the housing pathways framework. The links between themes and housing pathways concepts as articulated by the co-researcher can be found in Table 4. In summary, mobility does not always involve a physical move out of the home but can include a change in the configuration of the household, and this involves changes in the uses of the house by the individual household members. The outdoor physical features of a home can be as important as the dwelling design. Neighbourhoods and the local area can help to service the transport needs of a household and contribute to its perceived safety. Home ownership can be a goal in a housing pathway. Furthermore, the housing needs of a household can change depending on what the life plans are of the individual members of the household, including in relation to work, study, and relationships. Social discourses around housing can also be linked to wider social and policy discourses about the perceived needs of particular groups in society, such as funding models for people with disabilities. Finally, the ages and life stages of the entire household can impact the consumption of a dwelling and dictate plans for future housing and living arrangements of its individual members.

Table 4. Discussion of themes utilising the housing pathways framework (Clapham 2002). Housing pathways are reworded from Clapham's work in this table, for the purpose and context of our study.

	Themes			
	Transport Is Important	**Finances Are Important**	**Respite for Patricia**	**People's Ages**
Housing pathways				
Mobility		Carol cannot afford to buy another house for John to live in, so John and Carol have decided to stay in the family home.		
Physical features			Betty would like Patricia to have a good outdoor area that she can use in her house, just like she has at respite. At respite, the grounds are beautiful, and she can go for a walk or ride her bike.	
Dwelling use		Because Carol could not afford to buy another property, the plan is for the house to be used full-time by John and part-time by Carol and other family members.		
Neighbours and area	Areas where public transport is within walking distance and close to home are important, as are areas that are central and close to what people do.		Location is important for Patricia's safety, and Betty would like a place that is in a safe location for Patricia like her respite is.	
Tenure		John and Carol own their home. Jennifer wants to buy her own house.		

Table 4. *Cont.*

	Themes			
	Transport Is Important	**Finances Are Important**	**Respite for Patricia**	**People's Ages**
Life planning	Transport is linked to life planning. Jennifer wants to use public transport to continue to go to university and will need it in the future for her job. John needs the train to go to work. Betty thought it was important for Patricia to live close to home in the future so Betty could easily visit, and Patricia does not have to stay in the car long.	In Jennifer's case, she wants to move in with her boyfriend, and she is saving money for her own house and still living with her parents. Betty and Warren are thinking about their retirement, and Patricia moving out will help them retire financially.		
Social discourses on housing		John, Jennifer, and Patricia are all on the NDIS. Patricia is affected most by the NDIS because of her wants and needs for SDA and supported independent living (SIL).[3]		
Age and life-stage				Jennifer feels ready to move out because of her age. Jennifer's sister wants to move out of the family home too. Carol is older and wants to spend more time with her grandchildren who live faraway. In this case, John and Carol plan to share the house for six months at a time and for the other six months, Carol will be with her grandchildren.

4.1. Reflections on the Pilot Study

Our overall assessment of piloting the housing pathways framework is that it is feasible to use in this area of disability studies. Moreover, it can be used in an inclusive manner.

4.1.1. Lessons Learnt

This pilot study was an opportunity for the co-researcher and research team to try new ways of conducting inclusive research, particularly using the housing pathways framework. While there were many lessons learnt from the experience, the following five were the most impactful in terms of process and outcomes. Firstly, while the co-researcher and university researcher discussed the way in which the transcripts would be used and chose not to use other mediums through which to engage with them, having the transcripts presented in more than one way would have most likely improved the data analysis and helped to encourage engagement with the material (García Iriarte et al. 2023; Strnadová et al. 2022). Secondly, much of the work on the pilot study was completed by just the co-researcher and the university researcher. García Iriarte et al. (2023) and Stevenson (2014) convincingly demonstrated the benefits of the peer group in conducting inclusive research, both in terms of outcomes and in providing members with informal support. It may be useful to consider group data analysis for larger inclusive data analysis projects. Thirdly, through the plain language version of the housing pathways framework, we were able to effectively and inclusively use a complex conceptual framework for analysis and discussion. We suggest that accessibility is the key to previously closed off information and ways of knowing, and, in fact, accessibility is foundational to the inclusive research model proposed by Schwartz et al. (2020). Fourthly, while the presentation of the conceptual material was successful, its implementation requires further consideration. This process was time consuming and repetitive and while some of this cannot be avoided, again, it may be beneficial to consider different ways of making the process of using theory more accessible, such as through creative arts (Cousik et al. 2017). Finally, it is important to continue to engage with co-authorship processes and test different means of achieving co-authorship aims. In particular, as Strnadová and Walmsley (2018) suggested, information sharing through academic journals does not need to be the only method of co-authorship and dissemination. Other media may be more useful, particularly in terms of advocacy and awareness-raising. With regard to the pilot study, co-authorship in an academic journal was a goal of both the co-researcher and university researchers. However, identifying other co-authorship goals early in the inclusive research process would likely have expanded the co-authorship approach and related options.

4.1.2. Next Steps

In relation to the pilot work specifically, the next steps involve developing a method for using the housing pathways framework in an inclusive manner for the entire dataset from the second stage of the project. Secondly, it may also be beneficial to consider subsequently developed concepts by Clapham (2010), which seek to explore the relationship between housing and well-being. These concepts are personal control; identity and self-esteem; social support; and inequality and housing policy. Clapham (2010) argues for their importance when developing and evaluating housing policy.

4.1.3. Future Research Considerations

Inclusive research methodology needs to be an increasing focus of future planning and housing research with people with intellectual disabilities. The inclusive use of valuable conceptual frameworks in this area has much to contribute to better understanding complex and nuanced experiences. Furthermore, frameworks such as the housing pathways, which have a policy focus, can be especially useful in knowledge translation. Such an approach supports the three goals of inclusive research outlined by Nind (2017b), namely creating sound knowledge and supporting advocacy and sustainability.

4.2. Strengths and Limitations

This pilot study used a small dataset as a means of testing inclusive data analysis practices, the co-authorship approach, and the use of a conceptual framework. It would be useful to take the lessons learnt from the pilot study and apply these to a larger dataset, which would allow for greater generalisability of the results and would further test the methods employed. This study demonstrates that it is possible to undertake inclusive data analysis, use a conceptual framework, and co-author a manuscript while maintaining principles of academic rigor.

5. Conclusions

This study indicates that inclusive data analysis, co-authorship, and the inclusive use of a conceptual framework for analysis are all possible. Creating an inclusive and accessible environment on campus, engaging in a constant reflexive process with the co-researcher, allowing for enough time to complete tasks, and ensuring the accessibility of information were all positive aspects of the current pilot study that are easily replicated. Greater attention is needed to making research processes more engaging and accessible, such as through the use of creative arts approaches, like drama or creative writing. Furthermore, greater exploration of team inclusive research approaches is needed, in particular to balance the benefits, such as peer support, with some of the challenges, such as managing group dynamics. Finding ways to meaningfully present the outcomes of inclusive research requires further investigation. Furthermore, greater dialogue is needed regarding the place of co-authorship in academia. In particular, more co-authorship studies are required that challenge existing boundaries between what is considered traditionally academic writing and more informal writing and communication, while providing additional insights and strategies for how co-authorship goals can be achieved. Lastly, the use of the housing pathways framework allows for a consideration of housing experiences, which focuses on the perspective of the household and takes into account the household's housing behaviour, wider discourses around housing, and housing policy. This allows for a more comprehensive and nuanced analysis and understanding of housing behaviours, enriching the current approach to housing in the field of disability studies. Overall, the pilot study demonstrates that it is possible for all stages of research to be conducted inclusively with the aims of making sound knowledge contributions and empowering those involved in its production.

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Notes

[1] Specialist disability accommodation (SDA) refers to specialist housing for individuals with higher support needs (National Disability Insurance Agency 2022).

[2] The National Disability Insurance Scheme (NDIS) is an Australian Federal government initiative that provides individualised funding to support the costs of living with a disability (National Disability Insurance Agency 2023).

[3] Supported independent living (SIL) is funding provided through the NDIS that helps individuals who require a higher level of support to live in their own home (National Disability Insurance Agency 2021).

[3] Supported independent living (SIL) is funding provided through the NDIS that helps individuals who require a higher level of support to live in their own home (National Disability Insurance Agency 2021).

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Essay

Disability Theatre as Critical Participatory Action Research: Lessons for Inclusive Research

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Abstract: Informed by critical disability studies and disability justice, this article describes the reflections of two university researchers co-researching with self-advocates (individuals with intellectual disability), theatre artists, researchers, and a community living society to create social justice disability theatre as critical participatory research (CPAR), demonstrating how disability theatre can contribute to and advance inclusive research practice. Disability justice-informed theatre as CPAR has direct relevance to people with intellectual disabilities; offers a platform where self-advocates' diverse ways to communicate and be in the world are honoured and taken up as resources to the research and community; and can generate mentorship opportunities for self-advocates to learn, practice, and develop research skills. Significances include showing how the theatre creation process (devising, developing, and refining scenes) is research in itself and how tensions are recognized as sites of possibility. Future research should explore how increasing pathways to communication, co-creation of KT strategies, and protocols for power sharing and problem solving within disability theatre as CPAR impact the roles, outcomes, and experiences of disabled and non-disabled researchers and audience members.

Keywords: inclusive research; disability theatre; devised theatre; intellectual disability; critical participatory action research

1. Introduction

Prompted by the independent living movement, the people's first movement, and solidified by the United Nations' Convention on the Rights of Persons with Disabilities (CRPD), there is growing recognition of the importance and the rights of persons with disabilities to be included as active agents in research (e.g., Nind 2017; Nind and Vinha 2014; Walmsley and Johnson 2003). In fact, since the 1990s, scholars involved in disability research have argued for research informed by an emancipatory paradigm (e.g., Barnes and Mercer 1997; Oliver 1992). This is in response to research that was performed "on", "to", or "about" disabled people without them (O'Brien 2022). Since these early days of emancipatory research, researchers in intellectual disability research committed to working with self-advocates with lived experience (e.g., Nind 2014, 2017; Walmsley and Johnson 2003) have been theorizing, calling for, and advancing principles of inclusive research. Walmsley and Johnson (2003, p. 9) explained that inclusive research is "research in which people with learning disabilities [intellectual disabilities] are active participants, not only as subjects but as initiators, doers, writers, and disseminators of research". Nind extends this understanding rooted in participatory and emancipatory research to include "research with multiple labels that essentially 'reflect[s] a turn towards the democratization of the research process' (Nind 2014, p. 1)" (Nind 2017, p. 279). But this is easier proposed than enacted.

"The issues of what makes inclusive research, how it is done and what its implications are, are contentious for all those involved in it" (Walmsley and Johnson 2003, p. 11).

To guide researchers, Walmsley and Johnson (2003) outlined five principles of inclusive research. These principles are as follows: (a) "The research problem must be one that is owned (not necessarily initiated) by disabled people"; (b) "It should further the interests of disabled people; non-disabled researchers should be on the side of people with [intellectual disabilities]"; (c) "It should be collaborative—people with [intellectual disabilities] should be involved in the process of doing the research"; (d) "People with [intellectual disabilities] should be able to exert some control over process and outcomes"; and (e) "The research question, process and reports must be accessible to people with [intellectual disabilities]" (Walmsley and Johnson 2003, p. 64).

In this article, we offer our experience with disability and devised theatre as critical participatory action research (CPAR) to describe an example of enacting inclusive research where self-advocates, theatre artists, researchers, and a community living society collaborated to create a social justice disability theatre project titled, "*We Deserve to Work!*" Taking up a disability justice lens, we use the term self-advocates to refer to individuals with intellectual disabilities, "a term that positions individuals with [intellectual disabilities] as self-determining and acting with agency" (Schnellert et al. 2022). The purpose of this reflexive narrative is to demonstrate how disability theatre CPAR can contribute to and advance inclusive research practice.

In the following sections, we share our theoretical commitments to critical disability studies and disability justice and their relationship to disability theatre. Next, in Section 2, we set the stage for the paper by introducing our collaborative theatre projects. In Section 3, we describe how we enacted an inclusive CPAR theatre project by examining inclusion across three areas: setting the question(s) and co-constructing research methods, conducting the research, and knowledge translation. Finally, we discuss how our collaboration in a CPAR disability theatre project facilitated principles of inclusive research and present recommendations from our learnings.

1.1. Sensitizing Lenses

Critical disability studies (CDS) and disability justice inform our work. Rooted in traditional disability studies, CDS integrate new and transformative agendas and theories such as postcolonial (e.g., Sherry 2007), feminist (e.g., Garland-Thomson 2005), and queer and crip (e.g., Chen et al. 2023; McRuer 2006) theories (Goodley et al. 2019). This tapestry of "epistemological perspectives and ontological desires" creates a rich bricolage (Kincheloe 2001) of theorizations of what disability is and what it can do (Goodley et al. 2019, p. 976).

Central to CDS is the understanding that "disability is a political and cultural identity" (Dolmage 2017, p. 10). Rather than viewing disability as a deficit or defect needing to be cured or fixed, disability is understood as a valued part of human diversity, a social/political category that "serves and functions as a basis for political activism" (Schnellert et al. 2023, p. 296). In fact, "CDS informed by disability justice is a movement that challenges ableist normativity and privilege and is committed to 'revolutionary and accountable praxis to incite radical justice' (Erevelles 2014, p. 2)" (Schnellert et al. 2023, p. 4690). Given this, CDS researchers committed to the principles of disability justice (Sins Invalid 2019) are implored to critically think about how they enact and operationalize research.

Disability justice, a sociopolitical activist framework, centres the knowledge and wisdom of those most impacted by ableism and its complex entanglement with other forms of oppression—e.g., racism, heterosexism, and colonialism (Sins Invalid 2019). Disability justice in research thus requires engagement in activist practices to centre justice and reframe access, ethics, and equity (Keifer-Boyd et al. 2018), thus aligning with principles and practices of inclusive research described above (e.g., Walmsley and Johnson 2003). CDS and disability justice researchers, who work with individuals with intellectual disabilities, look to forms of inclusive research as a means to include individuals with intellectual disabilities in research in meaningful ways and to effect change that is central to self-advocates' concerns and desires. Disability justice-based methodologies offer a valuable framework to enact inclusive research principles.

1.2. Disability Theatre

Disability theatre strives to challenge societal norms through productions related to social justice. Johnston (2016, p. 15) writes that disability theatre is "broadly connected to impulses for social justice in the face of ableist ideologies and practices as well as a profound recognition of disabled lives and experiences as inherently valuable". Devised approaches to theatre such as Boal's Theatre of the Oppressed (Boal 2002) intersect well with disability theatre as both offer disabled actors opportunities to create characters, scenes, and messages that can directly address stereotypes and stigma. Disabled actors defining the issues, messages, and perimeter of disability theatre projects is an enactment of disability justice (Schnellert et al. 2023). Bringing together disability justice, disability theatre, devised theatre, "press[es] the boundaries of aesthetic convention on the other. [D]isability theatre is thus both activist and artistic in orientation" (Johnston 2016, p. 15).

Disability theatre is not only political seeking to address ableism, but also aesthetically challenging. This aesthetic sensibility aligns well with CDS as disability theatre recognizes that we experience the world through the senses—and "the body acts as conceptual glue. . .in broadly the same way disability aesthetics. . .changes the role of art and the artist" (Conroy 2009, p. 11). Disability aesthetics change art disrupting normalized concepts of identity and non-disabled privilege and offer access for those with diverse modes of knowing, being, and doing (Decottignies 2016). In a similar way to which disability aesthetics changes art, disability theater challenges and can expand theatre and research processes (Schnellert et al. 2022).

Disability theatre informed by disability justice requires us to change as artists and researchers when we engage in ethical theater-making and knowledge-sharing processes. Disability justice principles—e.g., centring the voices of those who are the most impacted, recognizing the wholeness of each person, interdependence, collective access as an ongoing flexible and creative process, and collective liberation where no body/mind is left behind—are clarion calls for action that centres the collective throughout the theatre research processes. Assumptions about how we communicate, how we live in the world, and how we make sense of the world can be transformed through research-based disability justice theatre (Schnellert et al. 2023).

2. Setting the Stage: "Romance, Relationships, and Rights" and "We Deserve to Work!"

In 2017, we undertook a participatory theatre research project regarding the sexual agency of individuals with intellectual disabilities (Schnellert et al. 2022, 2023). The development of the disability theatre project, "*Romance, Relationships, and Rights (RRR)*", was initiated when the executive director of a community living agency approached researchers at the University of British Columbia's Canadian Institute for Inclusion and Citizenship (CIIC) to learn about how their agency can better support self-advocates' sexual citizenship. To disrupt sexual ableism, and to centre the lived experience and perspective of individuals with intellectual disabilities, we turned to disability and devised theatre.

Disability justice connects disability and devised theatre through commitments to "transformative accountable praxis" (Erevelles 2014, para. 26). Our research highlighted the potential and contributions of disability and devised theatre within CPAR and also revealed tensions of power, representation, and voices (Schnellert et al. 2022, 2023). We took what we learned from this first collaborative disability theatre PAR study to plan and enact our next disability theatre project, "*We Deserve to Work (WDTW)*", a play on employment.

Self-advocates from the Community Living Society (CLS), researchers from the CIIC, and professional theatre artists undertook the creation and production of social-justice-oriented disability theatre—WDTW—as critical participatory action research (CPAR). CPAR aligns well with disability justice, disability theatre, and inclusive research. CPAR "is a framework for engaging research with communities interested in documenting, challenging, and transforming conditions of social injustice" (Fine and Torre 2021, p. 3). CPAR places participants at the centre of the research not only to illuminate their voices as they strive to make social change but also to encourage researchers to work alongside participants throughout the process. CPAR is "rooted in the activist call 'No research on us, without us'" (Fine and Torre 2021, p. 3).

3. The Praxis of Inclusive Research as Disability Theatre

As discussed above, inclusive research informed by disability justice necessarily requires researchers to reflect on how they enact inclusive practices and what they learn from the strengths and challenges of their process to inform future work. We have previously written about findings from disability theatre CPAR projects (Hole et al. 2022; Schnellert et al. 2022, 2023; Tidey et al. 2023). In this essay, we describe how we executed an inclusive CPAR theatre project with respect to three areas: setting the question(s) and co-constructing research methods, conducting the research, and knowledge translation with the aim to contribute insights for inclusive research via disability theatre.

3.1. Praxis Initiation: Setting the Question(s) and Co-Constructing the Research Methods

As researchers from the CIIC, we had collaborated with the CLS in a disability theatre project related to self-advocates' rights to intimate relationships. The self-advocate co-creators/actors were eager to develop another project, and the CLS agreed to support the development of another research funding application. To develop a focus for our next research-based theatre production, we held two sessions in a gallery and used applied theatre devising techniques to identify possible topics and questions for inquiry.

On two Sunday afternoons, we held devising sessions. We started together as one group where the fifteen co-creators from the RRR production shared what they liked about the previous production and why they thought we should have a second production. Using various communication techniques, all co-creators indicated how much they enjoyed the positive feedback they received about the first production, and many shared how proud they were to shine a light on an issue they cared about (Schnellert et al. 2022). They also highlighted how fulfilling it was to create scenes that communicated their messages. Then, we moved into two groups to generate possible topics for our next production. Through the use of tableaux and co-creating scenarios, each group arrived at two possible topics and presented them to the other group. As reported by one self-advocate, "We were coming up with what ideas we do for the next play and we settled on work [as our next play's focus]".

Researchers took notes on chart paper as self-advocates shared why employment can be an important and necessary topic for others to learn about. Group members shared a variety of reasons drawing from their lived experience: some of the self-advocates in the group had jobs but wanted new jobs or to advance in their jobs; others were not currently employed; and still others had no previous paid work experience. Across all participants, they felt that creating an employment-focused play could make a difference for themselves and others in the disability community, their families, and those who support them. One self-advocate shared, "[A lot of people think that people with disabilities can't work]. . .and we're trying to show them that that's not how it is. That there is work we can do. That we can hold down jobs; that we're basically just like everybody else". Another stated, "I want employers to hire people who are [disabled]".

At our third meeting, we gathered at the CLS to collectively develop the research proposal. In our previous production, the research proposal was written by researchers and the CEO of the CLS, but this time out, self-advocates were eager to be part of the entire process from identifying the topic for our next production to generating aspects of the research proposal. Revisiting our chart paper notes from the devising sessions, the self-advocate co-creators shared their confirmed commitment to a focus on employment. Using notes taken at the development sessions, they also shared and reflected on the previous production and theatre creation processes to decide what to keep and change. At this meeting, the self-advocates took part in developing a timeline for the production, building a research phase into the development of the play, activities to develop scenes (theatre devising processes), their desire to travel the show to other venues, and video-recording the play so that it can be shared beyond live performances. In addition to the self-advocates, the leaders of the Massey Theatre, CLS, and CIIC as well as theatre artists participated in this collective proposal development meeting.

3.2. Praxis Enactment: Conducting the Research

"To prepare for the play we had to do data research" (SA Co-Creator). As an initial phase of the *WDTW* project, we conducted focus groups with employers, employment specialists (coaches), and self-advocate employees as part of the theatre development process. The self-advocate co-creators were co-researchers in this process: "talking to employers, job coaches, and self-advocates, that's how we got our research" (SA Co-Creator). Similar to Seale et al. (2015), self-advocates in this project generated interview questions; chose roles for the research process (interviewer, note taker, and time keeper); practiced these roles; and conducted the focus group interviews on Zoom. Following transcription, the self-advocates collectively looked at the data in small groups and identified themes. They took cut-up sentence strips from the interviews and grouped them together in categories. Then, the co-creators, facilitated by theatre co-directors (one of whom is a CIIC researcher), used the findings to devise thematic messages from the categories. With the messages as references, the self-advocates created tableaux, developed them into mini-scenes and ultimately created two Acts within the *WDTW* production. These Acts were bracketed with an Introduction, Interlude, and Closing entirely composed of direct quotes from the research. In these ways, the self-advocate co-creators were involved in doing the research.

WDTW was produced in the Massey Theatre with one matinee performance and two evening performances, and then the play travelled to two conferences with large audiences. Audience feedback from performances was iteratively used to adapt and travel the show. The feedback was transcribed into charts and in two groups the self-advocates read and discussed the feedback, once again identifying themes. They used the data to clarify and emphasize certain line readings and messages in successive performances. Debriefing after the theatre performances and travelling shows, the self-advocate co-creators brainstormed directions for the next research proposal (e.g., housing).

3.3. Practice Enactment: Knowledge Translation

The theatre format allowed for knowledge translation (KT) that communicated themes and messages in multi-modal ways with embedded access points for audiences. The self-advocate co-creators were not only co-researchers in the more traditional focus groups in Phase One (through interviewing employers, job coaches, and employed SAs), but they were also active in developing and enacting KT strategies.

A staging of the draft performance was mounted at the Inclusion BC Annual Conference where the co-creators and production team received feedback on the draft scenes. They were able to ascertain if and how the themes from the interviews and data analysis were being translated to an audience composed of self-advocates and caregivers. Feedback forms were collected, and ideas were incorporated into the ongoing development process. The project spanned three years from initial planning to developing research skills and conducting focus groups to "play building" to producing and performing WDTW. Each year, three self-advocates from the production sat on the steering committee along with the CIIC, CLS, and Massey Theatre representatives. KT strategies were generated here, and the self-advocate representatives acted as conduits between the co-creators and actors in the theatre company and the steering committee and their organizations. In the first year of the project, the three self-advocate Steering Committee members presented with three CIIC researchers at a national conference for theatre researchers. With the three researchers, they brainstormed an outline for the presentation and who would present and/or co-present each item. One self-advocate described the process of using devised theatre to decide on the focus and timeline for WDTW; another explained how questions were generated for focus groups and how the group practiced conducting the focus groups; and a third member (who was video-taped ahead of time as he could not attend the conference) spoke about theatre as a medium to communicate disability justice messages. These self-advocates were translating and mobilizing methodological knowledge for an audience of theatre researchers.

Our central WDTW KT strategy was the theatre performances (and video-recording of the performance). Self-advocates played a central role in all aspects of this KT approach. One self-advocate explained, "We had the final say; the script, the lighting, the costumes, even the music selection with the playlists". The self-advocates in this project were part of creating, adapting, reflecting on, and revising methods. In reference to refining the themes and messages in the play, one individual noted, "We did a lot of creative improvisation, thinking outside the box". Audience members included high school students who attended the matinee performance with school groups, staff from the community living sector, families and caregivers, and researchers and staff from local universities. Mounting the show in the Massey Theatre allowed us to integrate inclusive design for co-creators and for the audience. The use of set, lighting, sound, and props were all purposeful in terms of communicating the themes derived from the initial focus groups. We also travelled the show to two conferences. One was an inclusive education conference with education leaders representing all school districts in British Columbia. The other was the World Congress on Supported Employment. This extended the research of the production across British Columbia and worldwide. The performance was video-recorded so as to be accessible beyond the live performance. A promotional video was also created that exclusively features the voices of the self-advocate co-creators describing the development process, the research process, and the themes of WDTW. This video has been widely shared in university, school district, and community education settings. Finally, of note, the WDTW program was written in plain language with summaries for each scene.

4. Discussion and Conclusions

Walmsley (2023, personal communication, 28 November) discusses how inclusive research can be a developmental process. Learning to practice inclusive research has been and is a developmental process for us (academic researchers of the CIIC); we continue to learn and grow as researchers committed to collaboration and inclusion. In this discussion and informed by Walmsley and Johnson's (2003) five principles of inclusive research, we describe strengths, tensions, and lessons learned as we engaged in a disability and devised theatre CPAR project.

