



Inclusive Research: Doing Participatory and Emancipatory Research with People with Intellectual Disabilities

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Abstract

This chapter discusses the origins, principles and practices of doing inclusive research with persons with intellectual disability as co-researchers. The relationship between inclusive research on the one hand and participatory and emancipatory research on the other is considered together with the link to self-advocacy. The chapter also provides examples of inclusive research and discusses the methods that are mostly used in inclusive research. The role of academic researchers and co-researchers with intellectual disability is also discussed, both in conducting research and in writing about the research carried out.

Keywords

Inclusive research · Self-advocacy · Intellectual disability

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Introduction

Although the slogan “nothing about us without us” did not originate with the disabled people’s movement, it has been used by disabled activists to such an extent that it has become practically synonymous with this movement (Charlton, 1998). Its premise – that nothing about disabled people should be done without their direct involvement – holds for the development of legislation and policies, for service provision, and also for conducting research. It also holds for all disabled people, including persons with intellectual disabilities (referred to as persons with learning difficulties/disabilities by British authors).

It is through inclusive research that persons with intellectual disabilities are directly involved in carrying out research. Inclusive research borrows from the principles and practices of emancipatory disability research, participatory research, and self-advocacy to create a unique approach to doing research. This chapter first traces the origins of inclusive research and then discusses some examples of inclusive research projects. It then considers the conceptual framework of inclusive research and the research methods that are typically used. Following this, the chapter discusses issues related to the provision of support for persons with intellectual disability to engage in research and how inclusive research is written about, before concluding by drawing together the main issues discussed.

The Origins of Inclusive Research

The term “inclusive research” was coined by Jan Walmsley in an article published early this century on “a range of research approaches that have traditionally been termed “participatory” or “emancipatory”, broadly speaking research in which people with learning difficulties are involved as more than just research subjects or respondents” (Walmsley, 2001, pp. 187–188). Walmsley identifies normalization (later known as social role valorization) (Wolfensberger & Tullman, 1989 cited in Walmsley, 2001) and the social model of disability (Oliver, 1983) as two main influences on the emergence of inclusive research. The ideas underpinning the theory and practice of normalization and the social model have also contributed, albeit in different ways, to substantial improvements for people with intellectual disability in many countries to enjoy their rights and experience a better quality of life.

One of the most significant developments has been the realization of the perspectives of persons with intellectual disability. “Realisation” is here being used in two senses: in the sense of people working and living with people with intellectual disability realizing that the latter’s perspectives were valid and that it was important to take them into account in their work; and in the sense of taking steps to make the articulation of these perspectives a reality. In research, the first step entailed involving persons with intellectual disability as research participants. In itself, this was a significant step given the long history of doing research about persons with intellectual disability without their perspectives being taken into account (Walmsley &

Johnson, 2003). One wonders if these persons even knew that they were the subject of research. Works which presented their perspectives – one of the earliest being Bogdan and Taylor (1982) – were therefore a very important development.

The second step built on this development through research projects including persons with intellectual disability in *all* stages of the research process and therefore also as researchers. Apart from the influences mentioned above, another influence on inclusive research was self-advocacy (Walmsley, 2001; Walmsley & Johnson, 2003). As Sutcliffe and Simons (1993) report, self-advocacy means speaking up for yourself and others, making choices and acting on them, speaking with people and holding meetings, and making things happen. All of these aspects of self-advocacy are compatible with conducting research, and inclusive research can be seen as a specific way of doing self-advocacy. In fact, Bigby, Frawley and Ramcharan (2014) link the development of self-advocacy in Australia with the development of inclusive research.

A very important aspect of self-advocacy is that persons with intellectual disability are provided with support from others, usually nondisabled persons. The parallel in inclusive research is that of professional (often academic) researchers providing support to coresearchers with intellectual disability. Discussions about inclusive research also refer to participatory research and emancipatory disability research as having had significant effects on the development of inclusive research (see Walmsley, 2001; Walmsley & Johnson, 2003; Nind, 2014). In line with participatory research, inclusive research involves those who are usually the subject of research as researchers in their own right. In fact, in North America it is referred to as a form of participatory action research (see McCulloch, 2011; Ward & Trigler, 2001). The links between the two are further reinforced by references to Paulo Freire's work by many of those writing about inclusive research, including Walmsley (2001), Stevenson (2014), Nind (2017), and Embregts et al. (2018). This article uses the term "inclusive research" since it refers to the specific way in which persons with intellectual disability are involved as coresearchers.

