



Article

Inclusive Research and Intellectual Disabilities: Moving Forward on a Road Less Well-Travelled

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Abstract: In reflecting on the title of the special issue: Inclusive Research: A road less or more well-travelled, this paper reviews the strengths of inclusive research that have augmented the global knowledge about the lives of people with intellectual disabilities across the lifespan. The successes of inclusive research are outlined with the respective ongoing individual challenges discussed. Authors will draw upon their own experiences of inclusive research, together with the seminal and current literature, as well as the dialogue between them. The conclusions of the article are in the form of recommendations aimed at increasing the traffic on the road of inclusive research through: 1. expanding its purpose and parameters across all forms of disability research; 2. developing systems for sustaining inclusive research as a funded model; 3. creating capacity to enable people with intellectual disabilities to be employed as researchers directing research projects; and 4. establishing bridges and crossroads with policy and practice through its findings.

Keywords: inclusive research; intellectual disabilities; capacity building; policy; and practice; funding; co-design; co-researching



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1. Introduction

“Two roads diverged in some wood, and I—
I took the one less travelled by,
And that has made all the difference.”

—(Frost 1915)

Inclusive research offers another road of travel, but one less taken. Walmsley and Johnson's introduction of inclusive research as a paradigm in 2003 followed on from the ethos embedded into the disability movement in the 1990s when it lauded that no longer should research *be done to* people with disabilities but rather that they should *be part of the doing* (Zarb 1992; Clough and Barton 1995, 1998; Stone and Priestly 1996; Barnes and Mercer 1997; Oliver 1997, 1999; Moore et al. 1998). Participatory research emerged that challenged the hierarchical divide between the researchers and the researched. Emancipatory models followed, moving the dialogue into research that would lift social oppression and disable life barriers. Making research accountable to disabled people and giving voice to their concerns was in line with a view expressed by Oliver (1996) that research needed to be “*more relevant to the lives of disabled people and more influential in improving their circumstances*” (p. 141).

These approaches, however, had much less impact socially and politically around intellectual disability (Goodley and Moore 2000; Chappell et al. 2002). In part, this reflected

a perception that people with the label of intellectual disabilities lacked the cognitive ability to understand research methods. More pertinently, they were marginalised even within the disability movement that was dominated by people with physical and sensory disabilities. [Walmsley and Johnson \(2003\)](#) took up this challenge and offered a framework to make research accessible to people with intellectual disabilities. They proposed five principles for their engagement with and ownership of the research process through one or more of the following:

- Being collaborators in doing the work.
- Exercising some control over the process and outcomes.
- Having access to questions, reports, and outcomes.
- Producing research outcomes that further their interests.
- Producing research outcomes most associated with participatory action or emancipatory paradigms (pp. 9, 10).

As a result of Walmsley and Johnson's work, the concept of inclusive research was born. In keeping with the theme of the papers in this special issue, the aim of this article is to provide an overview of the reach of inclusive research to date for persons with intellectual disabilities. Within the article, its successes and challenges will be identified, as well as its future resourcing, policy, and practice needs. We draw upon relevant literature, as well as our own research and experience. The article is a reflection piece that brings with it the limitations and biases of self and group reflection. We have aimed nevertheless to balance these by also embracing the current research of peers who are notable for their work within the inclusive research space.

2. The Authors' Approach to Writing the Article

It is important to acknowledge the terminology used to refer to inclusive researchers. Together, we determined our preferences. The three of us with university affiliation would be referred to as university co-researchers and the two of us with intellectual disabilities as co-researchers with intellectual disabilities.

The university co-researchers each have over 15 years' academic experience in inclusive research as principal investigators of inclusive research projects, authors of journal articles, and facilitators of inclusive research groups. All three academic researchers were experienced with both quantitative and qualitative methods within inclusive forms of inquiry.

The co-researchers with intellectual disabilities are foundation members of an inclusive research group in Australia with over 10 years' experience of contributing to a diverse range of research projects, conference presentations, and training workshops, as well as co-authoring papers and video making. Therefore, as a group, we all shared an insider's perspective of inclusive research and a commitment to its development and sustainability. It is from these personal experiences and through a dialogical approach that we have developed the content of this article. We all share a human rights-based approach to disability, where persons with disabilities are right holders. As co-researchers, we all chose to have our full names used initially within the text, followed by only our first names where the narrative reflected our verbatim contributions and/or personal experiences.