4.1. Relevance to People with Intellectual Disabilities and Furthering Their Interests

In line with Walmsley and Johnson (2003), the topic of *WDTW*, employment, had direct relevance to people with intellectual disabilities. Employment is a key aspiration for individuals with intellectual disabilities (Humber 2014; Tompa et al. 2022). Employment enhances the quality of life, improves financial wellbeing, and increases social inclusion for individuals with intellectual disabilities (Randall et al. 2022; Robertson et al. 2019). However, people with intellectual disabilities face significant barriers to labour market participation (Tompa et al. 2022). In British Columbia (BC), Canada, only 24.2% of individuals receiving community living supports reported income, and over 75% of these individuals earned less than CAD 10,000 per year with 53% of the 24.2% earning less than CAD 5000 per year (Community Living British Columbia 2019). This is in a province where recipients of the Persons with Disability Benefits have an annual earnings exemption of CAD 15,000 per year (BC Ministry of Social Development and Poverty Reduction n.d.). Given this, employment is a key priority of policy makers, community living service providers, families and supporters, and self-advocates themselves in BC. Of greater significance, however, is the importance of employment to the self-advocate actors and co-creators of *WDTW* themselves.

As described above, the topic itself was identified by the self-advocate actors and co-creators themselves. The direction for the play was decided by the self-advocate co-creators when they surfaced issues important in their lives. They identified their own experiences with employment as frustrating. One individual talked about struggling for any kind of advancement in her grocery store job. Several had never considered paid work as an option, yet another had many entrepreneurial aspirations but did not know how to enact them. The self-advocate co-creators believed that the performances (and videos of the play) would provide a platform to share their experiences and advance their rights to work. As one individual shared, "I think a social justice theatre piece is like. . .standing up for yourself and to fight for a good cause". The self-advocate co-creators recognized not only the benefits the messages of play could personally offer them but also the need for a broader societal discussion about inclusive employment.

Finally, one interesting aspect of *WDTW* is that audience members included members of the disability community. In their feedback, self-advocate attendees shared what resonated with them, what they learned, and how they want to see the messages of the play reach more self-advocates, employers, caregivers, and family members.

4.2. CPAR and Devised Theatre to Facilitate Inclusive Research

The development and production of disability theatre as CPAR offer a platform where SAs' diverse ways to communicate and be in the world can be honoured and taken up as resources to the research and community (Schnellert et al. 2022; Chalachanová et al. 2020). This study demonstrates how disability theatre as CPAR can bring SAs and community partners together to research significant issues with personal and structural elements and translate and mobilize knowledge by embedding themes from the research into scenes using diverse modes of communication. *WDTW* engaged SA co-creators, theatre artists, inclusion support staff, and audience members beyond spoken language utilizing body language, sound effects and music, and lighting (Goodley and Moore 2002) to illustrate research findings. We agree with Garbutt (2009, p. 12) that disability theatre as CPAR facilitates "participation to individuals who might otherwise be disabled by the research approach taken, rather than by their ability to communicate". In our research, we have found that self-advocates' ability to "communicate through theatre offers new possibilities for connection and understanding, as well as a sense of agency and of pride over the work itself" (Schnellert et al. 2022, p. 482).

In addition to increased opportunities for self-advocate participation in research, increased pathways to communication, and co-creation of KT, disability theatre as CPAR offers lessons regarding non-disabled research team members' roles in inclusive research practice. "One aspect of inclusive research that marks it out as different from ordinary qualitative research is the efforts to make transparent what roles different contributors to the research have taken on (Walmsley 2004)" (Nind et al. 2016, p. 544). We learned several lessons regarding the roles of researchers and community partners within disability theatre as CPAR. For example, we found that rotating self-advocate membership in the WDTW steering committee resulted in deeper participation for some who were less outgoing. The initial three self-advocates on the steering committee had communicated more involvement in the inner working of the partnership project after our first project, RRR. Their role on the steering committee offered them opportunities to use, be recognized for, and develop an expanded skill set (i.e., part of decision making about rehearsal schedules, travelling the show, and the research processes). Of note was when members of the Company with more profound intellectual and/or communication disabilities rotated onto the steering committee, staff who had previously worked with these individuals were surprised by the depth of insights offered and the ideas generated for marketing and promotion. This opportunity to prepare and share their insights with access to augmentative and alternative communication devices (including Zoom reaction buttons), a smaller group, ample wait time, and a previously circulated agenda led to increased recognition for their capabilities and opportunities to represent the CLS on other committees.

An overall contribution of disability theatre/CPAR within and beyond research projects is how self-advocates had opportunities to demonstrate their knowledge, agency, and skills. Across interviews with self-advocates, partners, and theatre artists, it was noted that many SAs' knowledge, insights, talents, and creativity had been underestimated—in many cases for years (Schnellert et al. 2023). In line with de Haas et al. (2022), we underscore that people with higher support and communication needs have assets and contributions to make. Meaningful inclusion thus requires creative and contextualized commitments to create new methods and practices.

Nind et al. (2016, p. 543) writes, "the process of learning to do inclusive research. . .is accentuated by the newness of the paradigm and the emphasis placed on the value of lived reality of, for example, people with [intellectual disabilities] in shaping the research goals and processes". The iterative process of theatre development showcased the improvisational skills of SAs as they developed their characters, responded to scene partners' improvised lines, and incorporated audience reactions and feedback. Thus, we point out that the theatre creation process (devising, developing, and refining scenes) is research in itself where self-advocates draw not only from the focus group interviews but also from their own lived experience and creativity and audience feedback.

A final contribution is what we learned about mentoring the development and practice of research skills. Researchers have noted that when conducting inclusive research, often times, individuals with higher support needs remain excluded (Jones et al. 2019; de Haas et al. 2022). Nind et al. (2016) explain, "It is through involvement in the various stages of research that people learn the 'rudiments of research methods so they can assume collaborative roles in the research' (Bagnoli and Clark 2010, p. 103)" (Nind et al. 2016, pp. 543–44). We found that all the self-advocates enjoyed the more traditional aspects of the research-brainstorming and developing the interview questions, leading focus groups, and analyzing data for themes.

4.3. Learning through Tension

We experienced several tensions in this disability theatre CPAR project. These included power dynamics, the diverse self-advocates' communication modes and needs, role clarity/conflicting goals, COVID-19, theatre accessibility, and travelling the show (reconstituting the show has many more factors to consider than travelling a traditional show). Related to praxis initiation, the theatre and inclusion facilitators sometimes moved the development phase in directions they interpreted as the desire of the self-advocates. With the self-advocates' diverse communication styles and inclusion facilitators' influence as leaders, decisions and directions were sometimes made too quickly and/or pre-emptively instead of iteratively and more democratically seeking confirmation and ongoing input from the self-advocate co-creators. Similarly, there were disagreements over how decisions should be made, especially under time pressure. Self-advocates, community living experts acting as inclusion facilitators, disability theatre facilitators, and theatre artists had several differences of opinion during the multi-year development, rehearsal, production, and performance phases (Schnellert et al. 2023). Throughout the development, rehearsal, and production phases, inclusion advocates and disability theatre facilitators raised and centred self-advocate needs that required constant tinkering with design elements, which interrupted the flow of technical and artistic decisions needed to stay on track with deadlines. COVID-19 added layers of unanticipated complexity—development online was difficult for self-advocates with little Zoom experience—in terms of using online platform elements, receiving and communicating messages about thematic content and theatre and research processes, and overall engagement and participation. Finally, we experienced physical challenges creating and mounting disability theatre productions in traditional theatres and travelling shows to community events and conferences.

In inclusive research, there will always be tensions. As Seale et al. (2015) assert, participatory research is shared space, and it is what Torre (2005) called a "messy social space" where people with different perspectives, strengths, and knowledge come together around a shared vision. This messy space is not necessarily a threat to the CPAR process (Seale et al. 2015). Rather, in this space,

> each participant is understood to be a carrier of knowledge and history; everyone holds a sincere commitment to creating change for educational justice; power relationships are explicitly addressed within the collaborative; disagreements and disjunctures are excavated rather than smoothed over, and there is a collective expectation that both individuals and the group are "under construction. (Seale et al. 2015, p. 487)

One of the benefits of disability theatre as CPAR is that tensions are recognized as sites of possibility—scenes in theatre are built from and around moments of tension. CPAR with individuals with intellectual disabilities involves developing a set of shared practices. As a group of self-advocate co-creators, researchers, theatre artists, and inclusion facilitators, we represented diverse perspectives and lived experiences—and among the self-advocate co-creators, these differences were also apparent. Thus, it is imperative to be proactive and set an expectation that there will be tensions within the research process.

McConn and Mason (2019, p. 3) summarize an international body of research that illustrates "logistical and cultural differences. . .create tensions within these potential collaborative partnerships". Theatre scholar Applebaum (1995) refers to tensions as "stop moments". We need to stop and explore the source of a tension, possible responses, and what we can learn. "The resolution of these challenges pushes the boundaries and in doing so opens up new and messy spaces" (Seale et al. 2015, p. 489). McDonough (2014) identified tensions related to loyalty, advocacy, and obligation in inclusive research. Developing, revisiting, and refining protocols to address disagreements; offer and receive feedback from different positionalities; and disassemble and reassemble writing materials spanning scripts to playbills to promotional materials were and are helpful. Researchers now recognize the importance of acknowledging the personal experience of inclusion from the perspectives of persons with disabilities (Cobigo et al. 2016, p. 226). In both *Romance, Relationships and Rights!* and *WDTW*, we worked to centre the self-advocates' perspectives that required ongoing reflexivity on our power in our positionalities as the researcher, theatre artist, and/or leader.

4.4. Recommendations for Inclusive Researchers

In this next section, we provide some of our learnings about inclusive research when engaging in disability theatre informed by disability justice. As mentioned in the introduction, disability justice in research centres social justice and, as such, necessitates reframing practices of access, ethics, and equity (Keifer-Boyd et al. 2018). Disability justice principles—centring the voices of those who are the most impacted, recognizing wholeness of each person, interdependence, collective access as an ongoing flexible and creative process, and collective liberation where no body/mind is left behind (Sins Invalid 2019)—all of these must inform disability theatre as a practice of inclusive research.

The following are some recommendations that aim to enhance the inclusion and success of disability theatre CPAR. Many of these learnings come from strategies that worked to enhance inclusion, access, ethics, and equity throughout the project, and others come from reflecting on the tensions in hindsight as a means of learning through reflexivity.

(1) Commit to the principle that social justice theatre necessitates that the topic and messages come from the people most affected: lift up, listen to, follow, and highlight the perspectives of those who are most impacted by the systems of ableism and other forms of oppression (Sins Invalid 2019).
(2) Develop, revise, and revise participation, reflection, and problem-solving protocols recognizing that collective access is contextual, improvised, and always changing (Sins Invalid 2019).

   (a) Within and across all phases of the project—e.g., research, theatre creation and rehearsal, and organizational processes—ensure intentional stop moments to reflect on whose voices are being heard.
   (b) Establish shared commitments and revisit them when tensions arise. For example, commit to the importance of hearing from all self-advocates via their communication preferences.

(3) Recognize the timelines needed for self-advocates to fully participate in data collection, data analysis, creation of messages and scenarios/acts/scenes, rehearsal, and theatre production and design elements ensuring that no one is left behind.

(4) Be aware of access needs (recognizing that this requires flexibility and creativity) when mounting the play at the home venue as well as when reconstituting aspects of the production when bringing it to different constituent groups in different venues.

(5) Ensure there are ongoing self-advocate consent and micro-consent processes "that are rooted in self-determination, active consent, and the needs of the collective" (Sins Invalid 2019, p. 70).
   (a) We learned that self-advocates may wish to participate in the data collection and analysis stages but not the theatre creation and performance phases.
   (b) We learned to set and revisit protocols for sharing ideas (to make space for everyone) and regarding physical touch within the creation process and performance (between self-advocate actors, and between facilitators and actor/co-creators).

(6) Scaffold the research skill development of self-advocates in all aspects of the research, offering different roles and participation access points based on tasks: "[remember] that moving together doesn't mean that we all participate in the same way; [it's important to value and adore] all the ways that we show up" (Sins Invalid 2019, p. 69).

Finally, it is important to note the underlying principle of collective access across these recommendations. As Sins Invalid (2019) explains, it is important to acknowledge the "iterative/repetitive/cumulative process of supporting [one another]", meaning this is a constant process and we usually do not get it right the first time (p. 71). Thus, we need to work collaboratively "committing to our collective stake in ensuring access and striving to be accountable to each other" (p. 71).

4.5. Conclusions

In conclusion, the question for those interested in inclusive research is, "How to be inclusive? And, what works best for this given project?" And as Nind and Vinha (2012) assert, regardless of methods and approaches, disability research should be authentic; should answer important questions we could not otherwise answer; should generate accessible knowledge for participants and communities; should involve the knowledge and perspective of people with intellectual disabilities; and should make a positive impact on the lives of people with intellectual disabilities. Over the past seven years, we have grown in our capacity to develop and enact disability-justice theatre as CPAR. Working with self-advocates to co-create goals, processes, and timelines together has resulted in more self-advocate ownership and agency of the topic studied and data collection and analysis; more collective access (Sins Invalid 2019); and more participatory knowledge translation and mobilization.

Future research can examine when and how self-advocates experience agency as (co)researchers. This would add further insight into how to enact Walmsley and Johnson's (2003) call for people with intellectual disabilities to be collaboratively involved in the process of doing the research. In our own CPAR and disability theatre work, we plan to build in more reflective opportunities as a collective where self-advocates, inclusion facilitators, and theatre artists surface and address tensions across the phases of a project. We have learned that time spent mentoring self-advocate research skill development fosters confidence and adaptability when self-advocates are engaged in research activities such as leading focus groups. Research into what self-advocates determine as themes from data and how they translate these into scenes/scenarios can prove fruitful for understanding how self-advocate perspectives and lived experience add depth to qualitative and arts-based research. Such efforts would help to see how people with intellectual disabilities exert analytical influence within research processes and outcomes (Walmsley and Johnson 2003, p. 64). Future research could also explore how increasing pathways to communication, co-creation of KT strategies, and protocols for power sharing and problem solving within disability theatre as CPAR impact the roles, outcomes, and experiences of disabled researchers. Finally, we have learned that we need to recognize from the outset that there will be tensions and issues and that we need processes—explicit shared commitments and protocols—to address them. Perhaps the most generative aspect of our research is the potential for engaging with tensions as a praxis point for disability justice. Developing research programs and productions with this in mind has transformative potential for inclusive research and practice.

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Perspective

Life Story Research with People Aging with Intellectual Disabilities: An Adaptation of the Lifeline Interview Method

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Abstract: A key feature of inclusive research is the accessibility of research procedures to meaningfully engage people with intellectual disabilities in research processes. Creating accessible research procedures requires innovations in methods traditionally used in research. This paper describes how the Lifeline Interview Method by Assink and Schroots was adapted and implemented in a study using life story research to better understand the experiences of older adults with intellectual disabilities. Twelve adults with intellectual disabilities over the age of 50 participated between two and seven times in interviews about their life histories. The interviewer assisted in the construction of timelines of key events in the participants' individual life stories, and the participants decorated their lifelines throughout the course of the interviews. The lifeline process was an effective tool to engage the participants in the research process, support participation, and provide access for people with intellectual disabilities to retrieve their life experiences. Challenges in the lifeline process included barriers to gathering sufficient information to construct timelines and gatekeepers withholding access to information.

Keywords: life story research; intellectual disabilities; inclusive research; aging; lifelines

1. Introduction

1.1. Including People with Intellectual Disabilities in Research

The ability of people with intellectual disabilities to participate in research has traditionally been questioned, and much disability research has been conducted within an oppressive paradigm that conceptualizes disability as a problem and tragedy. Consequently, the voices of people with intellectual disabilities have long remained unheard, and other voices have been heard speaking for them (Atkinson and Walmsley 1999; Stone and Priestley 1996). Emancipatory approaches to disability research that engaged people with disabilities in research started to be articulated with the development of the social model of disability in the 1970s and 1980s (Stone and Priestley 1996). To bring the unknown about people with intellectual disabilities into the known and to provide information about their lives and experiences, research that included people with intellectual disabilities significantly increased in the 1990s (Beail and Williams 2014). This research used qualitative methods, as detailed below.

1.2. The Use of Qualitative Research Methods in Research with People with Intellectual Disabilities

Qualitative research methods are particularly well suited to collect data from people with intellectual disabilities, as their use is based on the assumption that all perspectives on an issue or event are inherently valuable and, potentially, credible and useful (Taylor and Bogdan 1998; Taylor et al. 1995). Qualitative methods have the potential to empower people with intellectual disabilities to insist that their experiences matter.

The first category of qualitative studies exploring the views and experiences of people with intellectual disabilities consisted of ethnographies and life histories that documented their lives (Grant and Ramcharan 2001). When conducting qualitative research with people with intellectual disabilities, the impact of an intellectual disability on participants' ability to communicate does need to be considered, as does their ability to remember details about their lives (Beail and Williams 2014; Krisson et al. 2022; Vicari 2012). The challenge here is one of method (Booth and Booth 1996). Adaptations need to be made to qualitative research methods to enable people with intellectual disabilities to fully participate in research that addresses their lives and experiences (Booth and Booth 1996; Krisson et al. 2022). Creative and flexible research methods need to be developed that rely less on verbal communication or do not require verbal communication at all. Recent development of visual research methodologies has shown promise in empowering people with intellectual disabilities in research, for example, through using photographs, videos, and making drawings (Cluley 2017; Krisson et al. 2022; Rojas and Sanahuja 2012). Yet, more research is needed to explore and validate such inclusive research methods, an endeavor to which we aim to contribute with this paper (Krisson et al. 2022).

1.3. The Aim of This Paper

This paper reports on the development and implementation of a visual methodology to support life story research with older adults with intellectual disabilities through an adaptation of the Lifeline Interview Method by Assink and Schroots (2010). First, the paper provides a background on the application of life story research in bringing to light the experiences of people with intellectual disabilities and reviews considerations in using life story methodology with people with intellectual disabilities that helped inform this study. Then, the paper describes how the Lifeline Interview Method was adapted and how lifelines were used in a study with 12 older participants with intellectual disabilities. The paper concludes by analyzing the impact of using lifelines in research with people with intellectual disabilities and the implications of this work for future research.

2. Life Story Research

2.1. Life as a Story

Storytelling is a fundamental aspect of what it means to be human. People "story" their lives, who they are, and the world around them. Life stories are people's accounts of their lives as a whole: past, present, and future; they allow people to feel as though their lives have a sense of unity and purpose and contain various scenes and scripts that together create a person's identity (Basting 2009; Gubrium 2011; Kenyon and Randall 2001; McAdams 2001; Meininger 2001). Life stories do not develop in a vacuum. People's lives are impacted by the structures and cultures of the societies they live in and the larger stories within those contexts. Structural dimensions such as social policies and distributions of power and wealth can constrain individuals as well as stunt their stories, silence their voices, and limit their sense of possibility (Gubrium 2011; Kenyon and Randall 2001; McAdams 2001). Sociocultural dimensions give meaning to what experiences are valued in societies, often creating disadvantages for both older and disabled people (Jönson and Taghizadeh Larsson 2021). Finally, people live their lives in networks of shared relationships, which means that stories exist to be shared with others and are shaped and entwined with other people's stories and experiences (Gubrium 2011; Kenyon and Randall 2001; McAdams 2001).

Life stories are particularly important to older adults, as the longer their lives are, the more there is to tell (van Heumen 2021). The acknowledgement that how people feel about their lives is not only determined by what they experience today but also by what happened to them in the past and by their retrospective view on those life events has led to a body of research using the metaphor of life as story (McAdams 2001; Schroots and Birren 2001; Westerhof et al. 2001). Life story research has been adopted across disciplines as an umbrella term that includes different methodological approaches aimed at revealing the lives or segments of the lives of people. In addition to "life story research", many different terms are used interchangeably, such as "life history work", "biography", "oral history", "reminiscence", "narrative analysis", and "life review" (van Heumen 2021).

Gibson (2006) outlined the necessary approaches for researchers when undertaking life story research. They should listen actively and attend to the participants' needs, be non-judgmental, manage and be responsive to the participants' expressions of emotion during the research, enjoy their stories, show interest in their past, and be disciplined about inserting themselves while being able to share their own thoughts if asked. Finally, researchers need to be able to reflect on and critically evaluate their own work and be able to accept feedback and offer feedback to others. These considerations are important for researchers who implement life story research with people with intellectual disabilities who have historically been marginalized in research and excluded from meaningful participation.

2.2. A Background on Life Story Research with People with Intellectual Disabilities

During the last 30 years, life story research has steadily become a prominent approach in research with people with intellectual disabilities, particularly in Europe (e.g., Atkinson et al. 2000; Atkinson et al. 1997; Atkinson and Walmsley 1999; Cadbury and Whitmore 2010; Goodley 1996; Hreinsdóttir et al. 2006; Hussain and Raczka 1997; Mee 2010; Roets et al. 2007; Roets et al. 2008; Roets and Van Hove 2003; Van Puyenbroeck and Maes 2004). Life story research with persons with intellectual disabilities has been mostly conducted through face-to-face interviews (Aspinall 2009). A life story of a person with an intellectual disability may chart an entire life or be a collection of small stories that express a person (Meininger 2006).

Three main perspectives undergird research conducted with the life stories of people with intellectual disabilities (Meininger 2003, 2005; Van Puyenbroeck and Maes 2008). In the critical approach, people with intellectual disabilities are supported to become aware of their past and take ownership of their life stories (Van Puyenbroeck and Maes 2008). The person-centered approach aims to inform individuals who provide everyday support about the needs of persons with an intellectual disability. This process consists of retelling and discussing life stories between people with intellectual disabilities, their family members, and staff and can include activities such as creating a life book (Aspinall 2009; Meininger 2003, 2005; van den Brandt-van Heek 2011; Van Puyenbroeck and Maes 2008). In the clinical approach, reminiscence is used as an alternative diagnostic instrument and counseling method for people with intellectual disabilities (Van Puyenbroeck and Maes 2008). The focus of this approach is not on empowerment but rather on dialectical understanding and relational intimacy.

Retrieving and sharing the life experiences of people with intellectual disabilities brings their disregarded lives to the foreground (Bornat 2002). Their life stories, like those of women, black people, and mental health survivors (Atkinson 2010), can recount their resilience and struggle against discrimination and exclusion (Goodley 1996; Hamilton and Atkinson 2009; Stefánsdóttir and Traustadóttir 2015). It can be empowering for people with intellectual disabilities to represent their own life experiences (Meininger 2006), and it can also allow for community building when common experiences are shared (Hamilton and Atkinson 2009). The process of sharing life stories may not only assist individuals with intellectual disabilities in processing difficult past life events, but it can also promote epistemological connections by highlighting the structures and forces through which people with intellectual disabilities have come to be seen as inferior. This process can highlight the impact of the social construction of intellectual disabilities on the everyday lives of people labeled as such (Hamilton and Atkinson 2009).

Much of the literature on life story research with people with intellectual disabilities reports on experiences of institutionalization (e.g., Cadbury and Whitmore 2010; Hamilton and Atkinson 2009; Hreinsdóttir et al. 2006; Mee 2010; Roets and Van Hove 2003), though many other topics such as community living and experiences with disability, relationships, and self-advocacy have been explored as well (Caldwell 2010; Lifshitz and Shahar 2022; Ledger et al. 2022). A small number of studies retrieved the experiences of adults with intellectual disabilities with aging (e.g., Burke et al. 2014; Brown and Gill 2009; David et al. 2015; Kåhlin et al. 2015; Neuman 2020). Life story research can provide important information about how older adults with intellectual disabilities experienced living with disabilities over time, how their earlier life experiences impact them today, and how they experience getting older (van Heumen 2021). Despite these important benefits of using life story research, there are challenges to implementing it with people with intellectual disabilities.

2.3. Challenges in Life Story Research with People with Intellectual Disabilities

One of the most important methodological issues in life story research concerns how to best collect information from people (Van Puyenbroeck and Maes 2008). Challenges include participants' inarticulateness, unresponsiveness, and difficulties with the concept of time. These challenges are not unique to life story research with people who are labeled intellectually disabled but are more pronounced compared to life story research with people without this label (Atkinson and Walmsley 1999; Booth and Booth 1996; Schroots and Birren 2001). While strategies exist to address some of these challenges, they put limits on the important referential function of narrative, which is essentially a story in time (Booth and Booth 1996).

People with intellectual disabilities have little access to the written word and sometimes struggle with the spoken word as well (Atkinson et al. 1997). The concrete frame of reference typical for many people with intellectual disabilities can at times restrict their capacity to look back on their own lives with reflexivity (Booth and Booth 1996). People with intellectual disabilities may have some impairment of their memory and experience difficulty in providing details about their past, often confusing sequences of events (Aspinall 2009; Goodley 1996; Vicari 2012). They may also have a strong orientation toward the present and experience difficulties with dates, numbers, and the concept of time (Booth and Booth 1996; Sharp et al. 2001).

It has been argued that the challenges experienced by people with intellectual disabilities to understand time are indicative of lives that often lack the opportunities, life tasks, challenges, and milestones that people use to order their past and to mark the passage of time (Booth and Booth 1996). The implications of the challenges with time perception are less evident. It is unclear what the concept of time means to people with intellectual disabilities, whether they construct and structure their lives in chronological order of past–present–future, how they experience the present versus the past and the future, and whether they think and frame their lives in terms of stories.

Environmental influences impact the understanding of time, and it has been suggested that increasing the availability and reliability of external time cues in the immediate environment of persons with intellectual disabilities may improve time perception abilities (Owen and Wilson 2006). Owen and Wilson (2006) argue that time perception abilities are important as they "may reduce feelings of powerlessness and anxiety and increase feelings of self-efficacy and the individual's sense of self as having a past, and a future" (p. 9).