One particular characteristic of inclusive research is that it also builds on the principles of emancipatory disability research. In fact, in line with these principles – as set out by Barnes (2002) – in inclusive research, researchers hold themselves accountable to persons with intellectual disability, use a social model understanding of the nature of intellectual disability (and therefore focus on socially constructed barriers), address such barriers in research by using methods that are accessible, privilege the perspectives of persons with intellectual disability and their experiences, and use research as a tool for improving the lives of persons with intellectual disability. As Barnes (1992) writes elsewhere, "researchers must put their knowledge and skills at the disposal of disabled people. They do not have to have impairments themselves to do this" (p. 122). Inclusive research is an excellent example of how this can happen.

In her first article on inclusive research, Walmsley (2001) notes that inclusive research was at risk of being marginalized. Fourteen years later, she describes being "amazed to see it blossom into an international phenomenon" (Walmsley, 2015, unpagged). In fact, since the first projects carried out in the 1990s, inclusive research

has become a well-established approach to doing research. Some examples of inclusive research projects are discussed in the next section.

Inclusive Research Projects

In her 2001 article, Walmsley felt the need to create a new term to reflect the uniqueness of this research approach when compared to other ways of doing research, including participatory and emancipatory disability research. It is, however, not unique in the sense of comprising one way of doing research which is replicated by all those doing inclusive research.

Some of the first research projects that adopted inclusive approaches focused on telling the life stories of persons with intellectual disability. One example *Women with Intellectual Disabilities: Finding a place in the world* which, as the editors say, “is written by, with and about women with intellectual disabilities” from Australia, the Czech Republic, England, Iceland, New Zealand, Norway, Slovakia, and the USA (Traustadóttir & Johnson, 2000, p. 9). Other examples of this type of inclusive research are the accounts of the lives of persons with intellectual disability in Flanders, Belgium, compiled by the self-advocacy organization Onze Nieuwe Toekomst (referred to by Roets et al., 2005), and the personal stories in some of the chapters in Mitchell et al.’s (2006) *Exploring Experiences of Advocacy by People with Learning Disabilities: Testimonies of Resistance*. The majority of the authors with intellectual disability who contributed to this volume are members of self-advocacy groups, mostly but not all in the UK – an attestation of the close links between self-advocacy and inclusive research at least in the early stages.

These and similar publications build on what was achieved by work such as that by Bogdan and Taylor in their presentation of the life stories of Ed Murphy and Pattie Burt, which they reconstructed from hours of recorded open-ended interviews. As mentioned above, Bogdan and Taylor’s (1982) book was groundbreaking in presenting the lives of two persons with intellectual disability from their own perspective. What the contributors to books such as the ones by Traustadóttir and Johnson (2000) and Mitchell et al. (2006) did was to support persons with intellectual disability to write their own life stories and have them published in their names with the nondisabled people who provided support listed as coauthors. The result is that “[t]hey present to the reader an active and assertive group of people that counters the passive image of people with learning disabilities that is so often portrayed” (Mitchell, 2006, p. 7). Furthermore, by presenting the perspectives of persons with intellectual disability in pieces written (or cowritten) by the persons themselves, these and similar publications also show how they are capable of reflecting on their lives and articulating their perspectives.

Another development was for persons with intellectual disability to conduct research about the lives of other persons with intellectual disability. One of the first such studies, reported on by Sample (1996), was conducted in the USA and focused on the recreational and leisure needs of adults with developmental disabilities. Very often, such research is conducted by self-advocacy groups in partnership

with academic researchers, a clear indication of the similarities of inclusive research to participatory and emancipatory disability research. One study, conducted in the 1990s by the Bristol Self-Advocacy Group, was aimed at finding out about how other self-advocacy groups work (Williams, 1999). Self-advocacy has continued to be linked closely with inclusive research. McCulloch's PhD thesis is built on the use of participatory action research with four Canadian persons with intellectual and developmental disabilities "to practise being self-advocates" (McCulloch, 2011, p. i). More recently, Central England People First carried out inclusive research about the group's own history (Walmsley & The Central England People First History Project Team, 2014).

Inclusive research has also been conducted in various countries about different subjects that are of interest for persons with intellectual disability. Taylor et al. (2007) present the results of research carried out with service-users with intellectual disability in the UK. Frankena et al. (2019) synthesize the results of inclusive health research projects carried out in Ireland, Northern Ireland, and The Netherlands. Vega-Córdova et al. (2020) report on an inclusive research project on "the cognitive accessibility of public spaces and services in a Chilean city" (p. 318). Other research subjects include independent living in a study carried out in Catalonia, Spain (Coll et al., 2016), and overprotection in a study carried out in Malta, a study that I carried out with a coresearcher with intellectual disability (Callus et al., 2019). For these studies, ad hoc research teams were created. There are also research teams whose members remain more or less the same from one project to the next. These include the Building Bridges Research Group in the UK which is part of a nongovernmental organization (Building Bridges Training, 2020) and two inclusive research networks based at a university, one in Ireland (Trinity College Dublin, 2020) and one in Australia (Centre for Disability Studies, 2021).