The following sequential approach was taken to writing the article. The three university co-researchers engaged in a series of discussions to identify key issues for the article, drawing from our personal experiences with inclusive research, as well as a critical overview of the literature. We met via Zoom on three occasions and Patricia took notes that were then distributed for discussion in time for the second and third follow up meetings, respectively. We then organised the notes into themes that were added to each following meeting. The themes worked as content areas for the article, with each of us taking responsibility to expand the written ideas for certain sections. It was not until this stage that we invited two co-researchers with intellectual disabilities, whom one or more of us had worked with, to join the writing group. As we had not worked together as a writing team, we aimed to make the invitations to join us as meaningful as possible. Hence, Patricia developed a set of power point slides showing both the points of success

and the challenges associated with inclusive research, which we discussed as a group of five co-researchers. Our hour-long conversation was audio-recorded. A second draft of the paper then incorporated the verbatim voice of the two co-researchers with intellectual disabilities on the issues we had reviewed. Further discussion of this draft via Zoom again used a set of accessible slides and further changes to the content were agreed.

The ongoing journey of inclusive research over the last two decades is framed within the article as a series of successes with accompanying challenges that need to be addressed. We then reviewed two essential requisites in looking to the future: funding for inclusive research and policies relating to it. We end with a series of recommendations for extending the approach of inclusive research, ensuring its sustainability, and increasing its influence in policy making and the delivery of life-enhancing service supports.

3. Successes and Challenges of Inclusive Research

Five successes of inclusive research are now presented with the respective ongoing challenges outlined.

3.1. Success 1: People with Intellectual Disabilities Have Participated as Co-Researchers in a Range of Research Studies across All Stages of the Research Process

A major success of inclusive research is that the principles outlined in the original model (Walmsley and Johnson 2003) are evidenced within the peer-reviewed literature. A recent review (Jones et al. 2020) revealed 53 studies undertaken between 2006–2016 that all indicated partnership with people with intellectual disabilities with one of the most reported tasks their involvement in data collection through facilitating focus groups (10), interviewing participants (9), photovoice (7), telling one's own story (5), administering surveys and questionnaires (3), and journaling (2).

Furthermore, the Jones et al. (2020) analysis recognised that most articles reported on were collaborative projects between co-researchers with and without intellectual disabilities (41); however, only a minority (4) were being led solely by co-researchers with the lived experience of intellectual disabilities. Nevertheless, the outcomes of the review demonstrated that inclusive research as a paradigm has provided an alternative for people with intellectual disabilities from having *research done to them* to being involved in the *doing of it*. (Blinded co-author), in her role as both co-author and co-researcher with intellectual disabilities, shared that, as a result, people with intellectual disabilities are seen differently, *“as researchers with disabilities, advocates, and people always”*.

Likewise, co-researchers with intellectual disabilities brought added value to a large-scale survey of what life was like for people with intellectual disabilities in Ireland (O'Brien et al. 2014). Survey participants reported that they were more confident in speaking up in response to questions being asked by an interviewer with similar experiences of disability.

This value of co-researchers with intellectual disabilities as interviewers also surfaced in the dialogue between us as a group of co-authors, particularly in relation to where three of us, (Sarah Butler, Bruce O'Brien and Patricia O'Brien), had worked on a series of studies as members of the Centre for Disability Studies (CDS) Inclusive Research Network (IRN) examining the impact of the Convention on the Rights of Persons with Disabilities (CRPD) on the lives of people with intellectual disabilities (O'Brien 2018). Sarah commented: *“Rather than somebody who's a university researcher, they told me more and they felt comfortable rather than with a service provider.”*

Ongoing Challenge of Actively Involving People with the Lived Experience of Intellectual Disabilities and University Staff as Co-Researchers

Identifying the added value of inclusive research does, nevertheless, raise the question as to whether such value is enough to keep university researchers open to working with co-researchers with intellectual disabilities. Inclusive research projects take a long time to bring to completion, which arises from the need to support co-researchers with intellectual disabilities and training for all involved. Time commitment and the need to incorporate multi-dimensional strategies in working inclusively is not always recognised in the tradi-

tional assessment of research outputs for university researchers; instead, they are judged mainly on an active build-up of publications. University co-researchers engaged in making inclusive research happen should be acknowledged for their leadership, innovation, and collaboration with stakeholders with intellectual disabilities. This is beginning to happen. The League of European Research Universities (LERU) is calling for the contextualisation of research profiles when assessing university researcher outputs and will recognise that how and where research is undertaken is also important (Overlaet 2022).

Although people with intellectual disabilities are involved in undertaking research, there is still a great emphasis on having “research done” to them, as is illustrated by only 53 articles on inclusive research being selected in a scoping literature review covering a 10-year period between 2006–2016 in the Jones et al. (2020) review and, similarly, only 52 articles in a literature review by Walmsley et al. (2018) across the years 2003 to 2016. Consequently, there is a danger that many of our current research endeavours fail to focus on the expressed concerns of people with disabilities. Instead, issues relating to professional practice and service delivery are privileged and then justified on the grounds that they indirectly affect the lives of people with disabilities.