Sources of bias are well documented within life story research as well. These include participants' tendencies to misremember, rehearse a story, and/or, in some cases, lie. Checks for consistency between accounts of the same experience or event in different interviews have been one method suggested to address this bias (Goodley 1996). Additionally, oral historians have used personal stories alongside other sources of evidence (Manning 2010).

Finally, Goodley suggested that the question of whether people with intellectual disabilities are telling the "truth" when talking about their lives may be irrelevant (1996). It is more important to understand why people present their stories like they do. Ultimately, subjective experiences do not necessarily (need to) accurately reflect objective situations. This orientation is particularly important when it comes to life story research with people with intellectual disabilities, as they have historically been deemed "unreliable" research participants, and their perspectives have been dismissed.

Researchers have questioned how life story research is implemented with participants with intellectual disabilities. For example, as Henderson and Bigby (2017) aptly pointed out, almost every life story of a person with an intellectual disability is the result of a collaboration with an (often nondisabled) interviewer, with whom they have a unique relationship. The process of producing the life story through an interview tends to consist of a dialogue, but the product of the life story often takes the form of a monologue, centering the voice of the person with an intellectual disability. Henderson and Bigby (2017) warrant that attention needs to be paid closely to the process of amplifying the voice of people with intellectual disabilities in life story research and that delineating the roles played in the collaboration can promote self-reflexivity in this process. The ways in which researchers position themselves and reflect on their own functioning in the process of collecting, writing up, and presenting life stories are of crucial importance if they in any way strive toward an empowering approach (Goodley 1996). Additionally, there are important considerations of how to make the process of life story research more accessible for people with intellectual disabilities, as detailed below.

2.4. Making Life Story Research with People with Intellectual Disabilities More Accessible

Life story research is inherently inclusive, as it allows people to share their own stories. However, people with intellectual disabilities have had limited opportunities to share their life stories and to share in the stories of others like them in a way that is accessible to them. The acknowledgement that life story research is about more than the gathering of life stories and also includes the process of representing and sharing stories is particularly useful, as it acknowledges the importance of accessible dissemination of research that is about the lives of people with intellectual disabilities (McCormack 2020). Life stories of people with intellectual disabilities have almost exclusively been shared through text, such as books, articles, and reports, accessible to an audience with advanced literacy skills only (Aspinall 2009; Manning 2010).

Researchers have tried to develop strategies to make the process of life history research more inclusive and accessible for people with intellectual disabilities. Aspinall (2009) suggested that life stories be captured in different media, such as a photo album, an audio account, a video report, or a "memory box", which contains objects to represent important memories, and recommended that the storyteller pick the medium. Aspinall also explored the use of multimedia life stories produced through computer technology. After working with a facilitator to retrieve and create the life story, persons with limited or no verbal communication presented their stories by pressing keys on a computer keyboard or another device. Aspinall advised that music and sounds can be included in multimedia life stories to make them an animated and personal experience. Finally, Aspinall observed that the design, presentation, and content of a life story can demonstrate the personality of the storyteller and that the storyteller should have full control over those elements of the life story. Manning (2010) also used digital storytelling to produce DVDs with text, sounds, and images to make the outcomes of life story research accessible for people with intellectual disabilities and of interest to a general audience.

McCormack (2020) conducted life story research with people with profound intellectual and multiple disabilities and explored opportunities for storytelling in the broadest sense, including embodied stories (e.g., through performance, gestures, and muscle memory), sensory and visual stories (e.g., through photos and objects), and stories of places (e.g., through geographical locations and mobile interviewing conducted through situated talking while being on the move) (Brown and Durrheim 2009). McCormack combined creative life history research approaches (such as examining personal archive materials and conducting conversational interviews with allies) with ethnographic approaches (such as developing relationships with participants and learning to understand their communication) and immersed themselves in the lives of three people with disabilities and their circles of support for 18 months. McCormack describes the intersection of the communication strengths of participants with intellectual disabilities, of how their communication is supported, and of the location of their stories as "participatory life story spaces". In these spaces, McCormack sees opportunities to support inclusive life story research. When life story materials are constant, it is the characteristics of people, time, and the environment that promote people with profound and multiple disabilities to engage actively with their past.

People with intellectual disabilities have traditionally not been fully included in life story research as co-interviewers and investigators (Caldwell 2010). Additionally, their participation in data analysis and theory development has been limited (Nind 2008; Koenig 2012). Koenig (2012) reported on a project that involved people with intellectual disabilities in a reference group (accompanied by support staff and research staff) to co-construct theory through the shared analysis of life stories. Activities during the meetings included short inputs and presentations by the facilitator, small and plenary group discussions, open spaces, and group exercises. One life story was analyzed per meeting, and various scaffolded techniques were used to engage people with intellectual disabilities in the analysis. More research is needed to determine how to best engage people with intellectual disabilities in the collection, analysis, and dissemination of life story research.

2.5. The Use of Lifelines in Life Story Research

Another tool that can be used to make life story research more accessible for people with intellectual disabilities is lifelines, a tool we explored in this study. Lifelines have been used as a life story methodology as early as the 1980s. Lifelines visually depict the life events of individuals in chronological order and can include interpretations of life events. In some studies using lifelines, participants draw and label their lifelines; in other studies, the researchers produce the lifelines. The lifeline can be triangulated with other data collection methods to confirm and complete a life story. As a life story research technique, lifelines are developed over time and require repeated contact with research participants (Gramling and Carr 2004). Lifelines have been used in various ways in research with vulnerable groups, such as women who smoke crack (Boyd et al. 1998), incarcerated women (Hanks and Carr 2008), and people in the early stages of Alzheimer's disease (Dienstag 2003).

The Lifeline Interview Method (LIM), developed by Assink, Schroots, and colleagues, is a comprehensive approach to using lifelines in life story research. The LIM aids in understanding how individuals organize and review their behavior across their lives and uses the metaphor of life as a footpath, representing the life journey from birth to death. The LIM consists of a semi-structured interview and combines a quantitative and qualitative approach.

The lifeline in the LIM consists of a visual, two-dimensional representation of the course of a person's life, with time on the horizontal axis and impact on the vertical axis. In a LIM session, the interviewer asks the participant to demonstrate their perceptions of life visually by drawing a line representing the time from birth to the present age. After the participant draws the lifeline, the participant labels each peak and each dip by chronological age and explains what happened at these moments. After visualizing and describing the past, the future is explored in the same manner. The result of this procedure is a lifeline consisting of a series of life events organized in a chronological manner, representing the life story. The LIM's strength is its self-pacing quality and nondirective nature (Assink and Schroots 2010; Schroots and Birren 2001). Despite the perceived benefits and visual nature of this method, it has not yet been applied in life story research with people with intellectual disabilities. The section below discusses how this method was adapted and implemented in a study with older people with intellectual disabilities.

3. An Adaptation of the Lifeline Interview Method

3.1. Study Overview

The goal of this study was to gain insight into the experiences of older people with intellectual disabilities with their social relations across their lives. As part of the study, an adaptation of the Lifeline Interview Method was developed and tested (Assink and Schroots 2010; Schroots and Birren 2001). The Institutional Review Board of the university of the principal investigator approved the study. Recruitment occurred through service agencies for people with intellectual disabilities in a metropolitan area of the United States. Twelve adults with intellectual disabilities who were at least 50 years old (six men and six women) and lived in various residential settings (such as a family home, a group home, or an apartment) participated in between two and seven in-depth semi-structured qualitative interviews, during which their social network maps were completed (Tracy and Whittaker 1990) and their life histories were recorded.

The study was designed to first complete a life history interview with each participant and a key support person who was selected by the participant, followed by individual interviews with each participant, during which a lifeline was created. Lifelines placed life histories within a historical context and mapped the sequences of key life events in the individual life histories of the participants (Caldwell 2010). The lifelines also served as a visual cue for participants and assisted non-intrusively during the interviews. Each interview lasted between 30 min and 2 h, and the interviews were conducted several days to two weeks apart, within a period of a month to six weeks. The multiple contacts with participants over prolonged periods of time strengthened rapport (Mactavish et al. 2000; Taylor and Bogdan 1998).

The interview recordings were transcribed verbatim. The different stages of data collection resulted in interrelated data pieces: interview transcripts, field notes, social network maps, lifelines, and a journal, which explored the researcher's experiences during the research to draw upon later for analysis. Data analysis started with a case analysis, which used all these data pieces (Patton 2002). The case analysis resulted in 12 individual life stories that provided context to the subsequent thematic analysis of the interview transcripts (Braun and Clarke 2006). Discussions of the events presented on the lifelines were included in the interview transcripts, but the lifelines were not independently analyzed as a source of data, for example, by coding or categorizing events placed on the lifelines. Rather, lifelines were used as a visual tool to support the interviews. The findings of the study are reported in detail elsewhere. A few key highlights are that parents and siblings played an important role in facilitating positive experiences in the early lives of the study participants. Participants' lives were disrupted as they reached young and middle adulthood by life course transitions, such as moving out of family homes and the deaths of parents. Additionally, participants' well-being was negatively impacted by distressing social encounters they experienced throughout their lives. Finally, participants' social well-being in later life was characterized by parallel sentiments of longing and belonging.

3.2. Key Support Persons

Researchers have to make decisions about how to best retrieve information from people with intellectual disabilities in research and facilitate appropriate support for participation. This study carefully navigated this issue. The use of joint interviews with family or staff is a prevalent research strategy to supplement data gained from participants with intellectual disabilities or to provide a secondary or confirmatory source of information (Caldwell 2014). This technique can be problematic, as it has the potential for proxy or facilitated responses to suppress the voices of persons with intellectual disabilities (Caldwell 2014; Goodley 1997; Goodley and Rapley 2002; Rodgers 1999).

This study used the method of dyadic interviewing, as it carefully considered the selection and purpose of the involvement of a support person. A key feature of dyadic interviewing is that the participant with an intellectual disability identifies the key support person of their choice. According to Caldwell (2014, p. 11), this approach "removes an element of paternalism on the part of the researcher and facilitates the role of those individuals with intellectual disabilities in the research as having choice and a voice in how they are represented". The strength of this approach is that it acknowledges interdependence as a central feature of human relationships (McCormack 2020). This acknowledgement allows for accommodations that facilitate the participation of people with intellectual disabilities in research (Caldwell 2014).

The study participants picked staff, family members, or friends who knew them well to support them during the study. One participant selected two key support persons. The nature of support and the level of involvement of each key support person differed, as each participant had different support needs and preferences throughout the research process. Two of the twelve participants in the study had guardians who served as key support persons (both siblings), and they decided to meet with the researcher first before any interviews with their family members with intellectual disabilities were conducted. Three participants decided to have the key support person present for all the interviews. Eight participants were only supported by their key support person during the first interviews and completed their work with the researcher independently. Only one participant opted not to have a key support person present at all for any of the interviews. The key support persons assisted with rephrasing questions, complementing or clarifying answers provided by the participants, and facilitating the overall communication. At times, the key support persons would also ask questions as part of naturally flowing conversations during interviews.

In some instances, research participation is only possible for people with intellectual disabilities when an ally occupies a position alongside them (McCormack 2020). The involvement of the key support persons was a key feature of this study's successful implementation. Researchers need to be flexible to allow for a variety of different approaches with regard to the level and nature of involvement of a key support person, as individual support needs vary across participants.

Finally, researchers need to pay close attention to how the voices of people with intellectual disabilities are prioritized in life story research and what roles are occupied by those who are involved in life story research (Henderson and Bigby 2017). This study privileged the perspectives of the participants with intellectual disabilities in the results by sharing their stories from their perspectives and by including their direct quotes without correcting grammatical concerns in language, as often suggested researchers should do (Carlson 2010). The findings also included the distinctive views and experiences of the key support persons in the study to recognize their important roles in the lives of the participants and to acknowledge the interdependent relationships between participants and their key support persons.

3.3. Preparing for the Lifelines

To provide a starting point for the creation of lifelines, the researcher meticulously constructed vertical timelines of key events in the participants' individual life stories by combining information that participants and key support persons provided during life story interviews and, if necessary and available, casefiles. The life story interview explored topics such as participants' residential, educational, and employment histories, important life events, and experiences with social relations across their life course. Chronologies were ascertained in each life story by asking participants how old they were at the time of specific events, if certain life events happened before or after other events, or where they lived at the time of an event. The presence of key support persons during the life story interviews facilitated the retrieval of information about the participants' pasts. However, most of the key support persons did not have intimate knowledge of the participants' life histories. With the participants' permission, information from case files provided additional information about their life histories. These files often contained minimal information or were incomplete. One agency did not allow viewing of any files, even though the participants, who were their own guardians, gave the project permission to do so. This raised the issue of ownership of information about the participants' lives. In this instance, people with intellectual disabilities were not allowed to access information about their own lives and share it with people of their choosing. Such gatekeeping restrictions for people with intellectual disabilities by service providers are a common ethical challenge in research. The danger of overprotecting people with intellectual disabilities is that it may render them silent (Doody 2018; Witham et al. 2015). Researchers need to carefully navigate the involvement and concerns of gatekeepers as research is planned, conducted, and disseminated. This can include providing clear information on why the research is conducted, what it aims to accomplish, and what it involves.

3.4. Creating the Lifelines

The completed timelines of key events helped direct the remaining interviews with the participants, which explored their perspectives on their lives and enabled the creation of lifelines (with or without the presence of key support persons based on the participants' preferences). Focusing on knowledge-based questions can confront people with cognitive impairments with challenges, as it requires reproducing facts from memory (van den Brandt-van Heek 2011). In order to make the process of creating the lifelines more accessible, it was important to retrieve the participants' opinions and emotions surrounding life events and the people involved in them rather than exclusively focusing on facts related to those events. Each participant participated in the process of creating the lifeline differently and made different decisions in its creation regarding what life events they wanted to include and how they wanted to decorate it. As a result, each lifeline looked different. Only one participant did not have an interest in using the lifeline. The process did not seem to appeal to him. He was not sure what to write or draw. Even though the researcher rolled out the lifeline during two interviews, the participant did not use it. His direct support staff had not been able to find the photos he said he had in his room. Perhaps the use of pictures would have made the process appeal to him more. In this case, the timeline of key events was not decorated to support the interviews. Even without creating a lifeline, the participant was able to speak about his life experiences and complete the interviews.

This process of creating lifelines started with the drawing of a single horizontal line across the landscaped page on a piece of flipchart paper, with the birth year of the participant on the far left and the present year on the far right. With a pencil, the researcher marked the major life events discussed in previous interviews. In contrast to the original Lifeline Interview Method, no peaks or dips were drawn to visualize the negative and positive effects of life events, as this concept might have been too abstract for the participants.

As participants discussed various life events, they could choose whether they wanted to include them on their lifeline. This approach allowed participants to take ownership of the research process and decide how they wanted their story to be told. Participants decided both for and against the inclusion of certain life events on their lifelines based on what was most important to them, what they wanted to share, and how they wanted their experiences to be represented. Some participants decided not to include representations of particularly difficult events in their lives on their lifelines.

Participants also decided how they wanted their life events depicted on their lifelines. They had the additional option of writing or drawing something, and they were offered support with this when needed. Participants could decorate the empty paper using pens, markers, and pastels. Some participants chose to write or draw by themselves, while others asked for assistance. Life events were not necessarily discussed or placed on the lifelines in chronological order, and conversations flowed naturally while hopping back and forth in time. At times, the researcher or participants revisited life experiences across interviews to explore them in more detail.

Some participants and key support persons brought pictures and other personal artifacts, such as certificates, diplomas, and medals, to assist in communicating their life story in more detail. The artifacts served as visual cues and helped participants express their experiences, as prior research has also found (Caldwell 2010). Some participants included their pictures on their lifelines. The researcher explained to the participants that their lives would continue beyond the current year by gesturing toward the end of the lifeline and extending it by moving in an onward motion. This visualization helped participants express their desires for the future. To complete the construction of each lifeline, the researcher asked the participants if they wanted to give their lifeline a title. Some participants titled their lifeline, and others did not. After completing each lifeline, the researcher took a photograph for future analysis. One participant decided not to finish their lifeline.

Throughout the process of creating the lifelines, the meaning that various life events held for the participants could be explored effectively. The pace at which lifelines were created and completed varied across participants, as some needed more time than others to engage and share their experiences or share more details. Therefore, some participants engaged in more interview sessions than others to complete their lifelines. The repeated sessions built rapport and allowed for deep engagement with the participants' experiences. The participants who created a lifeline all took ownership and kept it. Some participants showed their lifelines to their friends and staff and asked for them to be put on display. The next section provides an example of the process of creating a lifeline with its finished product, after which a reflection on the overall lifeline process follows.

3.5. Example of a Lifeline

The story of Betty, a woman in her late sixties, provides an example of the process of creating a lifeline. Betty was one of the study participants and was supported to participate in the study by her sister and guardian, Amanda. Both names are randomly generated pseudonyms. Betty participated in four interviews, together with Amanda. The researcher had known Betty for several years and had interviewed her twice before. Throughout the interviews, Betty was extremely talkative and demonstrated that she had a very good memory. She recalled the names of all the children she played with in her neighborhood when she was a child. It was interesting to observe Betty remembering events that Amanda did not. In those instances, the conversations would turn into a family reminiscence session. Sometimes Betty would mention two events that happened decades apart in the same sentence. Amanda would clarify the chronologies. When Betty could not find the word she was looking for, she turned to Amanda for assistance. They finished each other's sentences on several occasions. Amanda helped Betty answer questions, but when the researcher asked Betty a direct question regarding how she felt about something, Amanda gave Betty the space needed to provide her answer independently. Amanda supported and encouraged Betty to draw on her lifeline without taking over the process. After completing the life story interview together, the researcher created a vertical timeline of the key events in Betty's life (Figure 1). After viewing some family photos, Betty decided to draw on her lifeline and not include these photos (see Figures 2 and 3). She drew her house, the family's lake cottage and boat, her mother and father, one grandmother playing the piano, one grandmother playing cards, her graduation cap, herself at her sister's wedding, her three friends (who are her sister's friends too), herself as a Girl Scout, the family car, and their two cats. She also wrote the name of the nursery school where she had worked on her lifeline. The inclusion of an image of the map of Europe provided a representation of the trips she took there with her father. She also included the logo of her workplace (removed from the lifeline pictures below for privacy reasons). Betty decided to complete her lifeline by shading the paper, so the result looked very colorful. Betty said she liked drawing on her lifeline. She was enthusiastic about adding drawings to her lifeline and would do so unprompted and then explain what she drew. Betty and Amanda gave permission for the use of photos of Betty's lifeline below.

	19XX	19XX	19XX	19XX/19XX	19XX----------------------19XX	19XX	20XX	20XX	20XX	20XX	
Birth year											Present year
	Moved to a new home	Started working in nursery school	Graduated high school	Grandmothers passed away	Travel with father	Car accident father. Amanda came for three months	Uncle died	Parents died. Amanda moved in.	Started day program.	Aunt died.	

Figure 1. Betty's timeline of key events.

Figure 2. Betty's lifeline.

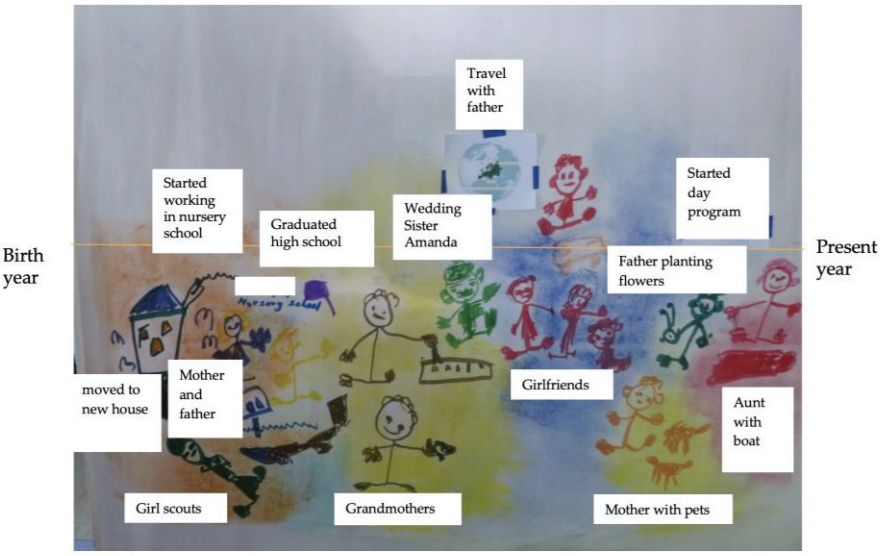

Figure 3. Betty's annotated lifeline.

3.6. Reflecting on the Lifeline Process

Even though the primary goal of using the lifelines was to provide a visual cue to support the interview process, the effort it took to create the timelines paid off in a number of less expected ways. Creating the lifelines was an interactive and empowering process that almost all participants actively engaged in. The work on the lifelines reduced tension during the interviews, built rapport, and helped the interaction between the researcher and the participants feel more natural and relaxed. Instead of questions being fired off while sitting on opposite ends of the table, the researcher and participants sat next to each other, both looking at the lifeline and collaborating in its creation. The participants seemed comfortable and excited during these meetings. Without being prompted, participants mentioned that they had a good time and had fun working on their lifelines and that they enjoyed seeing the researcher. Only one participant, though she did not offer negative feedback, decided not to complete her lifeline.

Participants decided for themselves what life experiences they wanted to include on their lifelines, which gave them ownership of the process and the representation of their lives. The lifeline process also provided participants with the freedom to express their experiences in a way of their choosing through drawing and writing, yet within a clear framework of the lifeline as a visual representation of their lives from birth to the present. Providing clear instructions to participants is important for visual research methodologies to be successful with participants with intellectual disabilities (Sigstad and Garrels 2021).

This study's adaptation of the Lifeline Interview Method also allowed for engagement with participants' experiences without asking for information that they were unable to provide. This is important because when participants experience a lack of mastery due to a gap between their ability and the demands of the research, they may not want to continue research participation (Sigstad and Garrels 2021). It is not effective to use research methodologies that emphasize participants' limitations and make them feel inadequate (Booth and Booth 1996; van den Brandt-van Heek 2011). The role of key support persons was important in getting to know the participants and supporting them effectively in creating their lifelines. Involving the people around the participant is another important strategy for facilitating the research participation of people with intellectual disabilities (Cluley 2017).

The completed lifelines provided the participants with access to their memories and a sense of history about their own lives. The lifelines became a source of pride for them. The chronological review of their live events and the presentation of their lives seemed to be new experiences for a number of participants. The lifelines provided staff with new information about the participants' lives as well. An important impact of life story research can be to offer those who provide everyday support more knowledge about the experiences and needs of people with intellectual disabilities (Aspinall 2009; Meininger 2003, 2005; van den Brandt-van Heek 2011; Van Puyenbroeck and Maes 2008).

4. Conclusions

The lifeline process was an effective tool to meaningfully involve and engage the participants in the research process and to retrieve their experiences. A few important adaptations were made to the original Lifeline Interview Method by Assink, Schroots, and colleagues (2010). Timelines were prepared with the assistance of key support persons before the lifelines were created. These timelines facilitated the creation of the lifelines in a way that did not rely on participants' memories of what life events happened when and in which order. Additionally, only the horizontal axis of time was used on the lifelines, and the negative or positive impact of life experiences was explored verbally during the interviews. The process of creating the lifelines also consisted of non-verbal creative expressions of experiences through drawings and the inclusion of pictures.

In life story research, interviewers need to be critical of their own role in the research and their representation of the participants' experiences (Henderson and Bigby 2017). Using the lifelines helped participants tell their own version of their lives by making their own decisions about which events and circumstances mattered to them in their lives and how they wanted them represented. This was particularly important with difficult life events, as participants were not forced to engage in memories they did not want to explore and discuss. The importance of this flexibility has been reported by other researchers as well, who indicated instances of participants with intellectual disabilities deciding not to include painful life events in the representation of their life histories (Atkinson 2010).

The lifelines provided participants with a clear, structured framework within which to represent their life experiences and assisted them in organizing their life story in chronological order (Atkinson 2010). Though life experiences during the interviews were not discussed in chronological order, the lifelines did rely on a chronological representation of time. This begs the question of to what extent instructions enabled participation and to what extent they restricted participation by prescribing participants to represent their lives as a chronological story, when that may not have been every participant's preferred approach (Aspinall 2009). Researchers should ask the question of whether the structure provided by the lifeline process might limit some participants' preferred storytelling methods. Future research on facilitating accessible and inclusive life story research with people with intellectual disabilities should explore this dilemma and consider diverse approaches to life story research.

Some participants with intellectual disabilities were not allowed access to information about their own lives to support their engagement in this study. Inclusion means information about the lives of people with intellectual disabilities should be theirs to access and share in ways of their choosing. The development of inclusive research enables more people with intellectual disabilities to participate in research, as well as it might facilitate research engagement becoming the expected norm and reduce instances of gatekeeping. Additionally, researchers should reflect in their reports on examples of gatekeeping so the field can explore effective solutions to reduce this barrier and better include people with intellectual disabilities in research. Researchers also need to grapple with limited access to and availability of information about participants' lives and discuss the implications of this reality when conducting life story research with people with intellectual disabilities.

The aim of this study was to develop and implement an adaptation of the Lifeline Interview Method by Assink and Schroots (2010). At this stage, participants were not explicitly asked about their experiences with creating their lifelines, and consequently, the interpretations of the process reported here are those of the nondisabled researcher. Future research should expand by evaluating how participants experienced the lifeline process and detailing their perspectives on the method's usefulness.

Additionally, further research should explore how to make all stages of life story research more inclusive and involve people with intellectual disabilities as facilitators and interviewers. This study's adaptation of the Lifeline Interview Method holds potential as an accessible tool not only for research participants but also for people with intellectual disabilities as co-researchers. Implementing this tool with research participants consists of a number of concrete steps, such as providing them with creative materials and engaging them in a process of including events and experiences and making additions to their lifelines. An accessible facilitator guide could support co-researchers with intellectual disabilities in leading this process.