The publications cited in this section provide some examples of the type of inclusive research projects that have been carried out in various countries. While they attest to the variety of topics researched, research team set-ups, and methods used – as seen also later in this chapter – one of the characteristics that they share is that, while the projects are situated in different continents, the countries mentioned are almost all placed in the Global North. There are examples of participatory research in the Global South, such as the video project with disabled people in Burkina Faso by Bezzina (2019). Any developments in the area of inclusive research itself would need to grow organically within the context of different countries. They would also need to take into account the issues faced by disability researchers in the Global South, especially the risk that researchers from the Global North carry out this research from their own epistemological standpoints and without regard of the socioeconomic and cultural context in which the research is being carried out. Rioux et al.'s (2016) reflection on their experience of doing research in Global South countries highlights the reasons why sensitivity to this context is essential. Another issue is the dominance of researchers from the Global North in research projects situated in the Global South – as attested, for example, by Hanass-Hancock, Chetty and Myezwa (2019) in the African context. As Katsui and Schwartz (2021) write,

The great heterogeneity of disability and its contexts, as well as its evolving nature, mean that we must all think deeply about interconnectedness, relationality, and continuity of disability with other phenomenon across different time and space. (p. 205)

Naturally, this observation is valid for all countries – regardless of their socio-cultural and economic contexts.

The Conceptual Framework of Inclusive Research

In her book on inclusive research, Nind (2014) says that she prefers referring to “doing research inclusively” than to inclusive research (p. 92), arguing that this term avoids an idea of inclusive research as being either monolithic or static. However, despite the varied and ever evolving ways in which inclusive research is carried out, there are kindred practices and conceptual underpinnings to the type of research projects mentioned in the previous section which make them identifiable as being inclusive. The practices and research methods used are discussed in the next section, after an exploration of the conceptual framework informing inclusive research in this section.

The most important concept underlying inclusive research is an understanding of disability as being something other than the sum total of one’s impairment. Within this framework, the nature of disability is understood in different ways: as standing in clear opposition to impairment as with the social model of disability (Oliver, 1983); as being in relation with impairment as with the social relational model of disability (Thomas, 2004); or as being a concept that needs to be critiqued alongside the notion of impairment as with critical disability studies (Vehmas & Watson, 2014). These and other models of disability complement each other by distinguishing between disabling barriers and impairment, even if the nature of the two and the relationship between them are contested to different degrees and in different ways. What is important is that the distinction is made and applying it to intellectual disability enables addressing the contextual barriers that persons with intellectual disability encounter in the research process, rather than attributing the cause of the difficulties they experience solely to the presence of cognitive impairment. This is not to say that the presence of impairment and its potential effects are ignored. On the contrary, it means that measures are put in place to cater for impairment-related limitations. Thus, persons with intellectual disability are conceptualized as being able to engage in all stages of the research process – from planning through to implementation and onto dissemination of results – once the required support is in place.

In this regard, the concept of “relational autonomy” can be seen as an inherent component of the conceptual framework of inclusive research, even if it is not used explicitly by those writing in the area. Davy (2015) calls for a conceptualization of autonomy “as enabled relationally, through a network of relationships that require support and advocacy, rather than as a status or psychological attribute” (p. 146). The relationships forged in the process of conducting inclusive research fit very well

within this concept, since persons with intellectual disability are provided with support to engage directly and actively in the research process and barriers to their doing so are addressed. As Davy (2015) explains, relational autonomy “captures the notions of interdependence and ongoing support” (p. 146). These notions apply to inclusive research as well – the different actors involved in such research are dependent on each other as they engage in different and complementary roles, with the academic (or other) researchers providing support to coresearchers with intellectual disability in the process of conducting research together. In fact, Nind and Vinha (2014) place support, negotiation, and interdependence at the center of inclusive research.

Another important concept underpinning inclusive research is that of knowledge being (at least partly) experiential in nature. The knowledge that persons with intellectual disability bring to inclusive research, which they have acquired through their lived experience, thus plays an essential part in inclusive research. In fact, coresearchers with intellectual disability are referred to as “experts by experience” by some authors (see Embregts et al., 2018; Vega-Córdova et al., 2020). The lived experience of coresearchers can – and should – inform all the stages of the research process, starting from the choice of research topic. From my own experience, I appreciated the importance of this when – in relation to the research on overprotection mentioned above – I first discussed with my coresearcher what we should do our research on. She immediately mentioned overprotection, a subject that I had not thought of but which is important for her and other persons with intellectual disability that she knows.