It seems that there is still much to live up to if the promise of ‘nothing about us without us’ (Charlton 2000) is to be achieved within the disability research community. There is still much space on the road for disability researchers to be joined by peers with the lived experience of intellectual disabilities.

3.2. Success 2: Acknowledgment of Being an Inclusive Researcher in Academic Publications

In 2013, McDonald et al. (2013) made the point that people with intellectual disabilities had “regrettably few opportunities to voice their opinions on aspects of research with which they have had direct experience” (p. 216) and called for more respect to be shown to them as participants. Walmsley et al. (2018) continued the call for respect, but this time between co-researchers with and without disabilities. In 42 of 52 articles selected by them for review, voice was attributed to co-researchers with intellectual disabilities through a range of approaches, the most common being the use of quotations or reported speech from co-researchers with intellectual disabilities. There were examples of where “we” was used, or use of a first-person account in the voice of the co-researcher with intellectual disabilities, or divided sections between the voice of researchers with and without intellectual disabilities. However, extending the acknowledgement to co-authoring articles and reports on the findings appeared more aspirational than real. Although the names of co-authors with intellectual disabilities could be listed, an explanation of how their contribution was achieved was rarely given. Walmsley et al. concluded their review by encouraging research teams to agree on how to enable and recognise co-researcher voices at the outset of the project in relation to the writing and publishing of the findings.

Ongoing Challenge of Active Involvement of Co-Researchers with the Lived Experience of Intellectual Disabilities in Co-Authoring Publications

Four of the five authors of this paper, (Patricia, Sarah, Bruce and Roy Mc Conkey) were involved in a study that aimed to identify the perspectives of inclusive researchers to writing with co-researchers with intellectual disabilities. Eleven authors who had published in this space were selected by the CDS Inclusive Research.

Network (IRN), based upon the group’s knowledge of the authors’ work that had been discussed in reviewing articles at the monthly IRN meetings. Oauthors they had met at conferences, local universities, and public seminars. To be eligible they needed to be available either face to face or by phone, either in Australia and/or overseas (Riches et al. 2020). Interviewing was done by a co-researcher couple, with one university co-researcher and one co-researcher with intellectual disabilities. Only one of the 11 authors acknowledged having a disability, which was sensory, and the overall experience of the group in co-authoring with co-researchers with intellectual disabilities was limited. The study concluded that more research skills in co-writing were called for, as well as a participatory

reframing of how outcomes needed to be written up and disseminated. The need for training was well-expressed by Sarah, who emphasised that it needed to be practical and embedded in “a course funded at the university for research for people with disabilities (with course members getting all the assistance they need to complete the course”. Edurne Garcia Iriarte has also found this to be relevant in a recent study where she, with co-researchers with intellectual disabilities, examined learning in inclusive research, stating that “the way we learn is practical, we get stuff done alongside learning” (García Iriarte and Donohoe 2022).

3.3. Success 3: The Reach and Networking of Inclusive Research around the Globe

A stronghold of evidence has begun to surface as the journey of inclusive research has deepened and diversified. A search on Scopus from 2004 to 2021, the start date being a year after Walmsley and Johnson (2003) introduced the principles of inclusive research, was done across five journals on disability research selected for the level of their impact factors (IF) and/or being known for accepting articles on inclusive research. They were *Disability and Society* (F 2.567), *Journal of Applied Research in Intellectual Disability* (IF 2.700); *Journal of Intellectual and Developmental Disability* (IF 1.347); the *British Journal of Learning Disabilities* (IF 0.633); and the *Journal of Intellectual Disability Research* (IF 2.424). The Scopus search was done using the specific journal as source and with “inclusive research” being searched for in the title, abstract, and keywords. The contents of abstracts were eyeballed across such entries to validate their relevance. Table 1 gives the details of the number of articles per journal, as well as the number of countries represented by the respective authors. The countries most represented in this analysis were the United Kingdom and Australia, followed by Ireland, Spain, the United States, and the Netherlands. Although such demographics are only from the one search index of Scopus, it does speak to the adoption of inclusive research internationally, at least among more affluent countries, while highlighting that certain journals seem to be more disposed to publishing inclusive research papers than others.

Table 1. Range of countries of authors of articles on inclusive research, 2004–2021.