This study's use of lifelines still relied on participants' verbal communication skills to some extent. We need to continue to explore visual methodologies that respond to a wide variety of skill levels, abilities, and interests of participants with intellectual disabilities. Finally, future research should also explore the use of lifelines as a visual tool to disseminate results and make the outcomes of life history research more accessible (Aspinall 2009; Manning 2010; McCormack 2020).

In exploring accessible life story methodology for research, we should not overlook the potential impact that exploring life stories can have in the everyday lives of people with intellectual disabilities. These stories are sometimes lost, especially when support is needed to retain and access memories (Gillman et al. 1997). Retrieving life stories can have a positive impact by facilitating reminiscence among people with intellectual disabilities as they grow older and by increasing understanding of their life experiences among those who support them. With more knowledge about the perspectives of people with intellectual disabilities, their needs can be better supported (Ledger et al. 2022).

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social sciences

Article

Structures of Oppression or Inclusion: What Systemic Factors Impact Inclusion in Disability and Rehabilitation Research?

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Abstract: This manuscript considers the drivers towards inclusive research in the field of disability and rehabilitation; including some of the tools and frameworks that may support its realisation. We, a group of researchers engaged in rehabilitation research from lived experience and 'conventional' (non-lived experience) positions, reflect on our collective endeavours to bring about inclusion in research and specify the systemic factors constraining inclusion in research. We conclude by asking the following: how might we reimagine systems where the mechanisms of research production are in the hands of those impacted by the research, and where are intersectionalities both sought and valued?

Keywords: inclusive; disability; rehabilitation; research

1. Introduction

In 2022, O'Brien asked the question, 'Is the road more or less well travelled?' The resulting Special Issue and published book explored the epistemological leadership of intellectual disability researchers and asked how inclusive research might be realised in different fields (O'Brien 2022). This work considers the drivers towards, and barriers to, inclusive research in the fields of disability and rehabilitation.

1.1. Positionality and Scope of This Paper

We are a group of researchers engaged in disability and rehabilitation research. We bring diverse perspectives to our research endeavours, including lived experience of disability (JB), occupational therapy (NL), physiotherapy (RM), and health psychology (NK). We share values of social justice and inclusion and a commitment to equity in access, experience, and outcome. In this paper, we ask how we might know what voices are included in our research and critically examine some tools proposed to support inclusion in disability and rehabilitation research, identifying what good might look like. In terms of scope, this paper is not intended as an exhaustive review of existing theory, evidence, and tools relevant to inclusion in disability and rehabilitation research. Rather, we relate our own research experiences which speak to the structural barriers and systemic factors that enable, or constrain, inclusion in research in our field in Australia and New Zealand. We would add a note of explanation on our focus on disability as a hallmark of inclusion, versus inclusion more broadly. Inclusion, or exclusion, is likely an intersectional experience, for example, for rainbow communities and different gender identities, migrant and ethnic communities, with many more factors contributing to the rich breadth of the human experience (Smith et al. 2024). In this paper, we refer to examples primarily relevant to inclusion in research for disabled[1] people to exemplify our points and as one example of a community who have been historically excluded, marginalised, and disadvantaged. We suggest many of the issues highlighted extend to other routinely excluded communities. Finally, we do not consider ourselves an authority on inclusion in research and recognise that the arguments we offer here are inherently partial, informed by our own perspectives and experiences. Notwithstanding these limitations, we hope the arguments and examples presented provoke critical discussion and reflexivity and contribute towards a culture of inclusive research in disability and rehabilitation.

1.2. What Is Meant by Disability and by Rehabilitation?

Our work as practitioners and researchers is, at times, within disability services structures, rehabilitation structures, or both. These contexts influence our practice, research, and efforts toward inclusion and so here we provide a brief background of each and how their epistemologies both intersect and depart. Disability, according to the *World Report on Disability* (World Health Organisation 2011), is ‘part of the human condition. Almost everyone will be temporarily or permanently impaired at some point in life, and those who survive [sic] to old age will experience increasing difficulties in functioning’ (p. 3). According to the World Health Organization International Classification of Functioning, Disability and Health, the experience of disability arises from the interaction of impairments, activity limitations, and participation restrictions (World Health Organization 2001). Rehabilitation is ‘a set of interventions designed to optimise functioning and reduce disability in individuals with health conditions in interaction with their environment’ (World Health Organisation 2017, p. 2). Global efforts to improve access to rehabilitation are underway (Heinemann et al. 2020) based on the premise that rehabilitation ‘may benefit any person with a long-lasting disability, arising from any cause, may do so at any stage of the illness, at any age, and may be delivered in any setting’ (Wade 2020, p. 571).

These definitions suggest that impairment and the resulting disability, operationalised as a decrement in functioning, can be addressed through the provision of rehabilitation. However, the disability academy describes tensions between this normalising discourse of rehabilitation and disability identities, providing a rich description of human engagements with difference. The biomedical approaches that have underpinned much of rehabilitation practice are critiqued as representing a limited lens on human functioning and wellbeing (Wade 2015). Failing to capture psychosocial and relational dimensions does not tell the whole story; see, for example, (Bright et al. 2023; Fisher and Goodley 2007). Rehabilitation has also (by and large) failed to consider the needs and aspirations of people over the whole of their lives. Rather than adopting a holistic approach that encompasses alterations in environments, personal factors, and resources over the lifespan, rehabilitation has predominantly been dispensed through isolated intervention episodes triggered by emergent or pivotal shifts in individuals’ health conditions (Palisano et al. 2017).

The systematic emergence of counter models (Brisenden 1986) and narratives (Shakespeare 2006) provide signposts regarding the imperatives of people living with disabling impacts or impairment. Shakespeare describes rehabilitation as ‘a controversial subject in disability studies, often discussed in terms of oppression, normalisation, and unwanted intrusion’ (Shakespeare et al. 2018, p. 61) but argues access to rehabilitation is a human rights issue of critical importance. Critical rehabilitation discourse is bridging this epistemic schism (Gibson 2016; Gibson et al. 2020). However, it remains an aspiration rather than routinely embedded in everyday practice (Gibson et al. 2020; Kayes and Papadimitriou 2023). Inclusive research, which values and legitimises the expertise of people with lived experience in knowledge production and dissemination, may be a critical step in realising these aspirations for person-centred and inclusive rehabilitation.

Epistemologies of resistance recognise that multiple voices are not heard within power structures within society, including the construction of knowledge through research (Barnes

1996; Fawcett and Hearn 2004). Implications of the partial representation of people with various lived experiences who have been typically underrepresented and undervalued are profound in terms of making decisions regarding agendas, priority setting, determining valued outcomes (Rist et al. 2008) and the representation of human diversity within society (Dirth and Branscombe 2017).

Rehabilitation services are commonly delivered through health systems, and some developments in health research are indeed positive. Research texts acknowledge biopsychosocial and critical alternative models of human functioning (Hathcoat et al. 2019). In health settings, ‘patient voices’ are built into structures through ‘patient mandates’ (Finset 2017; Te Tāhū Hauora Health Quality & Safety Commission 2022). In health research, lived experience expertise is frequently sought by funding bodies, and there is growing interest in research methods enabling research ‘with’ rather than ‘on’ participants (Kayes et al. 2019). The inclusion of people with various lived experiences is also promoted as one way to improve the translation of research knowledge into healthcare practice (Grindell et al. 2022) with networks such as the Cochrane Consumer Network (Cochrane Collaboration n.d.) focusing on knowledge translation for the users of health.

We suggest the initiatives described above provide many signals regarding ‘what good would look like’, yet responses resemble compliance rather than system transformation. Therefore, it is timely to examine research inclusion from our standpoints as disability and rehabilitation researchers and consider whether our field is making substantive progress towards ‘inclusion’ in research.

1.3. Intersectionality

A key metric for research is the production of research outputs, including reports and peer-reviewed artefacts. Therefore, one measure of representation, although rather blunt, might be the proportion of research authors identifying as experiencing disability. This question of the proportion of research authors identifying as experiencing disability immediately requires us to acknowledge the multiple dimensions of identity that people hold, the subjectivity and contested nature of identity, and the limiting binary of ‘disabled/non-disabled’ inherent in this question (Patston 2007; Smith et al. 2024). Given the history of marginalisation and exclusion experienced by people experiencing disability (Charlton 2000), it would hardly be surprising if some researchers choose not to articulate the dimension of disability experience (Brown 2020; Griffiths 2020). Authors experiencing disability may or may not identify as such and, where they do, may use inconsistent nomenclatures (what it is called) and locations (where it is written). The lack of common or agreed terminology is illustrated in Table 1 of phrases used within academic databases.

Table 1. Key phrases and words used within the literature.

Phrase
researchers with disability
disabled researchers
researchers with lived experience of disability
lived experience of disability
citizens with disability engaged in research
partnership with citizens with disability
lived experience led research
researchers with lived experience
co-researchers with disability

This situation calls for a critical examination of authorship, both to examine what identities are privileged and made to matter in peer-reviewed publication processes (implicitly or explicitly) and to mitigate the risks of disclosing one’s status as disabled. The development of reporting guidelines for research inclusion, for example, requiring that researchers include a positionality statement as standard, may be indicated.

An array of guidance relevant to inclusion in rehabilitation research can be found in allied fields and has the foundational concept of a hierarchy of participation in common. Since Arnstein's 1969 ladder of citizen participation (Arnstein 1969), hierarchies have been described for public participation (informing; consulting; involving; collaborating; and empowering) (IAP2 2018) for inclusion of people with disabilities in research (as participant, consultant, collaborator, colleague, or director of research) (Layton et al. 2022), and to guide culturally responsive ethical engagement (Hudson et al. 2010) (Table 2).

Table 2. Hierarchies of research inclusion.

International Association for Public Participation (IAP2) (IAP2 2018) Source: Social Sciences	**Ladder of Inclusive Research (Layton et al. 2022) Source: Disability**	**Te Ara Tika Framework (Hudson et al. 2010) Source: Māori ethics**
↑ • **Empowering:** the public is not only involved in all steps of the process, but the final decision sits with the public. • **Collaboration:** partner with consumers in all aspects of decision making, including engagement in the final decision. • **Involving:** work directly with the public throughout the process and ensure public perspectives are included. • **Consulting:** obtain public feedback, acknowledging concerns, but not necessarily incorporating this within decision making. • **Informing:** share information and support understanding of decision making.	• A **director of research**, in charge of research production: person commissions research and directs researchers in methods/research question/study design/outputs and dissemination. • **Research colleague:** person is an equal partner in establishing outcomes/findings/method/study design/research question. • **Research collaborator:** person collaborates about outcomes/findings/method/study design/research question. • **Research consultant:** person is consulted about outcomes/findings/method/study design/research question. • **Research subject:** person being researched is asked questions decided by others.	• **Best practice:** Kaupapa Māori Research addressing questions determined by Māori, for Māori; Māori lead and govern the research and lead research planning, development and execution; the research team and research participants are typically all Māori; Māori values underpin the research process, Māori research methods are used, and Māori knowledge is produced; data are owned by Māori and Māori determine how the findings will be used for the benefit of Māori; research meets expectations and quality standards set by Māori. • **Good practice:** Māori-Centred Research which aligns with Māori aspirations, and which is relevant to and addresses a question important to Māori; meaningful relationships are established with Māori communities and shape the research direction and process; Māori are typically senior members of research teams; research processes are informed by Māori cultural protocols; Māori-specific analyses are undertaken and produce Māori knowledge, albeit measured against mainstream standards for research. • **Minimum standard:** Research involving Māori which may or may not have direct relevance to Māori; Māori are involved as participants; researchers consult Māori and seek to protect the rights and interests of Māori; research processes are culturally sensitive; ethnicity data may be sought and analysed.

2. Analysis of Structural Barriers

Our collective experiences as researchers in disability and rehabilitation suggest that aspirations to enact inclusion are impeded by structural barriers (see also Williams et al. 2020). Figure 1 lists observed structural barriers to inclusive research. These are discussed in more detail below, alongside examples which demonstrate the opportunity for reimagining disability and rehabilitation research systems and creating the context for inclusive research practices.

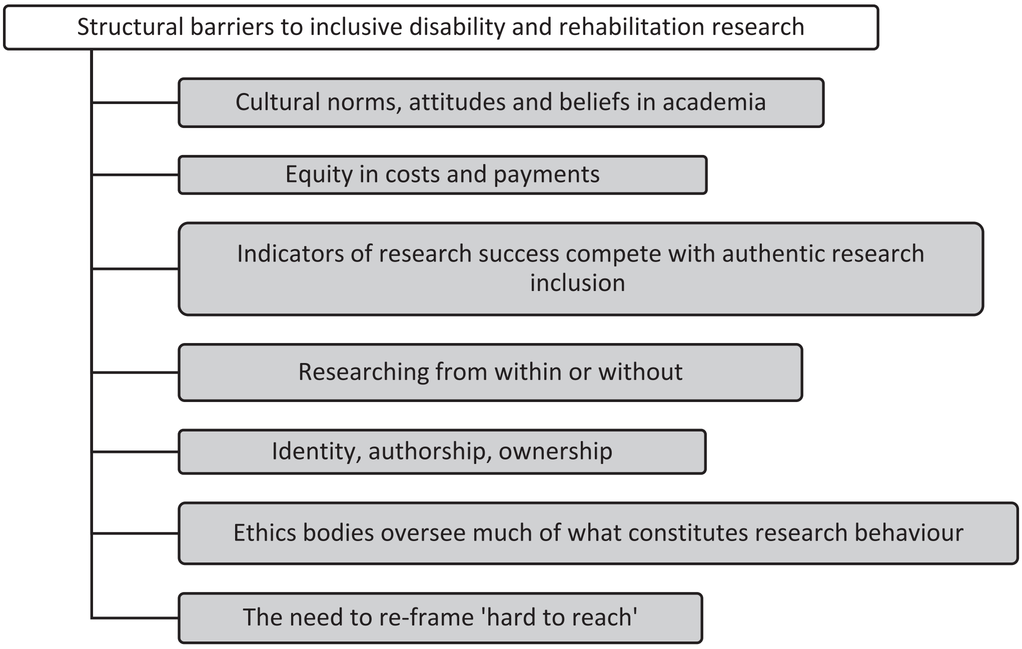

Figure 1. Structural barriers to inclusive rehabilitation research.

2.1. Cultural Norms, Attitudes, and Beliefs in Academia

Research is largely conducted with or by academic institutions. However, entry to academia is controlled through, for example, qualifications and subject to hidden curricula (Rossouw and Frick 2023). Institutional and collegiate norms and attitudes regarding, for example, academic workloads can bring about experiences of exclusion for academics experiencing disability. For example, the work of Brown et al. discusses challenges of interruptions, correct language, disclosure and emotional labour among academics living with fibromyalgia (Brown and Leigh 2020). Furthermore, the culture and institutional pressure in academia to complete work quickly is often contrary to slower participatory processes that typically require additional time and resources (Oliver et al. 2019). Conventional researchers who wish to conduct high-level participatory research can feel exhausted due to the often more labour-intensive work required of participatory research, which is often at odds with the 'do more with less' research environment (River et al. 2023). However, Williams et al. (2020) argues that the difficulty in conducting participatory research is not due to the process being inherently harder and more time intensive. Rather, it is more due to the academic context, which is incongruent with facilitating inclusive, participatory research (e.g., inflexible funding timelines, valuing of non-typical research outputs and metrics—see below).

In reimagined inclusive research structures, the mirror would be turned around to examine why the mainstream research structures fail to engage and accommodate a full diversity of humans, and what ought to change to enable their inclusion. If some populations do not engage with research, in what way is research seen as unattainable, unimportant, or irrelevant? What needs to change for research production to be attainable, relevant and a tool for epistemological justice? Promoting an academic culture that is more supportive of inclusive research could, for example, work to establish research metrics that support participatory research, acknowledge lived experience expertise in funding initiatives, and involve funding training initiatives that promote genuine partnerships (River et al. 2023). Intersectionality would be recognised as a feature of all researchers, and both sought and valued. It would be acknowledged as a dynamic concept and continuous reflexive steps undertaken to assure and uphold intersectional inclusion.

Williams et al. (2020) encourage a more structural analysis, questioning what research production processes and outcomes are seen as valuable within academia. For example, engaging in partnership-based research (e.g., co-production) is often thought of as a noble pursuit, but one that requires the investment of much funding, time, and effort with no guarantee of academic outcomes (Oliver et al. 2019). Williams et al. (2020) challenge such positions, arguing these barriers result from the status quo academic context and are concerning 'only if we accept that a narrowly defined output-focused culture is what academics should embrace' (p. 7). It is imperative that we reimagine the 'knowledge' paradigm within disability and rehabilitation research. What researchers (who currently hold the power in terms of funding acquisition and momentum, etc.) value as 'evidence' will influence the degree to which they are able and willing to engage in inclusionary actions.

As an example of work that is seeking to reimagine inclusion, we are working with developers to extend the functionality of an existing accessible survey tool (https://accessiblesurveys.com, accessed on 30 January 2023) as part of a research project developing tools to more meaningfully include disabled people's voices in policy (Martin et al. 2022). The tool was initially developed to collect quantitative data from disabled people; however, we have been collaborating to allow for the tool to also capture qualitative data. This has involved adding additional accessibility features (e.g., a voice memo function allowing participants to record their responses orally) and re-thinking how surveys can be used to support idea generation and diverse perspectives. Our key argument for developing this type of qualitative data collection tool is that in-person interviews or focus groups (which are currently the 'go-to' primary source of disabled person experiences) will always be limited in the range of perspectives they can gather due to pragmatic and cost considerations.

2.2. Equity in Costs and Payments

Living with disability incurs higher costs (Carers New Zealand 2010; Mitra et al. 2017). These costs may be visible and direct (such as attendant care costs, and the costs of disability accommodations such as assistive technology) or less visible (such as taking more time to complete tasks, which stretches paid time beyond 'usual' expectations of work speed). R.M. (author) has had the privilege of working closely with disabled colleagues from various organisations over the past decade:

> "However, there are challenging implications in supporting capacity building and genuine partnerships with other disabled researchers. There has been a frequent need for my disabled peers to work flexibly and take unplanned leave for health-related issues. This contributed to a more limited ability to increase their hours of work to meet work deadlines—and at times, this engendered stress for my disabled peers and placed additional demands on me. Processes and systems that allow for, and provide resources towards, this need for flexibility and increased capacity at high-demand times, would support long-term, sustainable partnerships for all."

Challenging such structural barriers and promoting higher levels of partnership and inclusion in rehabilitation research (which move beyond tokenism and consultation to involve genuine partnership or leadership of people with lived experience in research) can draw on examples such as the Raising the Bar model (River et al. 2023). The Raising the Bar model provides both lived experience and conventional researchers with the competencies and resources to undertake participatory research in egalitarian team structures. It has been successful in supporting lived experience and conventional researchers to successfully engage in high-level participatory research, helping to develop relational resilience in research teams, and establishing co-learning spaces that support lived experience researchers to challenge entrenched discourses and traditions of academia and negotiate new forms of non-traditional research outputs.

Ensuring full inclusion of disabled people in research frequently requires additional resource commitments. For example, as part of a realist evaluation of peer support for people with SCI, Burwood Academy Trust (2012) the lived-experience researcher who completed all the data collection and supported analysis required additional time to complete work, needed more researcher support for training, and had increased costs associated with travel and accommodation associated with using a wheelchair and requiring personal care support. However, his contribution to the process and outcomes of the research were pivotal to its success. In reimagined inclusive research structures, funded equity measures are an integral part of funding applications and are paid at benchmark rates. Building on health economic efforts to enable 'equal outcomes', the concept of equity weights can be useful in expressing just how many resources are required to enable all parties to achieve an outcome. Therefore, equity weightings could be calculated for disabled researchers to achieve equal outcomes (Ong et al. 2009).

The continual development of equity and learning in inclusive research can benefit from respectful dialogue and iteration (Langley et al. 2022b). Having open discussions surrounding team expectations, roles and the realistic capacity of team members, alongside potential mitigation strategies, is beneficial (Hoekstra et al. 2022). Such dialogue can occur when starting projects, be monitored throughout projects, and when projects are finished to see what worked, what did not, and what could be conducted differently next time. Such reciprocal, two-way conversations, allowing for sharing and reflecting on diverse perspectives, can challenge research practices, cultures and structures—including understandings of what knowledge is and how different forms of knowledge are valued (Farr et al. 2021).

2.3. Indicators of Research Success Compete with Authentic Research Inclusion

Research structures drive researcher behaviour. For example, university ranking systems such as the Times Higher Education World University Rankings and QS World University Rankings shape what is valued and legitimised in academic institutions. Similarly, research performance frameworks, such as the Research Evaluation Framework (United Kingdom) and Performance-based Research Framework (New Zealand), define academic success and filter through to institutional promotion practices. These structures value peer-reviewed publications, impact factors, journal rankings, citation rates, and hierarchy in authorship status. The 'publish or perish' imperative is alive and well in academia and sustains a particular way of working that can compete with authentic and meaningful research inclusion. Individual success often overrides collective endeavour within these systems, and the priorities and outcomes privileged within academia can sit in contrast to those of the communities we serve.

For example, a colleague used his sabbatical to immerse himself in a rural and remote region of Aotearoa New Zealand. During this time, he worked closely with a non-government health organisation on a collaborative piece of research led by the community, for the community. He shared the report produced through this work, reflecting to the authors of this paper:

> "Note my name is not on it, and it will not be in a peer-reviewed journal because it is their story and belongs to them. I have no doubt, though, that it will be used with great impact, and they have permitted me to disseminate it as I feel fit. This notion of supporting the agenda of others and fading into the background is indicative of the depth of the transformation that needs to occur." (McKenna, Brian. 16 June 2023)

This research has the potential to have an important and meaningful impact on the community. However, 'fading into the background' is likely to have a detrimental impact on this researcher, given this piece of work cannot be 'counted' in his research metrics. He has made a conscious and deliberate decision to push against these structures so that the community could lead the research and determine what form the findings take and how those findings are made to matter in their community.

2.4. Researching from 'within' or 'without'

Researchers within 'the system', that is, with recognised positions in research institutions, are afforded certain privileges which profoundly impact the capacity to 'do research'. For example, the cost of accessing academic databases is prohibitive without library access.

Free versions of reference management systems and analysis software may not exist, may be less powerful, or indeed not interact with other systems. Access to data storage and shared work areas is problematic without a university email address. Similarly, the cultural norms of academia can be implicitly exclusive for those participating without the system. Research funding systems can sometimes be paradoxical in their workings—on the one hand, requiring the involvement of consumers as co-investigators while at the same time expecting those consumers to conform to academic norms. For example, requiring them to submit an academic curriculum vitae where peer-reviewed outputs, not lived experience or community networks and engagement, characterise research track record and competency. It can also be the case that conventional researchers may be more securely employed and named on a research grant. This could lead to tensions for lived experience researchers who might be intermittently employed or reimbursed, unnamed on research grants, and may find it difficult to raise issues about the budget (River et al. 2023). This likely has the effect of communicating to consumers that they 'don't belong here'.

In reimagined systems, the boundaries between being 'within' or 'without' can be addressed in several ways. Associating research projects done in partnership with disabled people with a university means that they can also access the support they require (e.g., librarian expertise). To optimise collaboration, freely available alternatives such as Mendeley for referencing, and MIRO (an online interactive whiteboard to support qualitative data analysis) mean that all partners can access this without cost.

Reimagined systems would create the context for all to feel they belong, and that there is a place for them. As an example, when designing methods for a project developing tools to better include disabled people's voices in policy development (Martin et al. 2022) we focused on the attributes of engagement and participation we want to enable, rather than the impairments we might need to account for. As an illustration, when planning online interactive activities, we have brainstormed accessibility and inclusion requirements for optimising opportunities to build connections between participants, allow participants to connect ideas, and disagree or offer alternative solutions.

2.5. Identity, Authorship, Ownership

The wide array of terms for lived experience researchers has been canvassed above. Where an identity is established, it may not be present in the many existing author guidelines. For example, authors need an academic affiliation with a tertiary institution to publish in Australia's The Conversation. Therefore, authoring with a consumer necessitates a byline elsewhere, and authors are less privileged as a result (see, for example, Callaway et al. 2017). Closed academic systems also mean that even when the research production is inclusive, the findings end up within a gated community, so the communities that have helped to produce the research cannot access the research to ensure their community benefits. So inclusive research doesn't only require inclusion in knowledge production. It also requires communities to be self-determining in how that research is used. Guidance can be found in writings on indigenous data sovereignty (Prehn et al. 2023).

In reimagined systems, the fundamental principle is that anyone that the research is about has opportunities to engage within the research hierarchy. This expectation creates requirements for engagement (specified on a hierarchy and funded accordingly) and flips notions of identity, authorship and ownership such that there is an assumption people will be included, be authors, and be owners.

2.6. Ethics Bodies Oversee Much of What Constitutes Research Behaviour

Research ethics processes have an important role and function given they govern the standards of scientific research to protect the dignity, rights, and welfare of participants. However, it is important to recognise there are embedded assumptions in what constitutes ethical research, which can sometimes inadvertently result in exclusion. For example, ethical mandates which attribute vulnerability to populations can be paternalistic and limit choice and opportunity to participate in research. von Benzon and van Blerk (2017) argue that "vulnerability is context-dependent" and "relational" with the circumstances and ways of engaging and working with people having great influence. They argue that attributing vulnerability to individuals or groups can be problematic, particularly if the desire to protect them from harm removes their choice and opportunity.

Similarly, Eurocentric conceptualisations of what constitutes ethical behaviour can sit in contrast to what constitutes ethical behaviour from another worldview. Writing from the perspective of a Māori researcher, Linda Tuhiwai Smith (2006) reflects on 'researching within the margins' when the norms of research conduct have been established through other Western jurisdictions. She poses questions about some of the fundamental assumptions embedded in the assumed universality of some of our most basic ethical principles, such as respect, and artefacts, such as the consent form.