The dynamic nature of inclusive research, the attention given to socially constructed disabling barriers, and the importance placed on expertise gained from experience and on the relationship between those involved in conducting research place inclusive research within the interpretive research paradigm. As explained by Corbetta (2003), in interpretivism, reality is seen as knowable through the meanings attributed to it by different individuals. Consequently, what is seen as researchable is not the objective nature of a particular reality, but the subjective interpretations attributed to that reality by those who live it. Given these ontological and epistemological standpoints, the research methodologies used are ones that promote interaction between researchers and researched. As with participatory research, inclusive research goes even further by adding a researcher role to those (or at least some of those) who are researched.

Inclusive Research Methods

The interpretive paradigm in which inclusive research is situated means that it is qualitative methodology that is usually employed. There are some exceptions where quantitative methods have been used within projects that have been conducted inclusively to different extents. For example, Walmsley (2015) reports on research by Emerson et al. (2005) in which adults with intellectual disability helped to develop methods and questioning techniques that were accessible and also to ensure

that the results of the survey conducted were presented in an accessible manner. The research that Sample (1996) reports on used a mixed methodology.

Most other inclusive research projects use a qualitative research methodology, thus involving meetings with people. The types of meetings and the people concerned vary according to the nature of the project. For example, many of the projects mentioned earlier in this chapter through which persons with intellectual disability were supported to construct and write their life stories entailed meetings between these persons and those supporting them. There are also other projects – including some referred to above as well as others such as the one reported on by Mooney, Rafique and Tilly (2019) – in which the persons with intellectual disability involved were both coresearchers and the research participants themselves. In other projects, the research participants were not the researchers with intellectual disability and they were involved in different ways – for example, meetings with self-advocacy groups (Williams, 1999), interviews (Frankena et al. 2019), and focus groups (Callus et al., 2019). The input of persons with intellectual disability and other researchers in these studies varies. Bigby et al. (2014) identify three types of involvement of the former: as advisors, as the ones leading and controlling the research, and as part of a collaborative team.

In the research on overprotection, the coresearcher and I worked as a team in all stages of the research. At the planning stage, we both made suggestions which we discussed. We also carried out the fieldwork, transcription, and analysis together. I took care of the literature review and applying for ethical clearance. There were also areas where I provided guidance for the coresearcher, for example, in how to conduct the focus groups, do the transcription, put together the analysis, and present the research. We carried out this research collaboratively after working together on other projects in which I was more in control. Moving from one type of involvement to the other can therefore also be an evolutionary process as those involved in inclusive research gain more skills and experience.

Providing Support in Inclusive Research

An essential part of inclusive research is making the different stages of the research process accessible to the researchers who have intellectual disability. Providing accessibility in this context broadly means that the members of the research team who do not have an intellectual disability provide support to those who do. In fact, inclusive research poses challenges for those providing support to persons with intellectual disability to find the right balance between ensuring that the necessary support is provided without taking control of the process themselves.

An important area where support is needed is to ensure access to information. Since most publications are not written in easy-to-read language, persons with intellectual disability do not have direct access to information and are therefore rarely in a position to decide which information is relevant and how to make it accessible. It is left to those who can read and understand such information and, very importantly, know where to look for it, to decide what to render in an accessible

format and how. Cobigo et al. (2019) discuss access to recruitment letters and consent forms for persons with intellectual disability. While their focus is on the latter as research participants rather than coresearchers, what they have to say is also relevant for inclusive research. They note how they decided what information to include in the accessible versions of these documents and what to leave out. The process therefore inevitably entails interpretation. In fact, Williams (1999) observes how as an inclusive researcher she often acted as an interpreter for the self-advocates she was doing research with. Furthermore, even when written information is provided in an easy-to-read format, access for all persons with intellectual disability cannot be automatically guaranteed since many of them may still need support in understanding what is written (Oldrieve & Waight, 2013).

Persons with intellectual disability also need support with devising a research plan and implementing it, analyzing data, and writing up and presenting research results. One of the most important issues is that those supporting coresearchers with intellectual disability need to be wary that they provide guidance where it is needed without exerting control, even if unwittingly. On a personal level, I find Hanna's (1978) image of the balance-beam – in relation to providing support in self-advocacy groups – very useful as it depicts how one must find the right balance between providing the right kind and the right amount of support that is neither too little nor too much. As I argue in Callus et al. (2019), being reflexive in the practice of inclusive researcher, being attentive to questions that need to be asked, and seeking answers to them are very important.