Country	Disability and Society N = 28	British Journal of Learning Disabilities N = 43	Journal Applied Research Intellectual Disabilities N = 37	Journal of Intellectual and Developmental Disability N = 5	Journal of Intellectual Disability Research N = 9	Total
Australia	6	6	10	3	1	26
Austria		1			1	2
Belgium	2	1				3
Canada	3		1		1	5
Iceland		2			1	3
Ireland		7	4			11
Malta	3	1				4
Netherlands	1	1	3	1	2	8
Norway						
Singapore					1	1
Spain	4	1	4			9
United Kingdom	7	19	12	1	2	41
United States of America	2	4	3			9

Doing inclusive research brings with it the potential for networking across countries that could lead to joint research projects and publications. Such a model was introduced by

the International Initiative on Disability Leadership (IIDL), (<https://www.iimhl.com/iidl-homepage>, accessed on 25 August 2022). This is a vehicle created by participating national governments to link leaders across international participating countries on many diverse aspects of disability. Exchanges are co-ordinated between members to meet between the bi-annual conferences to work on projects of interest that are then presented at the conference. This model could be transferred into active networking between those who are publishing inclusive research and is co-ordinated by an international association or a consortium of journals.

Core to the success of the journey of inclusive research has been the development of co-researchers, both with and without disabilities, forming initial inclusive research teams, many of whom have matured in research capacity and leadership, culminating in their sustainability. The work of the following two groups exemplifies what is possible. Ten years of work of the Irish Inclusive Research Network has been reflected upon by its members (García Iriarte et al. 2021). Such reflection coincided with a long-running network working to become a registered organisation directed by its self-advocate members who, for years, had been responsible for choosing what is to be researched and for the choice of data collection, analysis, interpretation, and dissemination strategies, including accessible reports (García Iriarte et al. 2014). Similarly, in the story of the Centre for Disability Studies Inclusive Research Network (Riches et al. 2017) discussed how they acquired their skills and abilities for becoming and being inclusive researchers. A major theme was the support they gave one another in coming together as a group to be mentored by more experienced researchers. As the group stayed and developed together, its members with intellectual disabilities in turn became the mentors of new members. Social capital was gained through being a member of an inclusive research network.

Networking internationally has added to the potential of inclusive research becoming a credible research paradigm, particularly with the launch in December 2021 by the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) of a special interest research group (SIRG) on inclusive research (IASSIDD 2021). The purpose of such a group is to advance inclusive research by creating an international forum for discussion and debate and a safe space to share knowledge based upon the lived experience of disability where researchers with intellectual disabilities are, as envisioned by Sarah “*talking to somebody with a disability; and they have the same experience and the same interests as what they enjoy doing and many know from you what you experiences are, what your values are*”. Only time will tell if the SIRG has success in impacting not only its membership but also succeeds in raising consciousness of all IASSIDD members in how to approach all disability research inclusively.

Ongoing Challenge for Researchers with the Lived Experience of Intellectual Disabilities to Gain Equal Opportunities to Network at Conferences and Other Events in Step with Other Researchers Who Are Not Disabled

A major opening for inclusive researchers to network has been that of attending conferences and presenting findings crossing state, national, and international boundaries. The number of such groups presenting at conferences has risen over the last two decades with both the Irish and Sydney inclusive research groups being trailblazers, presenting not only in their home countries, but internationally in multiple countries across Europe, as well as New Zealand, Japan and South Africa. Bruce and Sarah both shared the challenge of presenting in other countries where not everyone spoke English, but it also taught them about other cultures. Sarah indicated that when you hear people face to face in their own countries talk about their research, you get a better idea of “*what they did*”.

However, even before COVID-19 struck, the costs of registration, flights, and accommodations were creating a barrier for attendance of co-researchers with intellectual disabilities. Sarah discussed the issue by saying, “*It’s definitely a problem and if people are on a funding package it’s a problem in that the NDIA (Australia funding agency) is not always open to see conferences as reasonable and necessary . . . and they see it as more of a holiday and they expect the*

people with disabilities to pay for it out of their own costs rather than there being grants available for people to be able to attend without having to afford from their own pocket.”

Nevertheless, lack of such funding has not necessarily hindered conference presentations on inclusive research, as can be seen in an annual edition of the *Journal of Intellectual Disability Research* that presents the IASSIDD conference abstracts. The question nevertheless remains as to how often co-researchers with intellectual disabilities are at the forefront of such presentations. Sarah has thrown some light on this: “Rather than people with disabilities (speaking) on the research, support workers come along, speak on behalf of people with disabilities rather than speaking with them.” Equity in funding has yet to be achieved. Inclusive researchers with intellectual disabilities are rarely funded by university or employer grants, unlike their nondisabled team members. Inclusion would surely demand that all members of an inclusive research team be treated equally; otherwise, co-researchers with intellectual disabilities may travel on the same road but in a second-class carriage.