Our reimagined ethics bodies are informed by a 'bottom-up' or 'community-up' defining of ethical behaviours (Smith 2006). We provide some examples of ethical challenges and workarounds here. During one study (Layton et al. 2023), research participants requested to be named as 'owners' of the stories they were telling related to assistive technology use in their lives. An ethics revision was submitted to vary the standard clauses about non-identification and protecting potential re-identification. The ethics board queried the purpose of this change, stating, 'Don't they realise then people will know who they are?'. This query was felt to be highly patronising, by the research participants.

In another study, when seeking approval for an amendment to our data collection processes (to move from in-person to Zoom interviews during a COVID-19 lockdown), we were asked to provide 'justification for undertaking this part of the research during a time when everyone, in particular those with added vulnerabilities, are under considerable stress'. In our response, we noted that our research sought to engage people from the access community as experts. We argued that a key principle that guides our research is to 'make no assumptions'—including not assuming vulnerability as a starting point—and that we did not want to assume that people with access needs would not be able to contribute to this research at this time. Rather, we wanted people with access needs to have the opportunity to take part should they wish to, while proceeding with caution and ensuring the research process mitigated any perceived or real vulnerabilities. We noted that every situation is unique and specific to individuals and their families. We acknowledged that some people will be under stress, and their focus will rightly be on navigating their way through the lockdown period. However, others will be grateful for an opportunity to connect with the outside world and will be looking for opportunities to meaningfully and purposefully contribute to life beyond COVID-19. For the latter group, contributing to research where their opinions are sought and valued, could be a mechanism for achieving a sense of purpose.

In 2021, a group of leaders from non-government organisations supporting people with age-related neurological decline called for research that captured their experience of providing support to their communities during Aotearoa, New Zealand's COVID-19 response. We took up the challenge and worked with these community leaders to design the research to capture their experiences. The organisational leaders were keen to ensure their experiences were captured so they could inform decisions and policy making when facing similar situations in the future. When we sought ethics for this community-initiated, designed and led research, we were asked by the ethics body to give further reconsideration and justification of this research given that at least one group of potential participants has already been surveyed a number of times. This had the effect of immediately minimising and belittling the communities' endeavour to have a voice and felt entirely counter to an inclusive research approach.

2.7. The Need to Re-Frame 'Hard to Reach'

We frequently define underrepresented populations in our research processes as 'hard to reach' (Shaghaghi et al. 2011). However, in doing so, we attribute the problem to individuals, not the processes by which research typically seeks to reach those individuals (van der Ven et al. 2022). A comparative example in health care occurs when health literacy is situated as an individual determinant of health and a barrier to accessing care. Countering this, there has been a call for a focus on the development of health-literate organisations, putting the onus on health organisations to design for and respond to the needs of people with limited health literacy (Palumbo 2016; Palumbo and Annarumma 2018). We similarly argue here that we need to move away from the narrative of 'hard to reach' people to talk about 'hard to access' research. This makes it clear that the problem lies with us. Our failure to design accessible research inevitably means that our research fails to adequately account for many perspectives.

Accommodations, that is, reasonable adjustments to enable a diversity of people to engage, exist for a multiplicity of use cases and contexts. They may involve products and technology, the built and sensory environments, or indeed, ensuring that multiple formats are presented to accommodate visual, auditory, motor, and cognitive preferences. Accommodations may include more time (for preparation and processing) and multiple formats for materials (visual, plain language, accessible to screenreaders and switching software) and for meetings (virtual, accessible spaces, flexible to accommodate care partners, transport, and fatigue). Inclusion is unlikely to be fully realised without budgeting for such accommodations—and expertise in identifying supports and setting these parameters lies with the experts by experience whose inclusion is sought. Such changes to the culture of research strike at the heart of addressing systemic factors involved in the inclusion of disabled people in research and demonstrate how the 'bigger picture' of rehabilitation research can change towards a more egalitarian imperative (Williams et al. 2020).

Van der ven suggests 'Hard to reach' populations are not really hard to reach, they just require a different mindset and skillset from the researcher' (van der Ven et al. 2022, p. 193). We agree, and note the role of creative practices in co-production (Langley et al. 2022a), the development of research protocols to better include disabled people's knowledge in health policy development (Martin et al. 2022), and the synergy between health planning and design fields in developing novel approaches to accessible and inclusive design, see, for example, Good Health Design (n.d.).

3. A Way Forward

As we have illustrated, tensions and challenges continually arise in inclusive research endeavours, often related to structural research processes such as compliance with various funding and ethical and institutional systems. Strategies are needed to relocate the onus of inclusion from people to systems. In the above, we have stepped through the structural barriers we perceive and made some suggestions as to how systems might be reimagined to create the conditions for inclusive research. Further leadership can be found in the literature, and specifically in two relevant frameworks presented here. The Dignity Framework, developed in an extreme citizen science context, offers four principles (human rights, elimination of barriers, diversity, and transparency) alongside four processes (vision, uncover, discuss, change) to support inclusion (Chapman et al. 2022). In parallel work from the intellectual disability sector over the past decade, ten Disability Inclusive Research Principles have been developed and used to guide the inclusion of intellectual disability researchers (Disability Inclusive Research Collaboration 2012). The principles offer clear direction around ownership of knowledge and power in establishing the rules of engagement with research, diversity of methods for data capture and dissemination, and consent. The structural barriers discussed above can readily be linked with aspirational principles from these frameworks (see Table 3). Drawing on the Dignity Framework principles (Column 2 in Table 3 below) and Inclusive Research Principles (Column 3) to critically examine and shape the structures and processes that shape disability and rehabilitation research practice may provide some starting points for mitigating these structural barriers. Doing so creates opportunities to reimagine egalitarian systems, and to question the duty holders involved in the status quo.

Table 3. Mapping structural barriers to principles for inclusion.

Structural Barrier	Principles Which, If Enacted, Could Address Structural Barriers	
	Dignity Framework (Chapman et al. 2022)	**Disability Inclusive Research Principles (Disability Inclusive Research Collaboration 2012)**
Cultural norms, attitudes and beliefs in academia.	Principle 1: Grounding research in a human rights conceptualisation of disability.	● **Research that is informed by and/or led by people with disability**—the need for research, and its design must be identified and led by people with disability. ● **Ownership**—the research process, its design, management, implementation and findings must be owned by people with disability and their representative organisations.
Indicators of research success compete with authentic research Inclusion, Identity, authorship, and ownership.	Principle 2: Eliminating barriers to participation—intersectionality and authenticity.	● **"The right people asking the right questions and getting the right answers"**—inclusive disability research must be careful to ensure that research questions are relevant and important to people with disability (determined/informed by them), and that answers are sought from the correct sources using the best inclusive methods (identify "right people").
Researching from 'within' or 'without'. Ethics bodies oversight much of what constitutes research behaviour. Need to re-frame 'hard to reach'.	Principle 3: Diversity in engagement—accessibility and inclusion.	● **Inclusive and participatory**—the research process, and its methodologies, must ensure that people with disability, about whom and for whom the research is designed, play a central role as researchers and as research participants; and the voice of people with disability is validated as data. ● **Co-presenting**—people with disability must be provided with opportunities to present research findings. ● **Materials that are accessible**—information about the research process, research tools, and research reports must be provided in ways and in formats that are accessible. ● **A range of types of activities**—adjustment must be made to the design of research to render research appropriate to the participants and accommodate a variety of approaches (research design reflects the diversity of potential research participants). Good research design must emphasise the need for a variety of approaches to ensure that a diversity of views is researched. ● **Consent**—researchers must apply processes of ethics approval that ensure that people with disability are included in the research as willing and supportive participants.
Lack of equity in costs and payments.	Principle 4: Transparent ways of working.	● **Re-defining what research is**—inclusive disability research is part of the universal research endeavour, and as such must contribute to ongoing discussions about the role and form of research in general. ● **Research that transfers through to real life**—research by and with people with disability must provide tangible benefits to individuals and the constituency of people with disability, and work toward greater inclusion of people with disability in the community.

In applying these recommendations, we promote two cautions. First, we acknowledge the diversity of disability, capabilities, needs and preferences. We are mindful that it is not uncommon for strategies seeking to support access and inclusion to inadvertently marginalise some sub-groups. For example, when access initiatives prioritise physical impairment to the detriment of sensory impairment. We conceptualise access and inclusion in its broadest sense, i.e., as a physical, emotional, cognitive, and temporal experience. As such, we acknowledge the examples, recommendations and solutions proposed above are not a panacea—they are not going to be the right thing, for all people, in all circumstances, all the time. Rather, we suggest instead that the above is viewed as a menu of possibilities, but also that the most meaningful solutions will reside within the people with whom you are seeking to include. Second, an ongoing challenge to researchers and practitioners is to ensure the meaning and intent of principles are not lost during their operationalisation. It remains essential that all frameworks, principles, or ladders are utilised critically, reflexively, and with a mind to avoiding unintended consequences.

4. Conclusions

Structural barriers constrain many aspects of inclusive research. Signposts can be found from parallel disciplines, some of which are canvassed here and in other Special Issue papers. As global rehabilitation policy moves to a more encompassing position regarding all people with functional impairment at any point in their life cycles and health journeys, we suggest it is timely for rehabilitation systems to consider and adopt successful inclusive research practices and the epistemological positions which enable them to be imagined.

A reimagined system understands that research is too important to leave in the hands of conventional researchers alone. It values and recognises intersectionality, where people with diverse perspectives, in the spirit of appreciative inquiry, can locate themselves and their vantage points and limitations. This likely leads to the seeking of missing voices, and the formation of a research community, thereby bringing the mechanisms of research production within reach of those whom the research is about.

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Note

[1] We use the terms 'disabled' or 'people experiencing disability' as that has been the preference of people we have engaged with in our research to date and who have strongly identified with the social model of disability.

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social sciences

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Review

Self-Advocacy in Inclusive Research

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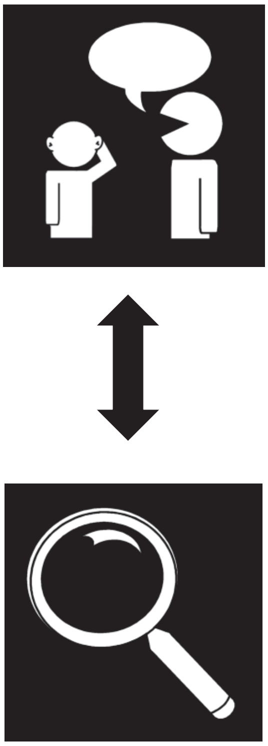
Abstract: The literature on inclusive research has established its relationship with self-advocacy for people with intellectual disabilities. Self-advocacy has been described as both a requirement and a result of inclusive research. Additionally, the process of becoming an inclusive researcher can be seen as self-advocacy for people with intellectual disabilities. As inclusive research continues to become more prominent, and more people with intellectual disabilities become inclusive researchers, we need to continue to consider this fundamental relationship and how self-advocacy and inclusive research can inform and support each other. In this paper, we first discuss the history of self-advocacy and inclusive research and what inclusive researchers have shared about the relationship between self-advocacy and inclusive research. We then present the experiences of an inclusive researcher with intellectual disability with self-advocacy and how the process of becoming an inclusive researcher impacted those experiences. We conclude the paper with reflections on how future inclusive research should consider the role of self-advocacy.

Keywords: inclusive research; self-advocacy; intellectual disabilities; history; plain language summaries; research with people with intellectual disabilities

Plain language summary:

• Self-advocacy is important for people with intellectual disabilities to do research.	
• People with intellectual disabilities can also become self-advocates because they do research.	

• This article is about how self-advocacy and inclusive research go together.	
• We talk about the experiences of a person with intellectual disability who is a self-advocate and an inclusive researcher.	

1. Introduction

1.1. About This Article

This article is about the relationship between self-advocacy and inclusive research. We discuss the history of self-advocacy by people with intellectual disabilities and inclusive research. Inclusive research aims to more effectively include people with intellectual disabilities in research, for example as research team members. We explore what inclusive researchers have written about the relationship between self-advocacy and inclusive research and present the experiences of an inclusive researcher with intellectual disability with self-advocacy.

1.2. About Us

Three authors wrote this article together. The first author [Courtney] identifies as a person with intellectual disability. She has been a self-advocate for 20 years, and a co-researcher for 5 years. The second author [Lieke] is a university researcher with over 10 years of experience conducting research with people with intellectual disabilities. Courtney and

Lieke have been doing inclusive research together for five years and have completed three research projects together. The third author [Claire] is a graduate student who has been working with the second author.

1.3. How We Wrote This Article

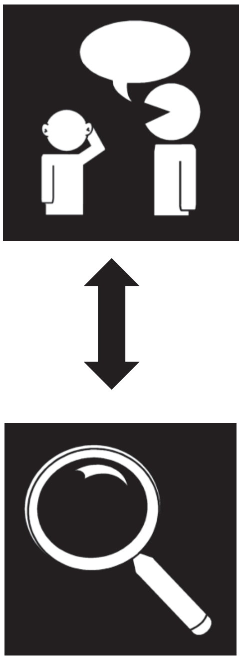
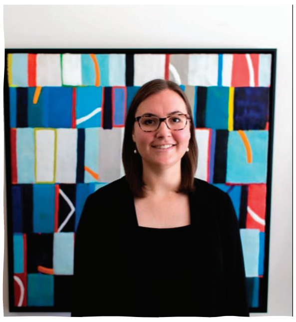
Lieke and Courtney discussed writing an article together for this special issue. Lieke proposed several topics to write about for this article. Courtney selected the topic of self-advocacy and inclusive research. We wanted to write about this topic as we believe it is important for people with intellectual disabilities to be strong self-advocates and that being a self-advocate is important for being an inclusive researcher. While others have touched on the link between self-advocacy and inclusive research (Atkinson 2002; Henderson and Bigby 2016; Hopkins et al. 2022; Walmsley and Johnson 2003; Walmsley 2014; Walmsley et al. 2018, 2022), these publications tend to do so only briefly and they do not provide much space for the perspective of a researcher with an intellectual disability. To contextualize the experiences of Courtney, we provide a discussion of the history of both self-advocacy and inclusive research. These histories are strongly connected, but they are rarely discussed together in detail. This is important, as critical reflection and analysis of the relationship between self-advocacy and inclusive research can help to inform the future development of inclusive research.

Courtney wrote down the first ideas of what we could discuss in the article, and Lieke added to these ideas and drafted the abstract for the article. Lieke wrote down a list of questions about Courtney's experiences with self-advocacy and inclusive research for Courtney to answer. Courtney wrote down answers to the questions. Lieke then helped to organize the answers into writing for the article and asked Courtney follow up questions about her experiences. Lieke and Courtney went back and forth several times until we had all the information we needed to include in the article. Lieke and Courtney decided to ask Claire to help to write the article. Claire helped to find literature about self-advocacy and inclusive research and helped to write the sections of the article in which we discuss this literature. Lieke and Courtney helped to finalize these sections. Together, we came up with ideas for the conclusion of the article and Lieke wrote that section. We decided to include plain language summaries with each section of the article. Lieke drafted them, and Courtney and Claire reviewed them. Lieke coordinated the timeline of finishing the article and submitting it.

The perspectives of researchers with intellectual disabilities are often absent from articles or only selectively presented (Strnadová and Walmsley 2018). We need to pay attention to power relationships in inclusive research teams and make sure that the voices of researchers with intellectual disabilities are heard in academia (Strnadová and Walmsley 2018; Tilley et al. 2020). In an earlier article we wrote together (van Heumen et al. 2024), Lieke and Courtney decided together that Lieke would lead the writing of the article and be the first author, as Lieke had more experience with writing, and this was the first writing project for Courtney and hence her first opportunity to learn about the writing stage of the research process. For the current article, we deemed it appropriate for Courtney to be listed as the first author as she took the lead on deciding the topic of the article and her writing about her experiences as a self-advocate and researcher added most significantly to the content of the article.

A large number of different terms are being used in the field to refer to individuals with and without disabilities who are involved in inclusive research, such as 'academic researcher', 'university researcher', 'inclusive researcher, 'co-researcher', etc. Sometimes these terms are used interchangeably (Ghaderi et al. 2023). In this article, we use the term 'inclusive researchers' to refer to all individuals involved in inclusive research. When needed, we make a distinction between researchers who identify as having an intellectual disability and those who do not.

1.4. Plain Language Summary

• This article is about how self-advocacy and inclusive research go together.	
• We wrote this article with three people. • Courtney is a self-advocate who does inclusive research, Lieke is an inclusive researcher from a university, and Claire is a graduate student.	 Courtney  Lieke  Claire

- In this article we say 'inclusive researcher' for each person who does inclusive research. - Inclusive researchers are people both with and without intellectual disabilities.	

2. The History of Self-Advocacy

2.1. A Background on Self-Advocacy

Self-advocacy is often defined as an act of speaking up about and defending one's needs and rights, while also being able to make choices based on those needs and rights. People First London's definition of self-advocacy is frequently cited in the literature. Their definition consists of the following elements (cited in Atkinson 2002):

- Speaking up for yourself;
- Standing up for your rights;
- Making choices;
- Being independent;
- Taking responsibility for yourself.

The U.S.-based Self-Advocacy Resource and Technical Assistance Center adds an element of community to the definition of self-advocacy (SARTAC 2023). This definition is in line with Bersani's argument that self-advocacy is a social movement that seeks out ideological change in the ways people with intellectual disabilities are thought of and treated (cited in Walmsley and Johnson 2003). Collective organizing happens through self-advocacy organizations such as 'People First London' in the UK, 'Self Advocates Becoming Empowered' (SABE) in the USA, and 'Reinforce' in Australia. According to SARTAC (2023), all people with intellectual disabilities can participate in self-advocacy, and doing so helps them to accomplish their goals. A key aspect of self-advocacy is that people with intellectual disabilities speak up for what they and those identifying with them need, and that allies support them but do not speak on their behalf (Nelis 2018). Self-advocacy is important to many people with intellectual disabilities (Henderson and Bigby 2016), and membership of self-advocacy groups has a positive impact on their lives. For example, Frawley and Bigby (2015) reported that members of a self-advocacy group in Australia gained a sense of belonging, social connections, and meaningful work opportunities through their involvement in self-advocacy. Others have reported that self-advocacy groups help to develop leadership skills and promote the claiming of a disability identity among people with intellectual disabilities (Atkinson 2002; Caldwell 2010; Tilley et al. 2020).

2.2. The History of Self-Advocacy

Though historical records tend to demonstrate that self-advocacy movements emerged in Western countries during the second half of the twentieth century, there is evidence that people with intellectual disabilities started advocating for their own needs and wellbeing much earlier in history. For example, people with intellectual disabilities frequently tried to escape (abscond) long-stay hospitals as an act of resistance in the UK during the first half of the twentieth century (O'Driscoll and Walmsley 2010). However, actions such as these have not always been interpreted and credited as self-advocacy (Buchanan and Walmsley 2006; Walmsley 2014). This credit is important, as it shows that people with disabilities have long persisted to change their circumstances (Nielsen 2012).

After World War II, the protection of universal human rights became a global concern. Civil rights movements gained worldwide traction in their struggle against the dehumanization of women, Black people, people of color, and indigenous people. Disability movements emerged alongside these civil rights movements and included groups that specifically promoted the rights of people with intellectual disabilities (Carey 2009; Nielsen 2012).

In the U.S. and countries such as the UK, Sweden, and Denmark, advocacy groups were originally spearheaded by parents and professionals. These groups, such as 'The Arc' in the U.S., called for educational opportunities for people with intellectual disabilities as well as deinstitutionalization (Nielsen 2012). Their advocacy was inspired by normalization theory which originated in Sweden in the 1970s. Normalization theory proposes that disabled people should live a life that resembles that of non-disabled people, live among non-disabled people, and be able to make their own choices (Wehmeyer et al. 2000).

Though advocacy of parents and professionals is important to support people with intellectual disabilities, they should not dominate conversations. In response, people with intellectual disabilities started to organize themselves into self-advocacy groups. The UK self-advocacy movements developed "in opposition to parents' organizations" (Buchanan and Walmsley 2006, p. 134). In contrast, the largest self-advocacy group in Denmark emerged from a parent- and professional-led organization that acknowledged the need for self-advocacy (Bylov 2006). In Australia, self-advocacy group 'Reinforce' developed from a camp organized by Middle Park Social Club, a drop-in center for people with intellectual disabilities (Henderson and Bigby 2016). Shoultz reports in 1991 that during the preparation of their first convention by a group of self-advocates in Oregon, in the U.S., in 1975, one member criticized the use of the slur 'retarded' and stated: "We are people first" (cited in Hayden and Nelis 2002). The U.S. self-advocacy movement was named 'People First' after this statement. The conferences organized by self-advocacy groups in the early stages of the movement were crucial for the development of international connections and the emergence of self-advocacy groups around the world. For example, after attending the International Self-Advocacy Conference of 1984 in the U.S., UK self-advocates started 'People First London' (Walmsley et al. 2022).

Self-advocacy groups around the world fight to improve the participation of people with intellectual disabilities within all parts of society. Self-advocacy groups have provided information and resources to empower individuals with intellectual disabilities and to support the development of their self-advocacy skills. The Illinois Self-Advocacy Alliance, for instance, provides documents with guidelines for organizing online meetings and asking questions during committee meetings (Illinois Self-Advocacy Alliance 2011). Self-advocacy groups have also engaged in political activism. For example, SABE, a nation-wide initiative of U.S. self-advocacy groups, launched their first campaign by and for people with intellectual disabilities against their institutionalization in 1994 (Friedman and Beckwith 2014). Similarly, the Australian self-advocacy group 'Reinforce' occupied buildings and held protests for policy changes in the 1980s (Henderson and Bigby 2016). Self-advocacy can also show up in smaller ways that do not challenge the power differences between people with and without intellectual disabilities (Aspis 2002). Aspis (2002) argues that self-advocacy can focus on small issues like getting a coffee machine or changing labels on buses. Efforts by people with intellectual disabilities and other disabled people have led to substantial changes to their rights both in the U.S. and worldwide. For example, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) recognizes the importance of advocacy organizations in overseeing the implementation of the UNCRPD and promotes the right to accessible research results (art. 4, art. 29, art. 31, United Nations 2006).

Self-advocacy groups have had to grapple with a tension between building confidence among members and recruiting new members, and their collective action and representation. Additionally, issues of importance to self-advocacy groups have included the role of supporters without intellectual disabilities such as family members and staff, the inclusion of people with high support needs, their level of independence from organizations that provide services to people with intellectual disabilities, and having sufficient funding available (Walmsley et al. 2022).

Though some literature has explored the life histories of self-advocates (e.g., Caldwell 2010; Goodley 2000; Traustadottir 2006) and the history of individual self-advocacy groups (e.g., Walmsley 2014; Frawley and Bigby 2015), a gap remains in the knowledge on the history of self-advocacy moments (Walmsley 2014; Walmsley et al. 2022). Most research on the history of self-advocacy focuses on developments in specific countries (Bylov 2006; Callus et al. 2022; Ferguson 2019; Henderson and Bigby 2016; Hutton et al. 2017; Walmsley 2014; Waltz et al. 2015), which does not necessarily provide insight into international self-advocacy movements. Additionally, a lack of research on the development of self-advocacy in non-Western countries might skew attempts to understand the history of international self-advocacy movements. Finally, more research on self-advocacy should be conducted by people with intellectual disabilities to capture their experiences and perspectives. Walmsley et al. (2022) argue that the general lack of research on self-advocacy might be caused by concerns about whether non-disabled people are allowed to write this history. However, researchers without intellectual disabilities can serve as important allies in supporting self-advocates in recording and accessing their own histories. Applying the principles of inclusive research to this dilemma (which are explored in detail below) holds promise.

2.3. Plain Language Summary

• Self-advocacy by people with intellectual disabilities is about five things: ○ Speaking up for yourself; ○ Standing up for your rights; ○ Making choices; ○ Being independent; ○ Taking responsibility for yourself. • Others do not speak for self-advocates with intellectual disabilities. Self-advocates speak for themselves.	 
• Self-advocacy is about making life better for people with intellectual disabilities.	

• People with intellectual disabilities advocate for themselves and with others. Self-advocates can be a member of a self-advocacy group. • Being a member of a self-advocacy group has helped people with intellectual disabilities.	 
• Advocacy started after the Second World War. First parents and professionals advocated for people with intellectual disabilities. • Then, people with intellectual disabilities started to advocate for themselves. • Self-advocacy groups from around the world learned from each other.	   

• Self-advocacy groups think about how others without disabilities can help them without taking over. • Self-advocacy groups need money.	 
• We need to know more about the history of self-advocacy. • Self-advocates should write about their own experiences. Non-disabled researchers can support them.	 

3. The History of Inclusive Research

With the rise of civil rights and disability movements, debates about the dehumanizing effects of traditional approaches to research became more prominent (Walmsley and Johnson 2003). Walmsley and Johnson (2003) situated the emergence of inclusive research within and alongside developments in knowledge production aimed at highlighting the voices of oppressed people in research such as the increased presence of qualitative research, feminist research, and participatory action research. Research that included people with intellectual disabilities significantly increased in the 1990s (Beail and Williams 2014). The shift from research 'on' to 'with' people with intellectual disabilities has been found to be instrumental in combating their social exclusion and fostering social change (Björnsdóttir and Svensdottir 2008; Johnson 2009).