The issues that these support needs give rise to have been well discussed in the literature on inclusive research since its inception. For example, Williams (1999) discusses her role as academic researcher providing support to the Bristol Self Advocacy Group. She is honest about her own influence over the group (for example, being the one to suggest that they do research) and her access to information which is often beyond the reach of persons with intellectual disability. As she writes,

most of us do have the advantage of being able to read research journals, books and other literature. We also go to conferences and meet other researchers; we might work in centres where other colleagues can be consulted quite easily. (Williams, 1999, p. 49)

Williams also discusses the method used for data analysis, pointing out that making this process accessible means that more time than usual is needed for this stage. The issue of needing more time to carry out inclusive research is also mentioned by Embregts et al. (2018). Stevensons' (2014) article about the process of analyzing data in a collaborative manner with coresearchers with intellectual disability is a clear example of how this process can be facilitated once there is enough time allocated to it.

Issues regarding data analysis do not rest only with how it is done and how long it takes. The process of discussing the data beyond the immediate experience of the researchers with intellectual disability is also considered. Williams (1999) argues that persons with intellectual disability do engage in such processes:

If a theory is broadly taken to be a model that helps us to understand why things are as they are, then self advocates do engage in theory building incessantly. For instance, the theory that labelling influences people's thinking is a very powerful one. (p. 51)

This position is also taken by Roets et al. (2005) in their discussion of how self-advocates could reflect on their life experiences and consider social factors impacting those experiences. Labeling is one such factor, and they quote Patrick Scheffhout, a self-advocate:

I find the word 'mentally retarded' a pityful [sic] word. It's made up by them to put a stamp on your head – you're simply not able to do one thing. I don't think they are right. I find out it only is a label – to make you stay where you are. (Roets et al., 2005, p. 106)

However, there are also levels of theorization that are inherently difficult for persons who have intellectual disability to achieve because of the cognitive limitations experienced (Schalock et al., 2021). This situation creates dilemmas for academic researchers. For example, Walmsley (2001) draws from her own experience of working together with other academics and with women with intellectual disability on a book about the women's life stories. The academics wanted to bring in feminist and disability theories to bear onto these stories, whereas the women with intellectual disability "wanted the stories to speak for themselves" (Walmsley, 2001, p. 198). While this group of researchers were able to compromise, others find it difficult to do so especially when persons with intellectual disability are involved in research projects which are also the PhD project of the researcher providing them with access and support. This was the case, for example, for Williams (1999), Björnsdóttir and Svendsdóttir (2008), and McCulloch (2011). Walmsley (2001) also makes the point that not engaging in theoretical discussions about the findings generated by inclusive research project can risk holding back its development.

The ways in which the issues and challenges discussed here are tackled to ensure that inclusive research is carried out effectively depend to a large extent on the competencies of those involved. In this regard, the research by Embregts et al. (2018) is very useful because it throws light on the competencies that are needed for people with and without intellectual disability to engage in inclusive research. Some of the competencies are needed by both – building a mutual relationship, communicating, and being adaptable and flexible. Then, those who do not have an intellectual disability need to be able to respond to the support needs of persons with intellectual disability. The third set of competencies are relevant for persons with intellectual disability, including the ability to learn and develop and the ability to ask questions and to reflect.

This last set raises a perennial issue faced in inclusive research – the tendency for the persons with intellectual disability involved in it to be ones who are articulate and do not have high support needs. The inclusion of persons with severe levels of cognitive impairment is a challenge that has yet to be taken on. One of the main challenges is that of communication. Even involving persons with communication difficulties as research participants can be challenging (Nind, 2008; Valade, 2004).

This is not to say that there cannot be other ways of doing inclusive research that are better adapted to those with communication difficulties. But it certainly is an area that needs to be developed.

How Inclusive Research Is Written About

There are potentially as many publications presenting the results of research projects conducted inclusively as there are publications discussing how the research was conducted and written about. Broadly speaking, the latter tend to be written by academic researchers for peer-reviewed publications, including a significant proportion of the publications cited in this chapter. The former tend to be cowritten with persons with intellectual disability and published in easy-to-read formats as research reports. This twin track responds to the dilemma discussed above about keeping writing accessible – and therefore outside what is usually expected for an academic publication – and developing inclusive research and its output conceptually within academia – with the result of making it largely inaccessible for those who have intellectual disability. Publishing inclusive research findings accessibly and discussing inclusive research methodology academically are a way of dealing with these two demands.