3.4. Success 4: Making Inclusive Research Accessible to All Co-Researchers

A range of different training models has been developed to make inclusive research procedures accessible to both co-researchers with and without intellectual disabilities. Nind and colleagues (Nind et al. 2016) identified five such approaches for capacity building in inclusive research, including an apprenticeship model, a lifelong learner model, a challenging inequality model in which researchers with and without learning disabilities learn together, a deficit model in which gaps in the learner’s knowledge are upskilled, and formal training involving a curriculum. Nind et al. argue that immersion in the research context and dialogical learning approaches are more suitable to inclusive research. Moreover, we, as a group of co-authors all experienced in working inclusively, would stress that the insider perspective of researchers with intellectual disabilities on what constitutes training needs to be foregrounded, whichever training options were undertaken. That said, both Saran and Bruce felt that the content of the training should be no different to what other researchers without disabilities are offered. For Bruce, this fitted the equality model, which he reflected was “more inclusive”.

Another aspect of accessibility beyond that of training can be seen in the development of materials that promote inclusive research. The University of New South Wales recently produced a set of guidelines on how to create inclusive research using co-production as an equaliser with illustrated accessible graphics (Strnadová et al. 2022). Similarly, the Research for Development Impact (RDI) Network, which is a collaboration between the Australian Council for International Development and Australian universities, has published, with a free download, a resource entitled *Research for all: Making research inclusive of people with disabilities* (RDI Network 2020). This resource goes beyond working inclusively with researchers with intellectual disabilities providing tools and resources to ensure the best inclusive research practices across disabilities in general, broadening the scope and generic impact of inclusive research.

The adoption of accessibility can also be seen in the way the *British Journal of Learning Disabilities* (BJLD) has encouraged people with learning disabilities to respond to published research articles under the heading, *In Response*. Here, authors with intellectual disabilities can critique articles through writing text in easy-read formats, and/or other digital responses including video blogs. This is a breakthrough in supporting people with intellectual disabilities to contribute to discussions in academic journals.

Similarly, other journals have published articles in plain English language with pictures such as in the 2012 special issue of the *British Journal of Learning Disabilities* (e.g., Bane et al. 2012). Equally, *Disability and Society* now requires a plain English summary. Video abstracts across many journals are a new feature, indirectly resulting in making the articles’ information verbal, briefer, plainer, and more accessible.

Ongoing Challenge to Make Research Publications Accessible for People with the Lived Experience of Intellectual Disabilities

Even though in Bruce's words accessibility "*was happening right now with programs in easy English*", inclusive research reported in academic journals continues mostly to address academics and professionals through a required academic style, usually resulting in inaccessibility of the contents for people with intellectual disabilities and, possibly, many other non-academics. As a research paradigm, inclusive research has succeeded in becoming visible, but advocacy is now needed within the broader disability research community. Its members need to be encouraged to start making their publications accessible through incorporating alternative forms of digital accessibility as, "*written words don't help, when language is too difficult, it can pass people by*" (García Iriarte et al. 2022).

The internet and technology have significantly improved the communication accessibility for people with intellectual disabilities. Currently, this has been evidenced in enabling researchers with intellectual disabilities to attend and participate in Zoom meetings (and other online platforms) during the COVID-19 pandemic from 2020 onwards (Puyaltó et al. 2022). Nevertheless, the potential in using such technology to make research information more accessible is still untapped. This could be enhanced by a shared training course on advances in IT and accessibility for both co-researchers with and without disabilities. Journals could also promote awards for disability access in publications following the trend set in gender equity by the Athena Swan awards (<https://www.sciencegenderequity.org.au/athena-swan-awards>, accessed on 25 August 2022). Similarly, journals could be acknowledged for their approach to equity, diversity, and inclusion (EDI). For this to happen, an advocate body needs to emerge, a role that the International Association for the Scientific Study of Intellectual Disability (IASSIDD) has started with the introduction of its Inclusive Research Special Interest Group (SIRG).

3.5. Success 5: A Changing Conceptual Model

The uptake of inclusive research is a tribute to the vision of Walmsley and Johnson (2003), whose initial foundational principles triggered a growth in the conceptual development of inclusive research. Bigby et al. (2014a, 2014b) proposed a three-level framework of inclusive research that ranged from an advisory role to that of collaboration between co-researchers with intellectual disabilities and those without, and to that of researchers with intellectual disabilities leading and controlling the research process. Subsequently, Nind and Vinha (2014) and (Riches et al. 2017) identified a less divided landscape, placing importance on inclusive research being characterised by shared learning, mutuality, and reciprocity among the inclusive research team. Riches et al. (2020) heightened the value of such characteristics by additionally reporting a sense of belonging that came from being a member of an inclusive research team, encapsulated by Bruce in five clear words: "*of giving me more confidence*".