In 2001, Walmsley proposed 'inclusive research' as an umbrella term for any research that actively includes people with intellectual disabilities (Walmsley 2001). In 2003, Walmsley and Johnson established a definition of inclusive research that became the foundation for the further development of this field (Walmsley and Johnson 2003). The 2003 definition was updated in 2018, and includes five criteria. Inclusive research advances social change and fosters the belonging and life quality of people with intellectual disabilities; grounds itself in their concerns and shapes the research process based on their experiences; seeks to acknowledge, promote, and share their contributions; results in information that supports them in their (self-)advocacy; and consists of researchers that support their cause (Strnadová and Walmsley 2018). These criteria have provided an important framework as inclusive researchers have explored the importance, possibilities, challenges, and limits of inclusive research.

Nind (2016) made important contributions to conceptualizing inclusive research as well. According to Nind, the first generation of inclusive research established the need for people with intellectual disabilities to conduct research and showed how research can be conducted inclusively. Nind (2016) argued that the second generation of inclusive research should focus more on evaluating the quality of inclusive research and produce knowledge about more than the research process itself. However, Walmsley et al. (2018) argued that the field should not move to a second generation too quickly. They stated that such a move to focus on outcomes might ignore the necessity of further research into what inclusive research should look like. They argued that a focus on the process of inclusive research is still valuable, especially as it illustrates the possibilities for acknowledging and sharing contributions made by people with intellectual disabilities (Walmsley et al. 2018). Inclusive researchers continue to raise questions about the process of inclusive research and call for critical discussions on how inclusion is practiced throughout the various stages of inclusive research to establish a clear framework of best practices. These discussions are complicated by the fact that most articles do not include reasons for why people with intellectual disabilities are excluded in certain stages of the research and lack reflection on how inclusion actually took place within the research (Ghaderi et al. 2023). Inclusive research teams should prioritize documenting how they work together (as we have included in the introduction), and discuss what challenges they encounter, so the field can develop this suggested framework of best practices.

Not all inclusive research projects have included people with intellectual disabilities at each stage of the research process. Bigby et al. (2014b) observed three main approaches used in the field. In the first approach, people with intellectual disabilities are consulted on the design, topic, or process of research without being involved in conducting the research. In the second approach, people with intellectual disabilities take the lead and are in full control of the research process. The third approach is collaborative in nature, and this approach values the different contributions and skills of researchers with and without intellectual disabilities equally. In this approach, tasks and responsibilities are distributed as evenly as possible to move away from hierarchies, and the shared interests and concerns of researchers with and without intellectual disabilities are emphasized. This collaboration creates new knowledge that neither group could provide alone (Bigby et al. 2014b). Inclusive researchers may utilize more than one approach at the same time or switch their approach over time. For example, García Iriarte et al. (2023) discussed how the approach of their inclusive research team moved from non-disabled researchers making all decisions to researchers with intellectual disabilities making decisions on the team's research topics, methods, and reports. As we discuss as well, the way our inclusive research team worked together also changed over time as both the researcher with and the researcher without intellectual disabilities gained more experience with inclusive research.

Inclusive researchers have observed a lack of research where people with intellectual disabilities are involved in all steps of the research process or where they are fully in control of the research (Ghaderi et al. 2023). However, some researchers have expressed that research collaborations can be rewarding and meaningful for inclusive researchers with and without intellectual disabilities even when research projects are not fully inclusive at all stages of the research process (Björnsdóttir and Svensdottir 2008).

The extent to which people with intellectual disabilities are included in research projects depends on the opportunities and constraints of the context in which the research is conducted, and the attitudes, experience levels, and resources of everyone involved in the project. It has been argued that any kind of research can be made inclusive to at least some extent (Björnsdóttir and Svensdottir 2008). An important complication discussed by Ghaderi et al. (2023) is that non-disabled researchers experience difficulties recruiting people with intellectual disabilities for their research teams. Non-disabled researchers usually already know their team members with intellectual disabilities or they recruit them through (self-)advocacy groups. In some instances, local authorities, disability rights groups, or service organizations play a role in recruitment. A lack of self-advocacy has been identified as an obstacle for recruiting researchers with intellectual disabilities, as is the case in Africa (Kahonde 2023).

Systemic barriers to the inclusion of people with intellectual disabilities in research have been explored by inclusive researchers as well. The issue of people with intellectual disabilities providing informed consent has caused debates among researchers and ethics review boards who can take on a protective role (McDonald and Kidney 2012). Fears that people with intellectual disabilities are unable to understand research or might become the subject of abuse has at times led to them being excluded from research (McDonald and Kidney 2012; Santinele Martino and Fudge Schormans 2018). The exclusion of people labeled with severe and profound intellectual disabilities is especially at risk (McDonald and Kidney 2012). There is clear agreement in the field that they are underrepresented in inclusive research (Ghaderi et al. 2023; Milner and Frawley 2019; de Haas et al. 2022). de Haas et al. (2022) argue that inclusive researchers should develop a deep understanding of people with severe and profound intellectual disabilities and embrace new possibilities for inclusive research rather than modifying currently accepted models of conducting inclusive research. Additionally, inclusive researchers should communicate effectively about the principles of inclusive research and advocate for the inclusion of people with intellectual disabilities in research to combat discriminatory attitudes and other barriers.

The field has acknowledged that inclusive research requires adequate training and support for researchers both with and without intellectual disabilities to develop skills and confidence (Bigby and Frawley 2010; Flood et al. 2013; Di Lorito et al. 2018; Mikulak et al. 2022). Inclusive research teams have developed various approaches to training to support the inclusive research process (Nind et al. 2016). O'Brien et al. (2022) argue that training in inclusive research practices should be more widely available and recommend training to be developed jointly by inclusive researchers with and without disabilities. Scholars in Africa have recently pointed out the need to take into account local contexts when developing training and to make sure that training is accessible and meets the needs of people with intellectual disabilities in specific regions (Kahonde 2023).

Finally, though inclusive research was started in the academy by non-disabled researchers, inclusive research is now conducted in non-academic settings as well with or without relationships with non-disabled researchers. This research has strong parallels with the work of advocacy groups (Crombie Angus and Angus 2022; Hopkins et al. 2022). The field of inclusive research should spend more time considering how to support such community-initiated and community-led inclusive research.

Plain Language Summary

• When advocacy started, people with intellectual disabilities started to be a part of doing research too.	

• Researchers wanted to hear the voices of people with intellectual disabilities.	
• 'Inclusive research' means that research includes people with intellectual disabilities as researchers.	
• Inclusive research wants to make the lives of people with intellectual disabilities better.	
• Inclusive research is about what matters to people with intellectual disabilities.	
• Inclusive research shows what people with intellectual disabilities can do.	
• Inclusive research helps people with intellectual disabilities to be self-advocates.	

• Everyone who does inclusive research cares about people with intellectual disabilities.	
• Inclusive researchers want to learn more about how to include people with intellectual disabilities in doing research. • Inclusive researchers with intellectual disabilities do not always work on all parts of the research. Sometimes, inclusive researchers with intellectual disabilities are not in control of all parts of the research.	 
• Inclusive researchers without disabilities go to self-advocacy groups to find people with intellectual disabilities to do research with them. • Sometimes, inclusive researchers without disabilities cannot find inclusive researchers with disabilities.	 

• Inclusive research should include people who have significant disabilities.	
• All inclusive researchers need more training about how to do research.	
• Inclusive researchers with and without disabilities should make training together.	
• Inclusive researchers should support inclusive research that starts in the community.	

4. The Relationship between Self-Advocacy and Inclusive Research

The histories of self-advocacy and inclusive research are intertwined. Both developed alongside each other during a time in history when the oppression of people in the margins of societies was criticized and the pursuit of social justice and equality became a central concern. Self-advocacy and inclusive research share the common goal of celebrating the voices and choices of people with intellectual disabilities (de Haas et al. 2022). The acknowledgement that research participation is a part of community participation provided an impetus for the development of new research methodologies and created opportunities for people with intellectual disabilities to hold valued social roles in research (Walmsley and Johnson 2003). Self-advocacy has enabled people with intellectual disabilities to speak up about their lives and experiences and has resulted in some self-advocates participating in research.

Self-advocacy and inclusive research are closely related (Hopkins et al. 2022). Both self-advocacy and inclusive research can empower people with intellectual disabilities (Atkinson 2002). The relationship between self-advocacy and inclusive research can be characterized as one where both are influenced by each other (Atkinson 2002). Self-advocacy does not necessarily lead to involvement in research among people with intellectual disabilities, nor does involvement in research lead to engaging in self-advocacy (Atkinson 2002). However, self-advocacy has played a crucial role in making inclusive research possible (Atkinson 2002; Bigby et al. 2014b; Bigby and Frawley 2010; Walmsley and Johnson 2003). Involvement in research relies on and can strengthen the self-advocacy skills of people with intellectual disabilities and, in turn, inclusive research can lead to better self-advocacy (Ghaderi et al. 2023; Johnson 2009). The Irish Clare Inclusive Research Group, a group consisting of self-advocates, said they 'dig deeper' in inclusive research compared to advocacy, but that they use their advocacy skills to speak up about issues they want to raise, and use their advocacy skills to promote the findings of their research and to campaign for change (Hopkins et al. 2022).

The deep connections of inclusive research with the self-advocacy movement have been impactful in the representation of issues that matter to people with intellectual disabilities. At the same time, it has been argued that too strong of an emphasis on the capacity and abilities of self-advocates in inclusive research may exclude people with severe and profound disabilities on the grounds of cognitive incompetence (Davy 2019). Inclusive researchers should continue to critically examine who has been included in research and who has not and push the field to new levels and forms of inclusion.

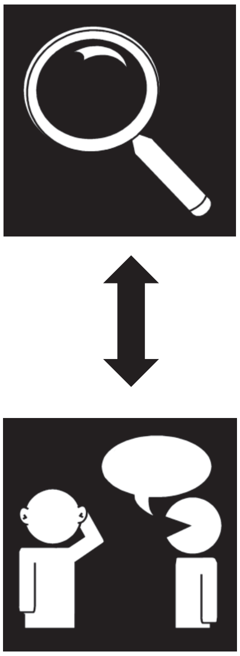
Self-advocacy groups equip people with intellectual disabilities to develop as researchers (Nind 2016). Additionally, people with intellectual disabilities are often recruited for inclusive research through self-advocacy groups (Johnson 2009). Nind's (2016) observation that the sustainability of self-advocacy groups is threatened due to a lack of funding therefore creates a concern for the future of inclusive research. Many inclusive researchers without disabilities already experience difficulty recruiting people with intellectual disabilities for their research teams (Ghaderi et al. 2023). We need to consider how systems and infrastructures hinder or foster self-advocacy and facilitate connections between researchers and self-advocates. Structures within universities, such as ethics review committees, have negated the autonomy of people with intellectual disabilities, making it hard for them to be included in research (McDonald and Kidney 2012; Santinele Martino and Fudge Schormans 2018). In the U.S., several government-funded programs aim to democratize research and policy by engaging with self-advocates. For example, the University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs) recruit self-advocates to serve on advisory committees (Association of University Centers on Disabilities n.d.), 60% of the members of State Developmental Disability (DD) councils are people with intellectual disabilities and their family members (Administration for Community Living 2023), and Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs include self-advocates as trainees (Association of University Centers on Disabilities n.d.).

Additionally, the link between self-advocacy and inclusive research needs to be made in the development of research training for people with intellectual disabilities. Most training models for people with intellectual disabilities focus on explaining what research is, discussing various research methods, and supporting people with intellectual disabilities to gain skills and confidence to engage in and conduct research; but they do not explicitly mention self-advocacy skills (Tuffrey-Wijne et al. 2020; van Heumen et al. 2024). However, it is important for inclusive researchers with intellectual disabilities to use their self-advocacy skills to shape their experiences in research, manage power differentials on inclusive research teams, and make an impact through their research.

Despite the important connections between the goals of self-advocacy and inclusive research and the similarities between the skills of self-advocates and inclusive researchers, there is not much inclusive research that explicitly addresses the relationship between self-advocacy and inclusive research, and at times the lines between the two are blurred. For example, inclusive research can lead into collective action where the line between research and self-advocacy is not always apparent (Johnson 2009). There is also no agreement on terminology. Where some inclusive researchers explicitly use the term 'self-advocates' to refer to people with intellectual disabilities engaging in research (e.g., García Iriarte et al. 2023; Garratt et al. 2022), other inclusive researchers discuss what people with intellectual disabilities can add to inclusive research without being explicit about self-advocacy. In both cases, it is not clear if there is a difference between ‘people with intellectual disabilities’ or ‘co-researchers’ and ‘self-advocates’ participating in inclusive research. Research does not always discuss the skills of co-researchers as self-advocacy skills either (Ghaderi et al. 2023). We argue that it is important to pay attention to the relationship between self-advocacy and inclusive research as we turn our gaze towards the future development of inclusive research and consider how best to cultivate and support the next generation of researchers with intellectual disabilities. In doing so, we need to learn from the experiences of inclusive researchers with intellectual disabilities such as Courtney’s below.

Plain Language Summary

• Self-advocacy and inclusive research started at the same time. • Self-advocacy and inclusive research have the same goal. They are about people with intellectual disabilities having a voice.	 
• Self-advocacy and inclusive research help to empower people with intellectual disabilities.	

• Not all self-advocates do research. Not all researchers are self-advocates. Self-advocacy did help to make inclusive research possible.	
• Inclusive researchers use their self-advocacy skills. When self-advocates do research, they also gain better self-advocacy skills.	
• Sometimes it is not so clear what the difference is between self-advocacy and inclusive research. Inclusive researchers should talk more about self-advocacy.	
• There should be more ways for self-advocates to join inclusive research.	

5. The Experiences of a Self-Advocate with Inclusive Research

In this section of the article, Courtney discusses her experiences as a self-advocate and inclusive researcher in the U.S. and explores what it means to hold both of these roles. In this section, Courtney uses a first-person narrative.

5.1. The Road to Become a Self-Advocate

Being a self-advocate means being included in decision making, finding your own voice, and using your own voice to be able to stand up for your own rights and needs as a person with intellectual disability. It is very important and powerful that we learn about self-advocacy as people with intellectual disabilities. The reason I wanted to write a paper about self-advocacy for people with intellectual disabilities is because I strongly think it is important for us to know how to self-advocate. I feel when we do not know how to advocate for ourselves or speak up for ourselves, people without disabilities will have low expectations of us and can take advantage of us. We need to learn and teach self-advocacy skills so we can have a successful meaningful life in anything that we do.

I have been a self-advocate for 20 years, since I went to college. Either you are born into having self-advocacy skills because you may be the type of person who does not hold anything back and "tells it like it is", or you learn along the way in life how to develop those skills. For some people with intellectual disabilities, it is not an easy task that will happen overnight or in just one day. It takes time and a lot of work and practice. When I was four years old, I had a clear understanding that I had an intellectual disability, and understood what that meant. I did not know what to do or how to handle myself. Life was hard for me when I was young and when I was in high school. Having a disability, I never understood what people would think and say when I would try to advocate for myself. My parents knew I had a disability and wanted to protect me; they did everything for me and advocated for me every step of the way. My dad said: "This is my last baby girl and I don't want anything to stand in her way so I'm going to advocate for her every step of the way in her life." When I had to talk to teachers, coaches, mentors, or parents, my parents did it all. I would always hide behind them because I felt scared and I was shy. I did not want to show my true identity. Once I went to college in 2003, my parents said: "You are going off to college, your parents are not going to be there to help you support your self-advocacy skills. You are going to have to learn to deal with this on your own. Come out of your comfort zone, come out of your shell and try to do it yourself." I advocated for myself for the first time when I was in college and taught myself how to do it. I was alone and people were not going to be by my side doing the work for me so I had to figure it out on my own. I am so glad I did, and I am proud of myself. I became stronger than I had ever been before and now have the courage to do anything I put my mind to. After I learned how to advocate for myself, I started using my new skills at work, in Special Olympics sports, and with friends and family. I am very blessed knowing how to stand up for myself now and to have a strong voice in speaking up for my rights as a person with intellectual disability. I do not let people speak for me and do the work of advocacy for me. I like to be able to handle or at least try to handle every situation on my own. I find my voice by representing myself and ensuring my rights as a person with an intellectual disability are upheld. If it is something I cannot handle on my own then of course I am going to let people help me and speak with me. I am not ashamed of letting people help me and I am not ashamed to ask for help. We all need help in life, even people without an intellectual disability.

At times I have to be persistent and assertive as a self-advocate to reach my goals. I wanted to prove to people at work that I was a person who was determined to do more in my career and move my way up to a higher position. When I eventually decided to talk to my supervisor about a position as an associate teacher, I had to sit myself down and plan out how I was going to approach them and self-advocate. I wanted people to know I was serious about this position and wanted to take full responsibility for it. My supervisor heard me but for a few years kept turning me down. It was not because I had an intellectual disability, it was because there were a few goals my supervisor wanted me to work towards first, such as being able to lead a toddler classroom. As the years went on and I achieved all my goals, I still never got the position. I was told there was someone else more qualified for the position than me. Eventually, my supervisor said that if the person who was hired would not stay the full school year, I could have the position on a trial basis. My supervisor said that we would see how it would work out and that we would evaluate how I did at the end of the year to see if I could handle the position for a full year going forward. I always kept pursuing the position with my supervisor, I never backed down, and I never gave up on my goals and dreams. I stood up for myself and what I believed was right. I believe my supervisor was absolutely right in their choice and decision because I have grown, reached many goals, and overcome many obstacles in my career as a teacher. It made me a stronger person, and I will do anything to achieve my goals in life. I am not going to back down on what I believe is right until I get the job done. I am a believer and a fighter. All people, no matter if they have an intellectual disability or not, should be treated equally and have the same rights, and everyone's voice and ideas should be heard. If you say a person who is disabled will never be able to achieve goals such as becoming a store manager or running a marathon, you are not treating every individual equally. If a person with a disability is qualified to be a manager and has trained hard to run a marathon, why not let them try and experience those things. If we fail it is okay, at least we were allowed to try something out of our comfort zone.

I use three steps in self-advocacy, inspired by an article written by Nancy Suzanne James (2014):

1. Knowing myself inside and out;
2. Knowing my needs;
3. Knowing how to get what I need in life.

For the first step, I feel that you need to know what type of person you truly are inside and out, before you can even think about advocating for yourself. You need to know yourself so you can be successful in your journey to become a self-advocate. You need to know if you are shy to assert yourself and need help to self-advocate, if you are outgoing and experienced and can self-advocate with no help at all, or if you need help with something like asking for time off but not with something else like getting help with a task at work. For the second step, it is important to believe in yourself as a unique and valuable person. It is also important to know your rights and to know that you are entitled to equality under the law. Then, you need to decide what you want and to clarify for yourself exactly what you need in your life. For the third step, you should reflect on your values and goals and work on your communication skills. You can start small with asking for what you need and work your way up to advocate for bigger issues that matter to you. Being a self-advocate makes you feel a sense of power and a sense of being in control of your own life and your own actions and words. I make choices based on my own values. I understand what matters most to me and why.

When I advocate for myself, I prepare. I have a plan and believe in myself, and prioritize my needs. First, I figure out what I am going to say. I make a list of things that may go well and things that may not go well. I think about how I can advocate for myself in a healthy way. I go in calm, cool, and collected. This helps to get my point across so that others listen and hear what I have to say. Nerves can get the best of us, so we need to recognize our worth. I feel that some people with disabilities who try to self-advocate will come out and say whatever is on their mind. Before we speak, we should know what we are going to talk about and advocate for. This way, what we say will mean something. It is a good idea to write down our ideas about how we will self-advocate rather than going up to a person without being prepared. If we do not have a strong message, others may not take the time to listen because they may not care about disabled adults or our issues may not be important to them. It can be sometimes very intimidating as a person with intellectual disability to go up to someone and talk to them about what we need or want in life. In my opinion, the world goes 50/50 on people with intellectual disabilities. Half of the world will listen to what we have to say and accommodate our needs and give us what we ask for. The other half of the world does not care to listen to us, or even if they do listen they will shut down our ideas and needs immediately. These people look past someone with intellectual disabilities, which I find cruel and wrong. People with intellectual disabilities are everyday people. Others may be very surprised at what we can say when we speak up for ourselves and what we bring to the table. I recommend to other self-advocates that before we speak up, we ask ourselves if the person we want to talk to is someone who cares about disabled people or if we may be wasting our time and energy with this person and this topic and we could be spending our time doing other things.

I have never advocated as part of a group of self-advocates. I think self-advocacy would be easier with a group, as each person gets to speak up to get the point across. The only time I advocate with another person is with my boyfriend Aaron. We are a couple and a team so we help each other with advocacy. Either we advocate together, I advocate for him, or he advocates for me. The Special Olympics programs I participated in did teach me how to support other people with disabilities to self-advocate. I am glad to support others, like people who do not speak.

5.2. Being a Self-Advocate and Inclusive Researcher

When I was asked by Lieke to be part of an inclusive research project, I did say yes right away to being a researcher, but I was a little skeptical about the project and the inclusive research process. When I first started as a researcher, I knew very little about inclusive research. I was not sure how it would eventually work out. Once I was able to test the waters and get a feel for what inclusive research is and what researchers actually do, I thought it was interesting and amazing. In the first project, we created accessible brochures and videos explaining the results of research using health screenings to Special Olympics athletes with intellectual disabilities. We asked a few athletes to read the brochures and to watch the videos. Then, we came back together as a group and asked them how they liked the brochures and videos and if they were easy for them to understand. The athletes gave us their feedback, and we went ahead to make those changes. For the second project, we recruited athletes to participate in an inclusive research training to learn all about what it means to be a co-researcher, like how to ask a research question, how to conduct research, and how to collect and analyze data.

Since the first day of working on our first project 5 years ago, I have been learning everything I need to know and my skills have grown and developed. I am proud of my work and the progress I have made. Lieke was able to help me, guide me, and give me the tools to be successful in my research career. I now know what research is, how to come up with a research question, how to answer that question by collecting and analyzing the data, and how to come up with a conclusion. I also now know how to conduct focus groups and interviews and how to give out surveys and review the survey results. I have learned how to talk to people with intellectual disabilities to get their input on the research and learn from all their ideas. Finally, I have learned how to write an article like this one about self-advocacy and how to be an author.

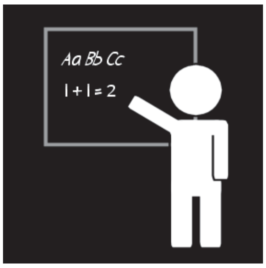
I use my self-advocacy skills in my work as a researcher. When I first started with inclusive research, I had to find my own voice and build my confidence and self-esteem to self-advocate in research. I needed to communicate clearly, so that others could help me and understand how to support me to be a researcher. Because of my disability, I need to read information to comprehend it. Telling me information in person is not enough. I explained this to Lieke, and now after each meeting I receive the notes about what we talked about. Also, Lieke will email me my tasks. Another example of me using my self-advocacy skills in research is me sharing my ideas for new research projects by email to Lieke. Whenever I have an idea, I always stand up for myself and explain my research questions. Lieke looks at my ideas and never turns them down. She always says what creative ideas I bring to the table, and at our meetings we talk about my ideas and we expand and elaborate on them and talk about how we can go about implementing them.

As an inclusive researcher, I tell my own story and share my personal stories and experiences with the world. Becoming an inclusive researcher has helped me to develop leadership skills. The role as a researcher made me step out of my comfort zone, as I started working as a researcher on a project that I knew nothing about at first. Ever since I started with inclusive research, I have grown and changed a lot. I have learned about so many research topics. Being an inclusive researcher has also boosted my confidence level in ways I never thought possible. I feel empowered as a person with intellectual disability, I have developed independence, and I have learned self-determination skills I did not have before. I also feel I have created a sense of ownership over learning that has increased my self-confidence. I am now more self-aware of my interests and desires and more motivated to share my ideas.

Becoming an inclusive researcher has changed my role as a self-advocate. I am not afraid to self-advocate, speak up, and tell people what is on my mind. I fight for whatever point I am trying to get across in a way that is healthy and respectful so that people will listen to me and take someone with an intellectual disability seriously. I realize that if I fail, I get right back up and never give up. I am always willing to keep on trying until I succeed and get the job done right. We have rights like anyone else, no matter what we look like or if we have a disability or not.

I have realized that inclusive research allows for people like me to be involved and included to share our personal experiences. I feel I am getting so many other people with intellectual disabilities interested and involved in something they do not know much about, just like I did not know much about research when I first started. I am letting other people with intellectual disabilities know exactly what inclusive research is, and I am supporting them to be more included in the research process. This way, they can tell others about inclusive research and tell their own personal stories and experiences. This is important because they are the people who truly have lived those life experiences.

5.3. Plain Language Summary

• Courtney became a self-advocate when she was in college. Courtney taught herself how to self-advocate. She learned how to stand up for herself as a person with intellectual disability.	
• At times, Courtney has to work hard to reach her goals.	

• Courtney uses three steps in self-advocacy: ○ Knowing herself inside and out; ○ Knowing her needs; ○ Knowing how to get what she needs in life.	
• Being a self-advocate makes Courtney feel a sense of power.	
• Self-advocates should prepare and have a plan so they know what they are going to talk about.	
• Courtney has not been part of a self-advocacy group, but she does advocate together with her boyfriend.	
• When Courtney started doing research, she learned a lot about how to conduct research. Lieke helped Courtney in her research career.	

- Courtney uses her self-advocacy skills in her work as a researcher. Courtney has talked clearly about what support she needs to be a researcher. Courtney’s self-advocacy skills have also helped her bring her ideas to the research.	
- Courtney feels more confident because of doing inclusive research.	
- Becoming an inclusive researcher has made Courtney a stronger self-advocate.	
- Courtney tells other people with intellectual disabilities about inclusive research and supports them to be more included.	
- Inclusive research can help people with intellectual disabilities to share their experiences. Others should not do this for them.	