Academics working within the inclusive research paradigm are well aware of the paradoxical situation they find themselves in when they do not write in an accessible manner (this chapter being itself one such instance). For example, Walmsley and Johnson (2003) explain why their book on inclusive research is not targeted at persons with intellectual disability. They felt that they needed “space to air arguments and debates before attempting to “translate” them into accessible formats” (p. 15). Williams (1999) and Björnsdóttir (in Björnsdóttir and Svensdóttir (2008)) both tackle the issue of not being able to make their PhD work accessible because of academic requirements.

There are also collaborative writings in academic publications. For example, Björnsdóttir’s coauthor is a self-advocacy group member. Other examples of such collaborations cited above are Roets et al. (2005), Walmsley and The Central England People First History Project Team (2014), Callus et al. (2019), and Mooney et al. (2019). With the exception of the latter, the lead author in these publications are academics. Such publications usually also have a section describing the different roles played by the authors in the writing process. They are then often complemented by non-peer-reviewed publications where the lead author is a person with intellectual disability. To return to the example from my own work, the coproduced article published from the research on overprotection in an academic journal (Callus et al., 2019) has a parallel more detailed report of the research findings written in a more accessible manner as well as an easy-to-read summary (in both Maltese and English) (see Bonello and Callus (2017) for the report in English). A similar strategy was also used by Nind and Vinha (2014), two academic researchers who, apart from the peer-reviewed article, also published the full report on their analysis of doing inclusive research (Nind & Vinha, 2012). Apart from having the advantage of allowing for

both accessible and academic types of writing, this practice enables researchers with intellectual disability to take the lead in some of the publications and provides documentation that is accessible for other persons with intellectual disability. Much of this documentation is published online, and in this regard, the Internet has made it possible for accessible research reports to be published and disseminated widely since they are also open-access. Moreover, this enables the publication of research reports in much greater detail than is ordinarily possible in peer-reviewed articles.

There are also articles written in easy-to-read language in peer-reviewed publications. One notable example is Docherty et al.'s (2005) chapter in Goodley and Van Hove's *Another Disability Studies Reader?* Another is the 2012 special issue of the *British Journal of Learning Disabilities* on "Research and work of people with learning disabilities and their allies and supporters" in which not only are the articles coauthored with persons with intellectual disability, but also the peer-review team that edited the issue was comprised of academics and researchers with intellectual disability.

Conclusion

The development of inclusive research is strongly tied with the disabled people's movement, especially self-advocacy. Within academia, it is connected with the evolution of participatory research and emancipatory disability research, which have enabled those who were once the passive (and even unwitting) subjects of research to set research agendas and carry out research themselves.

Inclusive research has developed into a unique way of doing research, especially through the way that professional researchers support persons with intellectual disability while simultaneously conducting research with them. Inclusive research operates within a recognizable conceptual framework which sits well within the interpretive paradigm of social science research. Most inclusive researchers use qualitative methodologies, with variations in the types of methods used and the respective roles of researchers with and without intellectual disability. One of the issues faced by the latter is how to provide the necessary support for coresearchers with intellectual disability without exerting control over the research process, especially since they are the ones with access to the relevant information and with professional experience in conducting research.

When it comes to publications, those involved in inclusive research seek a balance between publishing in a nonacademic accessible manner and using an academic nonaccessible style. Quite often, this balance is found by having research reports using plain language (usually published online) and peer-reviewed publications which usually discuss the processes used to conduct the research. Researchers with intellectual disability usually take the lead in the former.

Since its beginnings in the 1990s, inclusive research has developed considerably. There are also continuing challenges for it to deal with, most notably the involvement of persons with intellectual disability who have communication difficulties or

high support needs and the use of inclusive research methods in the Global South. The fact that inclusive research has a coherent conceptual framework while at the same time affording a high degree of flexibility in how it is conducted augurs well for developments that can meet these challenges in an authentic manner.