Johnson and Walmsley re-joined the conceptual debate in 2018, updating their original definition by calling for the second generation of inclusive researchers to work towards social change, campaign for others, and stand with them on issues they deem to be important (Walmsley et al. 2018). Likewise, Milner and Frawley (2019) have called for space for a third wave of inclusive research in which the focus is placed on a research praxis that is self-directed by the researcher with the lived experience of disability. Such methodology aims to circumvent the "othering" that can come from the unquestioned expectation that co-researchers with intellectual disabilities will fit into the mode of traditional research data collection methods. The evolving theoretical frameworks underpinning inclusive research augurs well for deepening the understanding of both the rationale for and the ongoing development of the concept of inclusive research.

Ongoing Challenge to Translate into Paid Reality the Concept of People with the Lived Experience of Intellectual Disabilities Being and Becoming Researchers

Co-researchers both with and without disabilities expend much time and effort in undertaking research together. During our conversations about the types of methods that we had all been involved in, the traditional ones in the applied social research of focus groups, interviews, recruitment through running information sessions, coding and member checking were all mentioned. Bruce also spoke of being involved in data analysis, describing it *“as breaking up information into categories and then deciding which categories the guy’s comments fitted into”*.

But for both Bruce and Sarah the challenge was not so much on learning how to acquire new skills like coding but more on experiencing the value of being an inclusive researcher. Bruce’s comments on inclusive research, noted that *“it gives people a voice . . . people can be heard”*, as similarly Sarah’s comment on how it *“helps you with speaking up for yourself and learning the skills of self-advocacy.”* What they considered was missing related more to its potential impact on quality of life and specifically on being employed as a researcher. summed up a major issue as, *“They (the government) don’t see people with disabilities as researchers and able. If you have a look at good jobs as researchers, it’s doing research the whole day like if you were working.”* Sarah and Bruce agreed that if they had qualifications in research, that would not only help them get employment but would also help inclusive research groups get funded. Bruce shared his thoughts: *“I reckon that would definitely help with the funding with the researchers because people got the qualifications and that’s what the government looks for.”* Such commentary touches on the provision of equal opportunities that are core to the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations 2006), thereby raising the question, *“What needs to be done to ensure that inclusive researchers, their employers, and funders work together to mitigate any discriminatory practices associated with undertaking and being employed as an inclusive researcher?”* The issues of funding and policy implementation are now explored in the next two sections, with the aim of enabling inclusive research to become a more well-travelled road.

4. Funding Inclusive Research

New sources and paradigms are needed for the funding of inclusive research: an issue that is hardly addressed in the literature. However, funding remains indispensable for any research endeavour and even more for research that is conducted in partnership between university co-researchers and co-researchers with intellectual disabilities who are generally unemployed and lack access to research resources, for example, by way of third level institution affiliations. Universities need to be encouraged to support inclusive researchers with the lived experience of intellectual disabilities. The Marie Skłodowska-Curie Actions (MSCA) programme is a prestigious fellowship programme in Europe that provides fellows with a generous salary, plus a family allowance, an international mobility allowance, and a *“Special Needs Lump Sum”* (up to EUR 60,000) for accessibility accommodation. Inclusive researchers with intellectual disabilities would benefit from winning or being associated with such a fellowship, particularly if the accessibility accommodation allowance could be additionally used to cover costs of a research coach for the fellow.

Notwithstanding sensible demands for payment, to their credit, people with intellectual disabilities have generally participated in inclusive research on a voluntary and nonpaid capacity. Both Bruce and Sarah had experienced intermittent limited payment as co-researchers. The need for payment was well expressed Sarah, who said that there *“should be some sort of payment for their time throughout projects . . . so that people felt like they’re getting something not just making friends or giving up their time to be able to share the findings from the research project”*. Lack of payment aligns with Wolfensberger’s concept of devaluation reinforcing the image of people with disabilities as *“objects of charity”* (Wolfensberger 2013) working for no fiscal recognition. In recent times, however, there has been an increase in acknowledging the need of payment to researchers with intellectual disabilities hired as

part-time or casual employees, as evidenced in projects coming out of both the Netherlands (Frankena et al. 2019) and Ireland (Magee et al. 2018).

Conversely, to enable inclusive research to develop, the funding needs to sufficiently cover not only the costs of researchers with intellectual disabilities but also to take into account the indirect hours that need to be deployed to support researchers with intellectual disabilities. This then raises the question as to “What is the incentive for funders to cover these costs if research in the area of intellectual disabilities can be conducted without the participation of co-researchers with intellectual disabilities?” The evidence gathered so far indicates that when people with intellectual disabilities are involved as part of the research team, the focus of the research addresses the real needs of people with intellectual disabilities and methods used to gather information are more accessible and better tailored for the research informants (O’Brien et al. 2014). In spite of this, the development of accessible interview tools, for example, the use of large print, picture prompts, and other digital audio guides (García Iriarte et al. 2021) requires additional funding.