6. Reflecting on the Experiences of a Self-Advocate with Inclusive Research

Courtney’s experiences illustrate the important relationship between self-advocacy and inclusive research. Courtney discussed how she developed self-advocacy skills as a person with intellectual disability. For most of her life, Courtney engaged in self-advocacy as an individual and not as part of a self-advocacy group. The literature often emphasizes self-advocacy groups as a place to train and recruit self-advocates for inclusive research

(Johnson 2009; Ghaderi et al. 2023). However, Courtney's experiences show how important it is to support people with intellectual disabilities in their individual self-advocacy as well, even when they are not a member of a self-advocacy group.

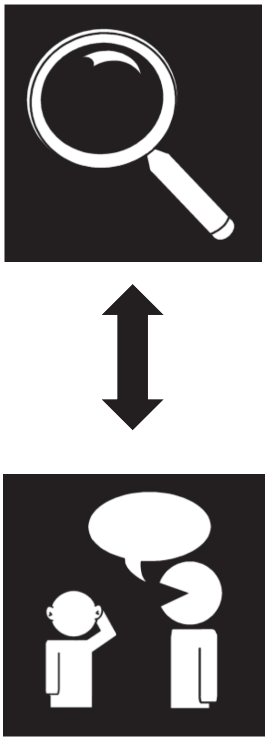
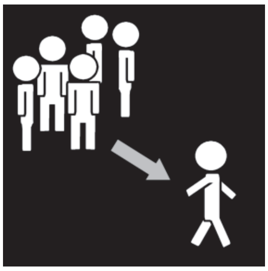
Courtney talked about how her self-advocacy skills helped her as she learned about inclusive research and started to participate in an inclusive research team. Courtney also shared her ideas about what the research should address. Finally, she used her self-advocacy skills to discuss her access needs which helped her to participate in the research. Highlighting what inclusive researchers with intellectual disabilities perceive as facilitators and barriers to getting their access needs met is an important issue in the inclusive research literature (Embregts et al. 2018; Schwartz et al. 2019).

Courtney's engagement in inclusive research has allowed her to connect with other people with intellectual disabilities on issues that matter to them, to tell them about inclusive research, and to share her experiences through the dissemination of the research. Though Courtney has been an individual self-advocate for most of her life, these are all activities that foster collective self-advocacy. Making a distinction between individual and collective self-advocacy in inclusive research helps us to consider how inclusive researchers with intellectual disabilities could assist others with intellectual disabilities in using self-advocacy skills while conducting inclusive research and the importance of building relationships with other inclusive research teams, especially when an inclusive researcher with intellectual disability is the only disabled researcher on the team. Courtney was in this position and did not know other inclusive researchers with intellectual disabilities, so she had to figure out how to use her self-advocacy skills in the research independently. When inclusive researchers with intellectual disabilities work with other researchers with intellectual disabilities or as part of a self-advocacy group (e.g., O'Brien et al. 2022; Flood et al. 2013; García Iriarte et al. 2023; Hopkins et al. 2022), their experiences may be different.

Courtney discussed how participating in inclusive research empowered her, developed her leadership skills, and increased her confidence to speak up and share her experiences and ideas, which in turn spurred on her growth as a self-advocate. Courtney's experiences are very much in line with what the literature on inclusive research has suggested: self-advocacy skills are important for people with intellectual disabilities when they engage in inclusive research, and the process of inclusive research can empower them (O'Brien et al. 2022). Courtney's experiences show that it is worthwhile to explicitly label and nurture self-advocacy skills in inclusive research, as they help to facilitate the process of inclusive research in addition to and beyond the development of research skills. Acknowledging Courtney's self-advocacy skills also demonstrates how self-advocates bring their own skills to inclusive research, skills that they have acquired before receiving research training. Labeling self-advocacy skills also allows the field of inclusive research to recognize its interdependent relationship with self-advocacy and the way the histories and goals of inclusive research and self-advocacy are intertwined.

Lieke also wants to add to Courtney's reflections that when Courtney shared her thoughts and needs, it also helped to improve the inclusive research. Not only did Courtney learn from Lieke, Lieke learned a lot from collaborating with Courtney as well. Our experiences are in line with the collaborative approach of inclusive research (Bigby et al. 2014a), and as described by García Iriarte et al. (2023) as well; as we got to know each other and both learned about inclusive research, Courtney became involved in more aspects of the research.

Plain Language Summary

• Courtney says that inclusive research and self-advocacy go together.	
• Not all inclusive researchers with intellectual disabilities are part of a self-advocacy group.	
• Because she is an inclusive researcher, Courtney advocates for herself and helps others with intellectual disabilities. • Other inclusive researchers have said the same things as Courtney. Self-advocacy skills help inclusive researchers with intellectual disabilities. Doing inclusive research can help people with intellectual disabilities to become stronger self-advocates.	 

- We need to support using self-advocacy skills in inclusive research.	

7. Conclusions

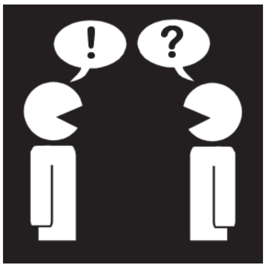
Supporting people with intellectual disabilities in their (self-)advocacy is an important part of the definition of what inclusive research is (Walmsley et al. 2018). Inclusive research should be conducted and disseminated with awareness and intentions that promote the goals of self-advocates and self-advocacy movements. This includes an appreciation of its possibilities for collective action (Johnson 2009). Inclusive researchers should have more knowledge about the history of self-advocacy to be able to support it. The gap in the knowledge about the history of self-advocacy movements can be filled by inclusive research projects that center the experiences of self-advocates with intellectual disabilities as they share their own histories. Disseminating inclusive research to promote self-advocacy includes making the outcomes of inclusive research projects accessible (McCormack 2020). Inclusive researchers can explore the most effective formats and procedures for the accessible dissemination of research in collaboration with the disability community (Hopkins et al. 2022).

Inclusive researchers should also continue to consider the important role of self-advocacy as a requirement, a tool, and a product of inclusive research. This includes highlighting why self-advocacy skills are important for inclusive researchers with intellectual disabilities, explicitly labeling the skills of inclusive researchers with intellectual disabilities as self-advocacy skills, and supporting the development of individual and collective self-advocacy among researchers with intellectual disabilities throughout the inclusive research process. Additionally, it includes ensuring that the outcomes of inclusive research promote self-advocacy.

Inclusive researchers should discuss their experiences with self-advocacy in inclusive research in more detail and explicitly address the important relationship between self-advocacy and inclusive research. Moreover, inclusive researchers should look for ways to build connections between self-advocates and researchers to foster more engagement between these communities to increase the relevance and impact of inclusive research. For example, this may increase the reach of inclusive research to more people (O'Brien et al. 2022). Finally, the field should continue to critically examine the possibilities and challenges within research infrastructures, such as barriers to including and hiring researchers with intellectual disabilities (O'Brien et al. 2022).

Supporting self-advocacy among people with intellectual disabilities may hold potential for inclusive research in several ways. It can promote more community driven 'bottom up' inclusive research that is initiated by people with intellectual disabilities themselves. Additionally, it can serve to strengthen the pipeline of future inclusive researchers with intellectual disabilities. Finally, it can strengthen the relevance of inclusive research, as self-advocacy cannot only support people with intellectual disabilities to participate in research but also influence how the research is conducted and what it addresses.

Plain Language Summary

• Inclusive research should support self-advocacy.	 ⬇ 
• Inclusive researchers should talk about self-advocacy. • Self-advocacy can help to make research better.	 

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Article

From Inclusive Research to Inclusive Evaluation: Empowering People with Intellectual Disabilities to Shape the Services They Use †

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† Following the UN Convention on the Rights of Persons with Disabilities we will use this terminology throughout this article. It covers other terms such as learning disabilities or intellectually disabled.

Abstract

This article explores how people with intellectual disabilities can be more involved in evaluating and regulating the services they use and the quality of their lives. Traditionally, these evaluations have been performed by professionals, but we argue that people with lived experience of intellectual disabilities bring unique insights and should be part of the process. The idea builds on 'inclusive research', where people with intellectual disabilities are not just subjects of research but active researchers. We use the term 'inclusive evaluation', to describe the active engagement of people with intellectual disabilities in inspecting and assessing services to ensure they meet standards and respect human rights. The paper describes a small exploratory study involving interviews with regulators, professionals, and people with intellectual disabilities across Ireland, Northern Ireland, Australia, and New Zealand who had been involved in inclusive evaluations. It found strong support for it, highlighting benefits such as greater trust and empathy during evaluations with users of services, more meaningful feedback for service providers, and increased confidence and employment opportunities for evaluators with disabilities. However, challenges remain, including funding and fair pay for the engagement of people with intellectual disabilities, training opportunities that meet the support needs of all stakeholders, and changing the cultural attitudes in support services that underestimate the abilities of people with intellectual disabilities. Steps to overcome these challenges are proposed such as piloting inclusive evaluation programmes, providing inclusive evaluation training to all involved, and lobbying governments to fund these roles. We conclude with a proposed implementation framework and a set of guiding principles that will nurture a spirit of inclusion and respect in service evaluations.

Keywords: inclusive research; intellectual disability; learning disability; inclusive evaluation; lived experience; training; attitude change; co-design; service assessment; policy change; cultural awareness; regulation; standards

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1. Introduction: Our Journey from There (Inclusive Research) to Here (Inclusive Evaluation)

1.1. Inclusive Research

The term inclusive research was introduced by Walmsley and Johnson (2003) building on the paradigms of both participatory and emancipatory research (Zarb 1992; Barnes and Mercer 1997; Stone and Priestly 1996; Oliver 1996, 1997, 1999) where people with disabilities were no longer 'being researched' but 'doing the research'. However, people with intellectual disabilities were largely ignored by these paradigms. As a result, Walmsley and Johnson's five principles of inclusive research had, at their core, people with intellectual disabilities having ownership over what was researched, and how it was researched, in keeping with the motto of the disability movement of "Nothing About Us Without Us" (Charlton 2000).

The development of inclusive research over the last twenty years has been well captured in various scoping reviews (Di Lorito et al. 2018; Jones et al. 2020; Hewitt et al. 2023), alongside outlining the added value it has brought to projects, albeit with some unresolved challenges. In her commentary on the review by Jones, O'Brien (2020) identified that inclusive research had been conducted in areas covering "community and independent living, employment, education, health, and wellbeing" (p. 121). Similarly, a range of methodologies was documented "covering traditional activities, such as, focus groups, interviews, member checking, and reflection, combined with more accessible ones of photo voice, role play, poetry, drama, storytelling, reflection, facilitated discussion, conversational interviewing" (p. 121).

Furthermore, the impact of inclusive research has gone beyond reports and academic publications. Research teams have been invited to present on inclusive research at national and international conferences and have been requested by governments to join steering groups to develop or change legislation that relates to intellectual disability (Hopkins et al. 2022) as well as being funded to co-produce and disseminate research outcomes (Puyaltó et al. 2022; Rojas-Pernia and Haya-Salmón 2022). In effect, being an inclusive researcher is intertwined with being an advocate and spokesperson (Hopkins et al. 2022). Consequently, there is now much greater awareness of the need to co-design policy and practice with people with intellectual disabilities who work as partners "in a wide range of circumstances such as planning an event, constructing or renovating a building or facility, developing or reviewing a policy or program, along with conducting research or delivering services" (JFA Purple Orange 2021, p. 6).

1.2. Advocates for Change

Fifteen years on from introducing inclusive research, Walmsley et al. (2018) reframed it as contributing to social change that was based on the lived experiences of people with intellectual disabilities. Moreover, research teams need to stand alongside the persons whose issues are being reported both within and after the completion of the projects. Hence academic researchers have to stand with advocates and agents for change.

Article 4(3) General Obligations of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) places emphasis upon involving people with disabilities in all decision-making associated with their lives and, by extension, those for whom they advocate (United Nations 2006). The co-design of support services presents opportunities for the involvement of people with intellectual disabilities in decision-making. For example, through the National Disability Insurance Scheme (NDIS) in Australia (National Disability Insurance Scheme n.d.), the government has committed to co-design, consultation, and engagement of people with disabilities across a range of NDIS activities, such as understanding the scheme and how it works, making plans for how they want to live their lives,

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making decisions on support, recruiting the right staff, and making a home in the right place with the right people.

Also the NDIS Quality and Safeguards Commission (NDIS Quality and Safeguards Commission n.d.) has responsibilities for monitoring the NDIS funding scheme for over 700,000 people with disabilities to ensure that their needs and aspirations are being met. Effective monitoring of service provision means researching information, and so the question arises: how can trained inclusive researchers bring added value not just to co-designing services but also to their evaluation?

1.3. Service Failures

The lived experience of many people with intellectual disabilities includes contact with various support services, of which residential care has been the most significant in terms of its cost and impact on people's lives. Sadly though, these settings—particularly where people are congregated together—have often heightened their risk to various inequitable and sometimes abusive situations (Codina et al. 2024). In Australia, New Zealand, UK, and Ireland, public enquiries have investigated serious shortcomings in residential services, especially the physical abuse of residents by nursing and care staff. Their reports make disturbing reading: in Australia (Disability Royal Commission 2023); in England (Winterborne View Hospital Review, Department of Health (UK) (2013)); in Northern Ireland (Muckamore Abbey Hospital Inquiry 2025); in the Republic of Ireland, (*What Matters Most Report*, Health Service Executive Ireland n.d.); and in New Zealand (*Whanaketia*, Royal Commission of Inquiry into Abuse in Care 2024).

As in other countries worldwide, these inquiries have often been triggered by media reports allied to whistleblowing by staff and the advocacy of family carers. By contrast, the reports cited above document the failure of the statutory regulatory inspection bodies and internal/external quality evaluation groups to initially identify even long-standing abusive practices. Why this failure? Could it be that inspectors and professionals do not spend enough time observing and listening to service users in their everyday settings? Equally could it be a lack of insider knowledge and hence not knowing the signs to look for (Fraser-Barbour et al. 2025)?

By contrast, inclusive researchers with the lived experience of intellectual disabilities, who are also often recipients of services, could be mobilised to draw upon their own personal experience and 'insider knowledge' to detect ongoing abuse of residents that outsiders do not see, notably low-level and well-disguised abusive practices. This is surely a primary reason for their inclusion in the monitoring and evaluation of services and better still if they have the experience in undertaking research. As Araten-Bergman and Bigby (2023) have argued, their deployment can form part of a safeguarding and prevention strategy in service settings.

For this paper, the involvement of people with intellectual disabilities as evaluators will be referred to as 'inclusive evaluation' to distinguish it from inclusive research. Similarly, government regulatory and inspection activities that include people with the lived experience of intellectual disabilities as regulators could be referred to as 'inclusive regulation and inspections'. For brevity though, we will subsume this term within inclusive evaluation.

1.4. Inclusive Evaluation

A combination of human rights, quality of life, and public and patient involvement frameworks provides a new paradigm for service planning, design, delivery, and, crucially, evaluation (Gómez et al. 2021). Inclusive evaluation finds a strong foundation in the UNCRPD, which states that people with disabilities "should have the opportunity to be

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actively involved in decision-making processes about policies and programmes, including those directly concerning them" (Article 12, United Nations 2006). Moreover, it places obligations on members to overcome discrimination towards people with disabilities (Article 4) and to support the right to work and to gain meaningful employment (Article 27), which authors 3 and 4 personally endorsed. Article 33 also outlines the requirement on member states to monitor their obligation to progress all 50 articles of the CRPD. These articles gave us a further rationale for involving people with intellectual disabilities in evaluation teams.

Furthermore, modern service supports increasingly use quality of life as a personalised framework for their assessment of needs and identifying the aspirations of individuals (Lombardi et al. 2019). This is coupled with an increasing uptake of 'Public and Patient Involvement' approaches to co-designing and monitoring health and social care services (Ocloo et al. 2021). Public and patient involvement has received increased attention in governmental policies within the United Kingdom, for example, albeit its implementation has been variable (Stuttaford et al. 2017).

Nevertheless, persons with intellectual disabilities are often excluded in these initiatives and instead represented by other advocates—family carers or paid support staff—if at all. Yet, as noted above, researchers with intellectual disabilities, when teamed up with university researchers, are effective in advising, interviewing, and listening to participants, facilitating their involvement in the co-designing of service policies and practice (Garratt et al. 2022; Ghaderi et al. 2023).

Inspired by the growing acceptance of inclusive research in academia, policy, and service provision, this paper examines the potential for researchers with the lived experience of intellectual disabilities to move outside of the partnership with academia and to become engaged as evaluators in service inspections and evaluations. Given the scarcity of published material on this topic, we embarked on an exploratory investigation to discover the perspectives of various stakeholders on the inclusion of people with intellectual disabilities as team members in both service evaluation and regulatory activities. These included people with intellectual disabilities, service managers, support staff, and officials from regulatory and inspection authorities. As our team spanned three different jurisdictions, we were keen to know if the same issues arose across them irrespective of their differing service histories and funding arrangements. Moreover, we had personal contacts with stakeholders in each who had experience of undertaking inclusive evaluations of services.

1.5. Aims of the Study

The aims of our descriptive study were:

- To identify where and how persons with the lived experience of intellectual disabilities were involved in inclusive evaluation activities.
- To discover, from various perspectives, the advantages and the challenges of taking an inclusive evaluation approach.
- To explore the prospects of inclusive evaluation activities being undertaken within service and regulatory organisations.

2. Method: The Stages in the Journey

2.1. Planning

The authors of this article first came together in 2023 via zoom from Australia, Northern Ireland (UK), and the Republic of Ireland, to discuss if we would like to work on a project that expanded our interest in inclusive research to inclusive evaluation and regulation activities. We are a group of three university researchers (traditionally employed by our respective universities) and two researchers who identify as having lived experi-

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ence. All five of us have had experience and membership of different inclusive research networks. We had previously collaborated on an article published in the *Social Sciences* first Special Issue on inclusive research (https://doi.org/10.3390/socsci11100483 (accessed on 26 September 2025)). For this current article we agreed to write up the lessons learned by collaborating on what we called the inclusive evaluation project.

Initially as a team, our discussions were guided by a set of accessible slides where the following questions were covered: Are there articles we should read before we start? Who should be interviewed and by whom? How will we go about discussing what people tell us? How will we write up what people say?

Authors 1, 2, 3, and 4 also met face-to-face in Sydney before the interviewing began and after ethics applications drafted by authors 1 and 5 had been approved in 2024 by University of Sydney Human Ethics Committee, 2024/037, approved on 30 January 2024 and Trinity College Dublin Ethics Committee, 1130, Approved on 2 April 2024.

2.2. Checking the Literature

Preliminary scanning by the first author in 2023, at the outset of the project, indicated that a formal review of the literature on inclusive service evaluation activities would not be fruitful. We used Scopus, Web of Science, and Google Scholar for the peer-reviewed literature. We applied a range of descriptors that focused on people with intellectual disabilities being included as evaluators/regulators in service settings, including search terms such as "people with disability and human services; people with intellectual disabilities and service evaluators; people with disabilities and evaluation and human services; evaluation of services for people with intellectual disabilities and consumers as evaluators; adults with intellectual disabilities and service evaluation teams and human services."

Three articles of interest emerged, with one describing a system in New Zealand where consumers of services, including people with intellectual disabilities, had been trained by the Standards and Monitoring Services (SAMS) (n.d.), a non-governmental agency to join integrated evaluation teams (Capie and Ahrens 1996). Using a set of standards developed by SAMS, people with intellectual disabilities joined family members and professional SAMS staff to visit a disability service, observing, interviewing, and feeding back outcomes of the evaluation to management as recommendations for change. The work of SAMS was developmental in New Zealand, with other auditing groups, in more recent times, including team members of people with disabilities and family/whānau working in partnership with professional evaluation staff (New Zealand Ministry of Health n.d.).

A second article by Meas (2003) challenged organisations to involve people with intellectual disabilities in the evaluation of services beyond being a source of information, through undertaking interviews and identifying service improvements.

In 2003, Inclusion Europe published a document on how to achieve quality in service evaluation that advocated for service users to no longer be viewed in a passive role but one where they would be "viewed as strong consumers who actively evaluate and influence the quality of their support—of which they expect that it meets their needs and wishes" (Inclusion Europe 2003, p. 1). They argued that service systems needed to be built on the perspectives of their users.

Of note was that all three articles were published over 20 years ago and preceded the United Nations Convention for the Rights of Persons with Disabilities (United Nations 2006).

The 'grey literature' was more forthcoming in terms of documenting the involvement in evaluation/regulation of services by people with the lived experience of intellectual disabilities. For example, a system of Quality Checking was evident in the UK, where people with intellectual disabilities were trained, supported, and partnered on a one-to-one basis with people without disabilities to check the quality of people's lives.

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Quality Checkers, as an evaluation system with its related tools, was developed by Choice Support, a UK Not-For-Profit (NFP) service (Choice Support n.d.), and then commissioned by the Care Commission, UK, to run the evaluation programme throughout designated parts of the UK. In 2018, Choice Support was contracted to work with Achieve Australia to pilot a Quality Checker Programme for use locally (Achieve Australia n.d.). A predominance of those trained as Quality Checkers had been previously trained as inclusive researchers through the Centre for Disability Studies at the University of Sydney. Following the outcomes of the pilot phase in 2021, Achieve Australia revised the programme, aligning it closer to Australian culture and the Australian Disability Standards (Australian Human Rights Commission n.d.) and rebranding it as Quality Champions (Achieve Australia 2024, DSC panel).

Overall, the initial search for documentation of people with intellectual disabilities acting as service evaluators and/or service regulators was thin, increasing the need for an exploratory study. However, several studies of relevance have been published from 2023 onwards and are spotlighted later in the discussion.

2.3. Inviting People to Join Us for a Conversation

We aimed to obtain a purposeful sample with a representative in each of the four categories outlined below, which was achieved through the authors' own networks across four jurisdictions. A total of 13 informants agreed to participate (see Table 1). (Note: The codes will be used to identify their quotations, which are cited in the Findings section.)

Table 1. Participants.

Code	Role	Country
P1	Evaluator with intellectual disabilities	N. Ireland
P2	Evaluator with intellectual disabilities	Australia
S1	Supporter for person	Ireland
S2	Supporter for person	N. Ireland
S3	Supporter for person	Australia
S4	Supporter for person	New Zealand
R1	Statutory Regulator	N. Ireland
R2	Statutory Regulator	N. Ireland
R3	Statutory Regulator	Australia
SM1	Service Manager	N. Ireland
SM2	Service Manager	N. Ireland
SM3	Service Manager	N. Ireland
SM4	Service Manager	Australia

Overall, 11 of the 13 participants had had some involvement in an aspect of inclusive evaluation, ranging from being on an evaluation team, organising such teams, inviting critique of disability resources/projects by people with intellectual disabilities, and providing funding for inclusive evaluation activities. Two of the thirteen participants had only been involved in research with people with intellectual disabilities as part of an inclusive research team.

In terms of categories of participants, the breakdown was as follows: people with intellectual disabilities who had been involved in research and/or evaluation (n = 2); professionals who had supported people with intellectual disabilities performing either inclusive research and/or evaluation (n = 4); regulators (n = 3); and support service directors/managers (n = 4).

2.4. Procedure

The interviews were online and mostly with one interviewee, except for one group interview with three managers of different support services and one duo where a support professional with a research background and a researcher/evaluator with intellectual disabilities were interviewed together. The interviews were semi-structured, covering any examples known of where people with intellectual disabilities had been involved in evaluation/regulation activities; the advantages, challenges, and risk of inclusive evaluator/regulatory roles being filled by people with intellectual disabilities; and first steps in getting government/Not for Profit (NFP) services to fund inclusive evaluation. In total eight individual interviews, one duo, and one focus group were spread across four countries as follows: 4 interviews and 1 focus group in Northern Ireland; 3 interviews in Australia; 1 in New Zealand; and 1 in the Republic of Ireland. Interviews were conducted by the authors mainly within their geographic base. They took place from mid-2024 to early 2025. The two researchers with lived experience of intellectual disabilities were Sydney-based and shared the task of asking the interview questions across three interviews alongside the first author and, similarly, in one interview with the second author.

2.5. Analysis

Each conversation was audio recorded and transcribed, and elements of grounded theory were used to inform the thematic content analysis that was undertaken under the three main aims of the study (Corbin and Strauss 2015). Through the use of open and axial coding, major themes were identified across the interview and focus group data, covering the perspectives of the 13 informants. Authors 1 and 2 met to discuss the themes and their credibility. Author 1 prepared an easy-read version of the identified themes for a zoom discussion with authors 3 and 4, and author 5 gave digital feedback. A consensus was achieved on the main themes, relating to each research question that are now described.

3. Findings

In this section, the experiences reported by our informants are grouped in line with the aims and structure of the interviews, namely how people with intellectual disabilities were involved in inclusive evaluation and regulation activities; the advantages of their involvement; the expected challenges and risks; and how these could be mitigated, leading to recommendations for extending and sustaining inclusive evaluation and regulation activities.

3.1. Involvement of People with Intellectual Disabilities in Evaluation/Regulation

Table 2 summarises the three ways in which people in our sample had been involved with inclusive evaluations.

Table 2. The types of involvement in inclusive evaluations.

People with Intellectual Disabilities Were Involved As
Members of evaluation teams
Consultants on service design and delivery
Advisers with lived experience

3.1.1. Membership of Evaluation Teams

Our informants described different forms of teams in which people with intellectual disabilities were members. Some joined a team of evaluators for large-scale evaluations

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being undertaken by statutory bodies or commissioned by non-governmental providers. The evaluation team might also include family members of persons who were in receipt of similar services. Sometimes the team consisted of two persons who worked together but with distinct roles, as an inspector described:

> *I was an inspector in (Name) and we undertake inspections of inpatient mental health and learning disability hospitals. During visits to those (facilities), we determined that we required some experts by experience. At that time, we called them lay assessors, it just would have been one inspector and the lay assessor, and then we may have had one of our session consultants (join us). I always like a lay assessor to walk around a ward and pick up anything,. . . you inspect services for so long, you could walk past something. Every day they picked up on things that I missed, well, I mean, I don't have a learning disability and I've never used a service, so they were ideal for the job"* (R1).