References

- Barnes, C. (1992). Qualitative research: Valuable or irrelevant. *Disability & Society*, 7(2), 115–124.
- Barnes, C. (2002). 'Emancipatory disability research': Project or process? *Journal of Research in Special Educational Needs*, 2. <https://doi-org.ejournals.um.edu.mt/10.1111/j.1471-3802.2002.00157.x>
- Bezzina, L. (2019). *Disability and development in Burkina Faso: Critical perspectives*. Springer Nature.
- Bigby, C., Frawley, P., & Ramcharan, P. (2014). Conceptualizing inclusive research with people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 27(1), 3–12.
- Björnsdóttir, K., & Svendsdóttir, A. (2008). Gambling for capital: Learning disability, inclusive research and collaborative life histories. *British Journal of Learning Disabilities*, 36(4), 263–270.
- Bogdan, R., & Taylor, S. J. (1982). *Inside out: Two first-person accounts of what it means to be labeled 'mentally retarded'*. University of Toronto Press.
- Bonello, I., & Callus, A. M. (2017). Over-protection in the lives of people with an intellectual disability in Malta: Research findings. https://www.um.edu.mt/_data/assets/pdf_file/0020/337502/Reportonoverprotectionresearch.pdf
- Building Bridges Training. (2020). Research group. <https://www.building-bridges-training.org/research-group>
- Callus, A. M., Bonello, I., Fenech, R., & Mifsud, C. (2019). Overprotection in the lives of people with intellectual disability in Malta: Knowing what's stifling control and what's enabling support. *Disability & Society*, 34(3), 345–367. <https://doi.org/10.1080/09687599.2018.1547186>
- Centre for Disability Studies. (2021). Inclusive research. <https://cds.org.au/promoting-inclusion/inclusive-research/>
- Charlton, J. (1998). *Nothing about us without us: Disability oppression and empowerment*. University of California Press.
- Cobigo, V., Potvin, L. A., Fulford, C., Chalghoumi, H., Hanna, M., Plourde, N., Taylor, W., & D. (2019). A conversation with research ethics boards about inclusive research with persons with intellectual and developmental disabilities. In M. A. Casco & E. Racine (Eds.), *Research involving participants with cognitive disability and differences* (pp. 185–196). Oxford University Press.
- Coll, T., Comas, J., Cornellà, A., Diaz, G., Fontané, À., Fullana, J., González, C., Martí, P., Pallisera, M., Puyalto, C., Riu, L., & Vilà, M. (2016). 'Where to live and with whom': Barriers to and supports for independent living from the viewpoint of advisors with disabilities. Institute of Educational Research, University of Girona. <http://recercadiversitat.wix.com/diversitat>
- Corbetta, P. (2003). *Social research: Theory, methods and techniques*. Sage.
- Davy, L. (2015). Philosophical inclusive design: Intellectual disability and the limits of individual autonomy in moral and political theory. *Hypatia*, 30(1), 132–148.
- Docherty, D., Hughes, R., Phillips, P., Corbett, D., Regan, B., Barber, A., Adams, M., Boxall, K., Kaplan, I., & Izzidien, S. (2005). This is what we think. In D. Goodley & G. Van Hove (Eds.), *Another disability studies reader? People with learning difficulties and a disabling world* (pp. 29–49). Garant.
- Embregts, P. J., Taminiau, E. F., Heerkens, L., Schippers, A. P., & Van Hove, G. (2018). Collaboration in inclusive research: Competencies considered important for people with and without

- intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 15(3), 193–201.
- Frankena, T. K., van Schroyensteyn Lantman–de Valk, H., Cardol, M., van der Crujisen, A., Jansen, H., Leusink, G., & Naaldenberg, J. (2019). Contributing to inclusive research policy and practice: A synthesis of four inclusive (health) research projects. *Journal of Policy and Practice in Intellectual Disabilities*, 16(4), 352–360.
- Hanass-Hancock, J., Chetty, V., & Myezwa, H. (2019). Advancing disability inclusive research in Africa. Retrieved from <https://www.samrc.ac.za/sites/default/files/attachments/2020-11-26/ADIRA.pdf>
- Hanna, J. (1978). Advisor's role in self-advocacy groups. *American Rehabilitation*, 4(2), 31–32.
- Katsui, H., & Swartz, L. (2021). Research Methods and Practices of Doing Disability Studies in the Global South. *Scandinavian Journal of Disability Research*, 23(1), 204–206.
- McCulloch, J. M. (2011). *Adults with intellectual and developmental disabilities utilize participatory action research to practise being self-advocates and researchers* [Unpublished Ph.D. thesis, University of Regina].
- Mitchell, D. (2006). Introduction. In D. Mitchell, R. Traustadóttir, R. Chapman, L. Townson, N. Ingham, & S. Ledger (Eds.), *Exploring experiences of advocacy by people with learning disabilities: Testimonies of resistance*. Jessica Kingsley.
- Mitchell, D., Traustadóttir, R., Chapman, R., Townson, L., Ingham, N., & Ledger, S. (Eds.). (2006). *Exploring experiences of advocacy by people with learning disabilities: Testimonies of resistance* (pp. 7–10). Jessica Kingsley.
- Mooney, F., Rafique, N., & Tilly, L. (2019). Getting involved in the community – What stops us? Findings from an inclusive research project. *British Journal of Learning Disabilities*, 47(4), 241–246. <https://doi.org/10.1111/bld.12283>
- Nind, M. (2008). *Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges*. ESRC National Centre for Research Methods. <http://eprints.ncrm.ac.uk/491/1/MethodsReviewPaperNCRM-012.pdf>
- Nind, M. (2014). *What is inclusive research?* A&C Black.
- Nind, M. (2017). The practical wisdom of inclusive research. *Qualitative Research*, 17(3), 278–288.
- Nind, M., & Vinha, H. (2012). Doing research inclusively, doing research well? Report of the study: Quality and capacity in inclusive research with people with learning disabilities. https://www.southampton.ac.uk/assets/imported/transforms/content-block/UsefulDownloads_Download/97706C004C4F4E68A8B54DB90EE0977D/full_report_doing_research.pdf
- Nind, M., & Vinha, H. (2014). Doing research inclusively: Bridges to multiple possibilities in inclusive research. *British Journal of Learning Disabilities*, 42(2), 102–109.
- Oldrieve, W., & Waight, M. (2013). Enabling access to information by people with learning disabilities. *Tizard Learning Disability Review*, 18(1), 5–15. <https://doi.org/10.1108/1359471311295950>
- Oliver, M. (1983). *Social work with disabled people*. Springer.
- Rioux, M., Pinto, P. C., Viera, J., & Keravica, R. (2016). Disability research in the global south: Working from a local approach. In S. Grech & K. Soldatic (Eds.), *Disability in the global south: The critical handbook* (pp. 531–544). Springer.
- Roets, G., Van de Perre, D., Van Hove, G., Schoeters, L., & De Schauwer, E. (2005). Apple tree of knowledge: Activist tales as theoretical discourse. In D. Goodley & G. Van Hove (Eds.), *Another disability studies reader? People with learning difficulties and a disabling world* (pp. 95–118). Garant.
- Sample, P. L. (1996). Beginnings: Participatory action research and adults with developmental disabilities. *Disability & Society*, 11(3), 317–332. <https://doi.org/10.1080/09687599627633>
- Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021). *Intellectual disability: Definition, diagnosis, classification, and systems of supports* (12th ed.). American Association on Intellectual and Developmental Disabilities.

- Stevenson, M. (2014). Participatory data analysis alongside co-researchers who have Down syndrome. *Journal of Applied Research in Intellectual Disabilities*, 27(1), 23–33.
- Sutcliffe, J., & Simons, K. (1993). *Self advocacy and adults with learning difficulties*. NIACE.
- Taylor, J., Williams, V., Johnson, R., Hiscutt, I., & Brennan, M. (2007). *We are not stupid*. People First Lambeth.
- Thomas, C. (2004). Rescuing a social relational understanding of disability. *Scandinavian Journal of Disability Research*, 6(1), 22–36.
- Traustadóttir, R., & Johnson, J. (Eds.). (2000). *Women with intellectual disabilities: Finding a place in the world*. Jessica Kingsley.
- Trinity College Dublin. (2020). What is the Inclusive Research Network (IRN)? <https://www.tcd.ie/tpid/research/irn/inclusive-research-network.php>
- Valade, R. M. (2004). Participatory action research with adults with mental retardation: “Oh my God. Look out world.” University of Louisville Dissertation
- Vega-Córdova, V., Álvarez-Aguado, I., Jenaro, C., Spencer-González, H., & Diaz Araya, M. (2020). Analyzing roles, barriers, and supports of co-researchers in inclusive research. *Journal of Policy and Practice in Intellectual Disabilities*, 17(4), 318–331.
- Vehmas, S., & Watson, N. (2014). Moral wrongs, disadvantages, and disability: A critique of critical disability studies. *Disability & Society*, 29(4), 638–650. <https://doi.org/10.1080/09687599.2013.831751>
- Walmsley, J. (2001). Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society*, 16(2), 187–205. <https://doi.org/10.1080/09687590120035807>
- Walmsley, J. (2015). An introduction to inclusive research. <https://www.oups.org.uk/methods-articles/an-introduction-to-inclusive-research>.
- Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and future*. Jessica Kingsley.
- Walmsley, J., & The Central England People First History Project Team. (2014). Telling the history of self-advocacy: A challenge for inclusive research. *Journal of Applied Research in Intellectual Disabilities*, 27(1), 34–43. <https://doi.org/10.1111/jar.12086>
- Ward, K., & Trigler, J. S. (2001). Reflections on participatory action research with people who have developmental disabilities. *Mental Retardation*, 39(1), 57–59.
- Williams, V. (1999). Researching together. *British Journal of Learning Disabilities*, 27(1), 48–51.