An investment in inclusive research means that its reach has the potential to spread outwards to many more people and contexts, particularly when co-researchers with intellectual disabilities are self-advocates or connected to broader advocacy groups. In essence, inclusive research, if funded adequately, can answer the challenge of meeting needs more swiftly, especially when local groups of inclusive researchers with intellectual disabilities are available to follow through on local changes to policy and practice. Such immediacy provides an alternative to relying on a common strategy of top-down government and/or government-funded policy implementation, which can take much longer, if it happens at all.

The challenge of inclusive research *to move the decision-making dial from a top-down approach to bottom up* needs to be viewed as a dynamic phenomenon where the journeying aims to refine and reframe the translation of research outcomes into evidence-based practice with co-researchers with intellectual disabilities playing a major funded role. One example of such is the consensus statement developed by Frankena et al. (2019) around what constitutes inclusive health research. Seventeen experts without and 40 with intellectual disabilities met through a series of three roundtables, with representatives from across Europe, the UK, and Australia, thereby reinforcing the global nature of inclusive research as a paradigm. The consensus statement covered the attributes and potential outcomes, as well as the reporting and publishing strategies associated with inclusive research. The work of Frankena et al. illustrates a process that has provided a framework for inclusive research to flourish, but not so well if ongoing funding is elusive.

5. Policy Development and Implementation

In considering policy development, we were able to reflect on inclusive research projects that we had all respectively been involved in or aligned with that had led to change in legislation and/or development and implementation of policies. The first example was a project that occurred in Ireland where the Inclusive Research Network conducted a study on relationships and supports (Bane et al. 2012) at a time when legislation on sexual offences that criminalised people with intellectual disabilities for having sexual relationships was being discussed by the Irish Government. A report by the Irish Inclusive Research Network gave additional credence to self-advocates who had been campaigning for equality in this area and who were invited to discussions with the Law Reform Commission on the necessary legislative changes. The *Criminal Law Act (2017)* (Sexual Offences) was enacted in 2017, as part of a programme of legislative changes to align with the CRPD, which Ireland ratified in 2018.

A second example was in Sydney where in 2015 the CDS Inclusive Research Network evaluated how the policy of closing a state government department that covered disability, arising from the introduction of the National Disability Insurance Scheme (NDIS), was impacting employees who were disabled. The involvement of co-researchers with intellectual disabilities in such projects speaks to the recognition of their strength as peer reviewers,

but what often follows is waiting on the road for the next policy review opportunity which can cast a long shadow. Nevertheless, as commented by Sarah there is enthusiasm within inclusive research circles for raising issues with politicians: *“Going down to Canberra is a great idea, I mean getting to meet them and have the day being able to talk to them and get them to learn and understand and know what they can do to make the systems work better for people that find it hard to access services and the support they need.”* The relationship between doing inclusive research and relevance to the work of governments can also be seen emanating from the Irish Inclusive Research Network’s voice *“We have not done research that is not relevant, that stays in the shelves, that is forgotten about, but research that is fundamental for the needs of governments, that contributes to what they do”* (García Iriarte and Donohoe 2022). As a group, its members acknowledged the value of involvement in specific research projects as catalysts for other investigations uncovering the need for change in policy. This link was expressed as follows: *“in the process of doing the research you hear stories and you realise maybe that’s not the way things should be done”* (García Iriarte and Donohoe 2022, in press).

Another incentive and opportunity for inclusive researchers to impact the policy scene would be involvement in monitoring service implementation. For this role, researchers with intellectual disabilities will have personal service experiences to draw upon, as well as those from networking with other people with disabilities and organisations. This was clear when Bruce and Sarah in 2016 were involved in a CDS Inclusive Research project entitled *Quality Checkers and Organisational Person Centredness: An Inclusive Research Approach* (<https://cds.org.au/research-development/research-projects/>, accessed on 21 July 2022). Members of the Inclusive research team all received training in checking the quality of residential services and support in implementing such strategies within a large NFP organisation. Bruce was part of the team that reported on the outcomes of the project with members of the service agency at the ASID (Australasian Society for Intellectual Disability) Annual Conference in Queensland in 2018, thereby promoting the praxis value of inclusive research.