The visit to the service could take between two to three days, with a formal report and recommendations being forwarded to the organisation in the week after. There was a variety of ways that the implementation of recommendations was monitored and followed up.

3.1.2. Consultants on Service Design and Delivery

A second approach was acting as consultants, where organisations or government divisions employed people with the lived experience of intellectual disabilities to give feedback on service models, platforms, policy, and resources. One such example was where members of a self-advocacy organisation were contracted by a disability service organisation to check on how well they were upholding the rights of those who use their services:

> *We now employ a team of people who work on our customer experience and our quality team, and they're people with a range of disabilities, including people with intellectual disability. They interview the people that we support about their experience using the services, about any problems that they might have, any policy issues that they might come up, any service improvements that they might suggest. And then they work directly with the local manager to make those changes, and where there are issues that come up that really are about things that are pertinent across our services, they come to the executive for suggestions around change and report regularly to the board about their findings* (SM4).

Less formal evaluation approaches were described, where the sharing of the lived experience of a person with intellectual disabilities was considered a form of self-evaluation—for instance, planning a move from the family home to supported accommodation and being asked to comment on how their participation in co-design was evident in the outcomes of the move. The same applied to their membership in advisory groups for broader service development and the evaluation of the impact their contribution had on the process:

> *All of the people we support live at home with their family carers. When we do our independent evaluations, we bring them inside to do that with both the families, the staff and the service users (people with intellectual disabilities) who give their feedback about what's good about. . . what's bad. . . what we could do differently. We get other wonderful ideas of what they'd like us to do better* (SM1).

3.1.3. Activities Undertaken to Support the Development of Evaluations

Informants were asked to speak about the activities they had undertaken to support the inclusion of people with intellectual disabilities in the evaluations they had undertaken. Those that were commonly mentioned across all three types of evaluations included training, development of accessible materials, participating as team members, mentoring, adaptation of evaluation materials, provision of feedback, and follow up (see Table 3 for more detail on these activities).

Table 3. Activities to support inclusive evaluations.

Accessible and adapted training opportunities were provided, such as role plays.
Easy read and plain English were used in developing evaluation tools and for the writing of reports.
Inclusive evaluators worked either in two's or as part of a team, that comprised people both with and without intellectual disabilities.
Inclusive evaluators were mentored in the field for their first evaluation activities.
Adapted checklists of standards relevant to the service/support setting were used in observing and discussing what was being evaluated
Feedback was given to the service personnel by all the evaluators.
A follow-up strategy was prepared to see if gaps identified in the evaluation had been addressed.

The first four features above are commonly found in inclusive research studies (O'Brien 2023) and mirror the supports provided for researchers with intellectual disabilities. In this study, the interviewees placed particular emphasis on ensuring that the training was attuned to the needs of the evaluator with intellectual disabilities.

> *After he had done the (evaluator) training we went through a lot of the training that took place… there were things they had not made clear. If somebody tells you something (sensitive), you can't ask too many questions. By doing scenarios—so by me pretending to be a patient and telling him things that could happen—for him to see how he could respond and know how to deal with it* (S2).

Likewise, the checklist of standards used in evaluations needed to match the national standards geopolitically for disability; for example, in Australia it would be the Australian Disability Standards (Australian Human Rights Commission n.d.) But the checklists may need to be adapted for language accessibility:

> *We have patient questionnaires which an inspector can use to ask patients questions, but together we developed a questionnaire that they (co-evaluators) could use to interview patients. So it was like using their language* (R2).

3.2. Advantages of Having People with Intellectual Disabilities Involved in Evaluation

Our informants were asked about their perceptions of the advantages of having persons with intellectual disabilities as co-evaluators. The main advantages identified across participant groups were embedding respect for people with intellectual disabilities in the evaluation, increased empathy and trust, more accurately capturing the lived experience of support, and paid employment opportunities (see Table 4).

Table 4. The main advantages of having people with intellectual disabilities involved in evaluations.

The Main Advantages
Respecting the rights of people with intellectual disabilities.
Greater empathy and trust.
Capturing the lived experience of being supported.
Opportunity for paid employment.

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3.2.1. Respecting the Rights of People with Intellectual Disabilities

Involving people with intellectual disabilities within evaluation teams was seen as a way of organisations meeting their obligations as a member country that had ratified the United Nations Convention on the Rights of Person with Disabilities (United Nations 2006):

> *If you want to make [it] real, the Convention on the Rights of Persons with Disabilities…and the saying "Nothing about us without us", it will bring to life our own international obligation to an international treaty to include people with disability into all aspects of the government's work. I would say that there is advantage in having that experience as part of an evaluation in house team, people with the lived experience of disability can bring in insight* (R3).

3.2.2. Greater Empathy and Trust

The lived experience of those with intellectual disabilities being on evaluation teams or performing regulation activities was credited with bringing more empathy and trust to the process, while at the same time making it easier and quicker for the interviewee with intellectual disabilities to connect to the process:

> *So, I tell them (the people in the residential service)…I'm here as one of yous (sic), because I've been through this. Because I've got that more of the t-shirt, you know. So that helped them, because they knew I understood what (their place) was like. I could have empathy. Is that the right word? I know what they're going through* (P1).

> *When they see trained evaluators with intellectual disability come in they trust them more to tell them things. They can see things that really matter to people with intellectual disability which often people who haven't been in services can't do. So, it's that consciousness of the important matters that are relevant in the lives of people with intellectual disability* (S4).

> *Invariably puts people at ease in being able to talk to someone who they consider is not a person who's caring for them day to day, not a person who's in charge of the organisation but someone that they really have the opportunity to connect with and to talk about their own experience and to share their experience with* (SM4).

3.2.3. Capturing the Lived Experience of Being Supported

The evaluators with intellectual disabilities could speak from their common experience as users of services to those receiving the services that were being inspected. And the service users would have more confidence to confide in them and talk to them about shortcomings and any sensitive matters, which they might not do with professional inspectors or their support staff:

> *One of the ladies I spoke to about abuse—she was very open and honest, and I ended up going to her after and going, are you OK? Yes, yes* (P1).

Having evaluators with intellectual disabilities on the team was thought to overcome difficulties encountered previously:

> *When we do our (own) evaluations and we're asking for their opinions …, we find that we had to work a lot with them to get them to open up on what their opinions are, what their thoughts were, because they're not used to being asked those things* (SM3).

When evaluators with intellectual disabilities were involved in giving feedback, greater attention was paid by the service, as they focused more on the life of the people being supported rather than procedural issues:

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> *We also find that giving feedback to the providers, the presentations by lay assessors seemed to hit home much more and it brought the reality of user experience and what could be improved* (R2).

> *Recognising lived experience within an organisation and employing people with lived experience of intellectual disability improves everything about that organisation. The communication, the dynamics and outputs and… the evaluation process* (S3).

Equally, the co-evaluators with intellectual disabilities gained more confidence from having value attributed to their opinion and being credited with staff taking action:

> *(We were) going through the process to make sure that services that people like are on track to get some good support… (they were) doing what they are supposed to do* (P2).

3.2.4. Opportunity for Paid Employment

Being on an evaluation team was also acknowledged as leading to employment opportunities:

> *We made a deliberate decision that this was a paid job… we were asking people to be professionals. They were doing the kinds of jobs that we would normally employ people without a disability to do and so we paid them an award wage… It's given them gainful employment, professional employment and award wages. So, I think they've been advantages all around in doing things like this for our board, hearing from people with lived experience about the experience of our service users* (SM4).

The inequity in not paying evaluators with intellectual disabilities was highlighted too by another of our informants:

> *We need to make sure that they were getting paid correctly and not being under paid because we are still facing that problem in 2024* (P2).

However, payments did not happen with all participants.

> *No (they did not get paid), no, just expenses, travel expenses and food and, you know, a meal allowance. That's a strategic decision (because) of the employment type restrictions that would be around. I think that comes in under the volunteer policy* (R1).

And for some participants doing the job was enough payment

> *I personally do it because I'm passionate about it. It depends where you come across. It's just like, well, I'm just doing this as a job. I want to give them hope. But if you're doing it as a passion, that's enough of a payment. Maybe I'm being stupid* (P1).

3.3. Challenges and Mitigations

Our informants recognised that there were some major challenges and risks they had faced and continued to face in undertaking inclusive evaluations (see Table 5). We also explored how they had tried to mitigate the challenges and risks.

Table 5. The main challenges and mitigation of having people with intellectual disabilities involved in evaluations.

The Challenges	Mitigating the Challenges
Resources needed for inclusive evaluations.	Awareness raising.
Valuing lived experiences	Meeting training needs
Whole systems change.	Managing risks
Handling sensitive information	Mentoring

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3.3.1. Resources Needed for Inclusive Evaluations

Among our informants, resource issues were among the biggest challenge, covering the need for suitable training materials and the time to provide training and ongoing support, evaluation resources to reflect universal design, including the use of easy-read and plain English materials, transport for people with intellectual disabilities to get to evaluation/inspection locations, and timetable flexibility from their employers to schedule follow-up meetings to check on implementation of recommendations.

Additionally, funding to pay people with intellectual disabilities to join evaluation or regulation teams, or even to cover their expenses, was raised as an ongoing challenge. It was suggested that government departments and Not for Profit organisations must secure a stream of funding for reimbursement. According to a participant, this is where policy and its resourcing are needed:

> *To be built in right from the beginning when organisations put up the proposal for the contracts* (SM4).

3.3.2. Valuing Lived Experiences

At the core of working to solve practice and resource issues was a cultural issue within services, as well as in wider society, where people with intellectual disabilities have a history of being seen aa needing care and protection and lacking the competence to make judgements about their supports:

> *There are several challenges, the first being a cultural challenge, not of the people with disability but of the professionals* (R3).

Valuing the lived experience of disability is central to the successful inclusion of people with intellectual disabilities as competent informers and evaluators.

> *With respect to how seriously the individual is taken, because a lot of people that don't work within this field take the disability before the person. And that is a barrier that we are continually striving to overcome with respect to the general population. But people need to listen with more respect to people with intellectual disabilities throughout life in general. And I think that's going to be a huge barrier still. We have progressed, but yeah, we have made progress, but it's so slow* (SM4).

3.3.3. Systems Change

The whole of a service organisation, and not just the section involved in evaluation or regulation, needs to be both accessible and inclusive attitudinally:

> *Some of the processes and systems even for our staff without disability is really challenging, so in becoming an accessible workplace, we had to do a whole lot of work around that and it's still a work in progress. We have to keep challenging ourselves about (it)* (SM4).

> *There needs to be inclusive systems . . . organisations need to change how they do things, whether that's day-to-day communication and/or online. . . I feel strongly that people with lived experience need to be brought into the centre of the evaluation process not as a separate side piece* (S3).

A systems challenge also arises for people with intellectual disabilities to be able to negotiate flexible working hours for evaluation activities in order to protect their other working positions:

> *Some of them have jobs, freeing them up from the job (is needed) so that they can do it (evaluation)* (S4).

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3.3.4. Handling Disclosure of Sensitive Information

The need for training in understanding and managing risks for those engaged in inclusive evaluation was a particular concern:

> *Some of the discussions and indeed the training was around how do we equip and enable an individual and expert by experience to feel equipped to respond to any potential safeguarding disclosures, to be emotionally supported post-disclosure, and knowledgeable and confident enough in what to do should it happen. (Even so) the peer researchers themselves always had, if you like, support in the interviews That was one of the mitigations* (R2).

3.4. Mitigating the Challenges

We probed how our informants had tried to mitigate challenges and risks, but the impression we gained was that it continued to be a struggle, which some opted not to take on:

> *Oh yeah, it's a great idea. What you're doing is really great, and then we sort of ran up against a bit of a yeah, we'll have to think about that. It's certainly something we've considered, but nothing came back* (P2).

The main strategies used to overcome some of the challenges are listed in Table 6 above.

Table 6. Recommendations for extending and sustaining inclusive evaluations.

Recommendations
Share examples from successful schemes where people with intellectual disabilities have been employed as evaluators. Guidelines are developed for people with intellectual disabilities and without disabilities who join inclusive evaluation teams on their role.
Develop and share training programmes for inclusive evaluation teams.
Support services should promote an ethos of valuing the lived experience of persons with intellectual disabilities in all aspects of their service.
Set up pilot programmes and collect and publish data of their outcomes and added value.
Seek out practiced evaluators with disabilities who would be available to support and mentor evaluation teams that include people with intellectual disabilities.
Advocacy groups should train and support their members to take on evaluation roles.
Contracts for services should include funding to cover payments for people with intellectual disabilities to be evaluators.

3.4.1. Awareness Raising

Foundational to a whole-of-organisation approach was that staff were supported to let go of their assumptions and beliefs about people with intellectual disabilities as evaluators, such as the following:

> *They would only be able to do half the job, and they (as support staff) would have to put down their jobs to help the person* (SM4).

Raising awareness about the potential of people with the lived experience of intellectual disabilities to join regulation and/or evaluation teams was needed to overcome the lack of belief in what they can achieve. The need to raise awareness was approached by one organisation in what they referred to as

> *A really purposeful approach. It's not just making things better for the people on that particular (evaluation) team, but also every other person in the organisation has benefitted from this. So, we're employing people with disability in other parts of the organisation, not just in these evaluation teams, because the organisation is more inclusive now* (SM4).

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3.4.2. Training Needs

The need for specific training opportunities was stressed, especially for evaluators with intellectual disabilities. Training in communication, confidentiality, the scope of what can be said in public, observational skills, and the use of specific tools and questionnaires to gather information was commonly considered as enhancing the inspection/evaluation process.

A feature of group evaluation training was that it would be delivered inclusively, with both people with intellectual disabilities and without disabilities attending the same facilitated sessions. However, for some evaluators with intellectual disabilities, this had its drawback. They found the pace was too fast, they were reluctant to ask questions, the language used was too complicated, and important issues were skimmed over. More individual tuition that was needed to hold down a job was expressed as follows:

> *So are people really able to do it for a job? And then if you're talking about a job, do you get a job description and you apply for the job and do you show that you have the ability because you're done some training? Or could you be observed on the job and given feedback?* (S.1).

Aligned with group training, the need for a more customised approach in preparation for some aspects of performing evaluation activities was reported. For example, government regulation teams need to react quickly to high-level complaints and thus require a customised approach, including individualised coaching and the provision of individual support through a buddy system. It was also argued that opening regulatory activities to people with intellectual disabilities needed piloting within both the government and NGOs rather than launching it as a 'ready-made' programme. Ongoing reflective reviews of all elements of the evaluation and regulation process, including training packages, field work, and report writing and follow-up activities, were favoured and reasonable adjustments, made in relation to both the physicality of locations and accessible resource materials.

Training was also stressed for those skilled in evaluation and regulation to enable them:

> *to provide a support mechanism, in terms of training and development, coaching, opportunities to buddy, and support the person with lived experience so that they can act as an evaluator and bring value to the team* (R3).

Indeed, our small-scale study was an example of how elements of reflective reviews could be implemented within ongoing training sessions, and the use of an external inclusive evaluation team to evaluate the impact of the training could be beneficial.

3.4.3. Managing Risks

Awareness raising and training, as noted previously, were also the bedrock on which mitigations around hearing disclosure of abuse or trauma could be managed. A whole-organisation approach, with staff and service users, was needed, and not just for those undertaking evaluations:

> *It's the same for anybody who hears some of those stories who might go in and hear that somebody's experiencing abuse or experiencing, you know, some pretty unpleasant things. And so, you know, I need to make sure that as an employer that I'm giving them the right support and I'm giving them the opportunity to be able to debrief, to be able to, you know, hand that information on to someone who can do something about it* (SM3).
>
> *(In the training) we talked too about the boundaries of what would be acceptable topics and issues to talk to service users about, and if there was any suspicion of abuse or there been any disclosures of abuse, that this should be reported to the inspectors (without intellectual disabilities}, who would then would deal with that* (R1).

3.5. Extending and Sustaining Inclusive Evaluations

Our third aim was to gather insights from our informants as to how inclusive evaluations could be extended and sustained. Table 6 lists their recommendations, but not necessarily in an order of importance, with the caution that they come from a very small sample of persons. We will examine these further in the discussion.

As we had commenced our study in 2023, we re-ran the literature search while writing this paper in mid-2025 and discovered that a number of articles had been published in peer-reviewed journals, describing the experience of other admittedly small-scale studies that could qualify as inclusive evaluations. In the main, they confirm and extend many of the insights documented here, so we urge readers to use them as additional resources on this topic. For example, service commissioners are willing to involve experts based on experience in health sector organisations, but practical challenges hinder them from actually doing so (van den Bogaard et al. 2023); there is a need to involve individuals with disabilities in every part of project planning processes (Douglas et al. 2024); tangible improvements are needed in the accessibility of information (Berg et al. 2024); the inclusion of adults with intellectual disabilities as co-researchers benefits investigators, co-researchers themselves, and project outcomes (Buck et al. 2024); ethics committees appear reluctant to include people with cognitive deficits in order to ‘protect’ them (Bishop et al. 2024); and an accessible research ethics training that leads to certification has been produced (Schwartz et al. 2025).

Hopefully in future years, the number of published articles will grow, as has happened with respect to inclusive research, as evidenced by this Special Issue and recent literature reviews (Garratt et al. 2022). A body of literature adds credence, as well as practical guidance, on how inclusive evaluation can become an established part of support services. We depend on others to overcome the limitations of the efforts we report in this paper. These findings are by no means the last word, but perhaps they qualify as being among the first words on this topic.

4. Discussion: Where to from Here?

The rationale for inclusive evaluation within support services for persons with disabilities—and indeed all recipients in need of social supports—has been clearly articulated within Human Rights and Quality of Life frameworks. Moreover there is greater recognition in democratic governments that fund social services of giving persons in receipt of these services a stronger voice in ensuring that their support meets their needs. These conceptual frameworks have seen growing acceptance internationally, especially with respect to ensuring that health and social services, which are funded through national taxation, are equitable, efficient, and effective. Nonetheless the rhetoric has been slow in becoming a reality in even the most affluent countries, especially for the most marginalised of their citizens, among whom people with intellectual disabilities prominently feature (World Health Organization 2011). Thus far, efforts to implement changes in mindsets and long-established practices are often driven more by the passion of individuals rather than commitment of senior managers who commission and deliver services (Scourfield 2015).

The challenge now is to translate these visions into practice. This small study, with its three main aims and allied with the emerging literature, confirms that people with intellectual disabilities have brought added value to service evaluations and the processes required in the inspection and regulation of support services. We are more aware also of the extra training and supports that they may require to enhance their engagement as team members undertaking inclusive evaluations. Nonetheless significant challenges have to be overcome, but a range of mitigation strategies have been identified and tested.

Recommendations have also emerged to guide future actions aimed at extending and sustaining inclusive evaluations.

Even so, these are early days in this new venture, but they are reminiscent of the early emergence of inclusive research. Looking back, its growth was fuelled more by academic researchers striving to put inclusive research into practice rather than engaging in scholarly debates about it (O'Brien 2023). Hence, we end by identifying what we perceive to be the core actions needed to nurture inclusive evaluations. We offer for discussion an initial implementation plan with indicative activities, as shown in Figure 1, for those interested in undertaking inclusive evaluation activities. It combines the actions described in this article and the wider inclusive research literature, to which this Special Issue is a valuable addition (https://www.mdpi.com/journal/socsci/special_issues/GF4S06N1TC (accessed on 26 September 2025)). Our hope is that others will expand the plan in the years ahead.

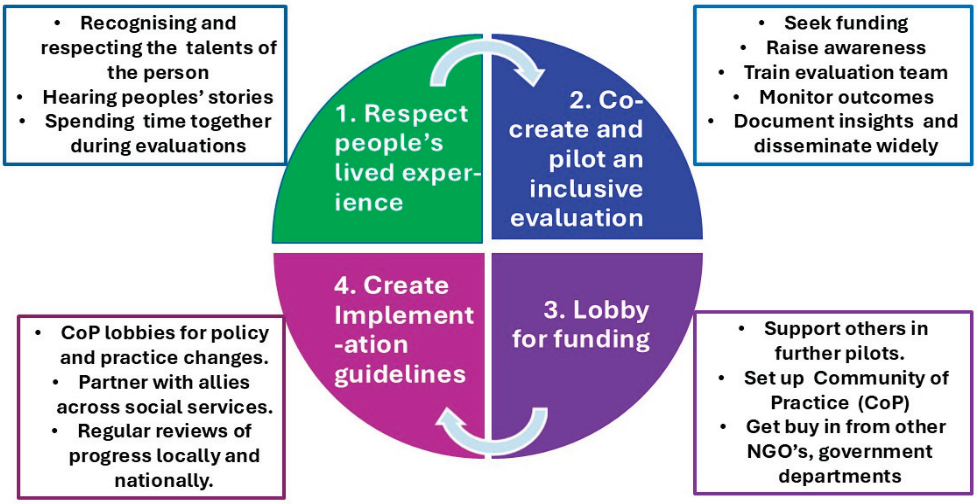

Figure 1. A plan for setting up inclusive evaluations.

The plan starts with actions in Stage 1, which value the lived experience of people with intellectual disabilities (Curryer et al. 2024; Kelly et al. 2024; Koning et al. 2024; Love 2023) and build respect for their capacity to be informed and competent evaluators. This stage embraces all the stakeholders involved in evaluations, from frontline staff to senior managers of services and advocacy groups, as well as professional evaluators in regulatory agencies and academia (O'Brien et al. 2025).

This leads into Stage 2, co-designing (JFA Purple Orange 2021) and piloting a small-scale inclusive evaluation, possibly emulating the approaches that our informants have described. This 'proof-of-concept' stage will yield valuable insights into unique and common challenges and find ways round them (Moxley et al. 2013). It is likely that each evaluation will need to be attuned to the particular service context and culture in any case, so there is little to be gained by waiting for the 'perfect' inclusive evaluation model to be discovered.

Stage 3 works towards extending inclusive evaluations, primarily through building solidarity with others committed to inclusive evaluations through communities-of-practice approaches (Ranmuthugala et al. 2011; Wenger-Trayner n.d.) and seeking funds to support this new style of evaluation. Communities of practice encourage the exchange of knowledge and good practices and will also assist with lobbying government agencies for the necessary funding, primarily to cover the cost of training and resourcing of co-evaluators with intellectual disabilities. These practices have proven successful in promoting inclusive research. It remains to be seen if they can transfer to inclusive evaluations.

In Stage 4 the focus shifts to making changes within systems. It may be desirable that leadership for change should come from the top, but in our judgement, this is very unlikely to happen in statutory systems. It is better to build from the bottom-up (Green 2016; Sergeant et al. 2022). The goal is not just to ensure that financial resources are available for more effective monitoring and evaluations of services but that the policy and procedures that guide them are redesigned to make them inclusive (Dew et al. 2018).

We envisage the plan spiralling into a further round of the same stages, as we anticipate that the first four-stage cycle we have outlined is likely to be only partially achieved in certain locations, for particular services, or for some of their users. For example, a further Stage 1 would widen the recognition of the lived experiences of people with intellectual disabilities among service commissioners, before moving forward again to pilot inclusive evaluation in other parts of the geographic service ecosystem, and so on.

Two further points of note: although we present the stages in order, it is possible for them to be worked on simultaneously or in a different order, depending on local contexts. Arguably there could be further sub-stages that may become apparent as the plan gets used in a variety of settings. This is only its beginning.

Finally, we end by summarising the key values that we believe need to drive frameworks for inclusive evaluation in Table 7, just as Walmsley and Johnson (2003) did for inclusive research. The fact that these values overlap is no surprise, although we have adapted the wording from the insights we gained from our informants and the recent literature.

Table 7. The key values driving Inclusive Evaluation.

The Values
The lived experience of people with intellectual disabilities is recognised as a cornerstone in evaluating the upholding of the human rights of persons with intellectual disabilities.
Membership for a person with intellectual disabilities on an evaluation team is equitable to those without disabilities in both philosophy and practice.
Accessible, customised, mandatory training is undertaken to develop evaluation skills for all members of the team.
Universal design is applied to make evaluation processes accessible to the evaluators and the stakeholders who are informants in the evaluation.
Customised, accessible support and supervision is provided throughout the evaluation process to ensure equity of engagement for people with intellectual disabilities within inclusive evaluation teams.
The members with intellectual disabilities are respected as trustworthy members in relation to handling confidential/sensitive material.

5. Conclusions

As inclusive research becomes more widely accepted, the time has come to explore how it might grow out from academia and extend into the monitoring and evaluation of services and allied functions such as their regulation and inspection, inquiries into malpractices, and the design of new support services. The informants across four jurisdictions confirmed its feasibility and voiced strong support for it, highlighting benefits such as greater trust and empathy during evaluations with users of services, more meaningful feedback for service providers, and increased confidence and employment opportunities for evaluators with disabilities. However, challenges remain, including funding and fair pay for the engagement of people with intellectual disabilities, training opportunities that meet the support needs of all stakeholders, and changing the cultural attitudes in support services that underestimate the abilities of people with intellectual disabilities. Steps to overcome these challenges are proposed, such as piloting inclusive evaluation programmes, providing inclusive evaluation training to all involved, and lobbying governments to fund these roles. We created an implementation plan to guide practitioners wishing to undertake inclusive evaluation. We conclude with a set of guiding principles that will nurture a spirit of inclusion and respect. Finally, threaded through the information we garnered was the theme of acceptance—accepting the competence and experience of people with intellectual disabilities and how they grow through being valued within inclusive programmes. Gaining acceptance of difference by others is the primary and arguably the more daunting challenge to be faced in making inclusive evaluations a reality.

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