Up to now, inclusive research has not been able to compete with traditional procedures for acquiring research funding as grants are based on the credibility of those leading the research—usually university staff—and the peer review process that tends to value commonly used methodologies familiar to the reviewer. Even so, it is debatable whether the policies and practices for funding research have resulted in effective and actionable guidance on policy development as this is rarely a topic for research across health and social care, still less with respect to disability. However, the need to do this is recognised in the UK by NICE (<https://www.nice.org.uk/>, accessed on 17 July 2022) and SCIE (<https://www.scie.org.uk/>, accessed on 17 July 2022), which produce evidence summaries to support their recommendations around treatments and services relevant to disability, although the implementation of such guidance is insufficiently studied. Nonetheless, opportunities are emerging that inclusive research could exploit more fully. Public patient and service-user involvement in policy making is more widely accepted and systems are in place to ensure that it is present when research proposals are being considered for funding. That is a necessary beginning, but the case needs to be made for the ongoing involvement of service users rather than entrusting the study only to professional researchers, given the many operational decisions required as a study gets underway that would benefit from the voice of those affected by the targeted research questions.

This same thinking can be applied to those with responsibility for formulating policy. Research that is inclusive would bring them into direct contact with the people who stand to gain most from the policy development, as well as ensure that the research addresses the issues on which decisions for better systems and lives must be made. This is of relevance when inter-sectoral policies are the focus of interest. People with disabilities do not live their lives within the silos that administrative systems have created. For example, decisions around housing are taken separately from policies on employment, which in turn gets ignored when mental health is the focus of policy development. People with lived experience of disability have had to integrate the intended—and unintended—

aspects of ‘silo’ policy making, which is possibly a major contributor to failures in policy implementation.

To realise the advantages of inclusive research, new ways of commissioning and undertaking research are required. This may place extra demands on the inclusive research teams for which grant-writing training is needed that includes an understanding of both the implications of research for policy development and implementation, as well as funding resources. On-the-job training for inclusive co-researchers with intellectual disabilities goes beyond methodology to active mentoring, also in grant writing.

6. Moving Forward on a Road Less Well-Travelled

In returning to the title of this article, inclusive research has been framed by an examination of its successes and the challenges still being faced on a road of research less well-travelled. We end by summarising the main recommendations to emerge from our review of the past two decades of inclusive research involving people with intellectual disabilities as co-researchers. We are confident of the knowledge base that exists to take us further along the road, strengthened by our own enthusiasm and commitment to take the road that will, as described in the opening poem, “make all the difference”. The “how” of the recommendations will be left up to you as readers as you partner with other stakeholders of inclusive research who are known to you as or who are potential travellers.

It is recommended that:

1. Key stakeholders of inclusive research both within and across geographic boundaries combine to offer workshops/events to raise the consciousness of all researchers to what it means to partner with co-researchers with intellectual disabilities through, for example, national service organisations/bodies, universities, and self-advocacy groups.
2. Training in inclusive research should be more widely available as part of research method courses within universities, other tertiary education, and private training settings. Features of such training are to include:
 - (a) Training in inclusive research practice is developed as a joint course undertaken by co-researchers both with and without disabilities. Such training is to be open to support staff and family members as allies in making research more inclusive.
 - (b) Co-researchers with intellectual disabilities act as tutors within training courses.
 - (c) Inclusive research training covers not only methodology but also co-authoring articles and reports, as well as the development of accessible training materials.
 - (d) Government policy relating to research enables on-the job research training for people with intellectual disabilities, as well as a paid career structure.
 - (e) How to engage in consultation processes on national research strategies raising awareness with researchers in government, universities and discipline associations.
3. Inclusive research is recognised for its accessible methodologies in identifying the issues affecting the quality of life of people with intellectual disabilities. Hence, the lack of equal opportunities locally, nationally, and internationally for people with intellectual disabilities to gain employment as inclusive researchers must be addressed.
4. The ‘bottom-up’ approach of inclusive research in the selection and development of research proposals needs to be recognised and supported by the traditional ‘top-down’ management systems used by university, government, and NGO organisational leadership.
5. Policy makers are to be invited to partner with people with intellectual disabilities in developing, implementing, and evaluating disability policy and the commissioning of research.
6. As part of partnering with policy makers, funding is made available for researchers with intellectual disabilities to be resourced for doing both the research and for the

dissemination and implementation of the findings, including conference presentations.

7. The global community of inclusive researchers should be invited by IASSIDD to discuss what it would take for inclusive research to have an impact on overall disability research, policy, and practice.

Finally, in conclusion, we return to what Bruce and Sarah see as the first steps needed if they are to continue on the road of inclusive research that they have valued to date. For Sarah, the first signpost needs to cover that “*people with intellectual disabilities are equal partners in conducting the research*”, particularly in “*asking the questions*”, and that they get paid for their time. For Bruce it was “*getting a research qualification and being supported to complete it*”. They both agreed that their journey of inclusive research to date, in response to Robert Frost’s opening poem, has made a difference.

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