

EDITORIAL

People with Intellectual Disabilities Conducting Research: New Directions for Inclusive Research

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One of the ‘fruits’ of the social model of disability and the ‘nothing about us without us’ movement is the adoption of an inclusive research approach. As the name implies, in this approach, both researchers without disability and people with intellectual disabilities conduct the research together on issues that are important and relevant to people with intellectual disabilities.

The terminology relating to inclusive research is not straightforward, with terms like ‘inclusive’, ‘participatory’ and ‘emancipatory’ research being clearly defined in the literature by some researchers, while others prefer to be more fluid in their interpretations. The term ‘inclusive research’ has been used for this special issue to represent the diverse faces of conducting researching *with* people with intellectual disabilities, rather than simply *on* people with intellectual disabilities.

There have been significant developments in this area of disability studies within last 20 years, especially since the publication of the seminal text ‘Inclusive Research with People with Learning Disabilities: Past, Present and Future’ written by Walmsley & Johnson in 2003. Many research studies that have been undertaken since then have also used an ‘inclusive research’ approach involving people with intellectual disabilities in the capacity of researchers. Most recently, the British Journal of Learning Disabilities (Blunt *et al.* 2012) has published the first special issue ever in the field that was both authored and edited inclusively.

In spite of this proliferation, or possibly because of it, there are many questions that still need to be answered, for example

1. What is the epistemological stance of inclusive research?
2. Is inclusive research a research paradigm or is it a research method?
3. Why is inclusive research important?
4. What is the added value of inclusive research?

5. What are the boundaries between inclusive research and advocacy?

6. What difference does inclusive research make?

7. Does inclusive research change lives of people with intellectual disabilities?

This special issue attempts to address at least some of these questions.

The editors of this issue acknowledge that inclusive research is not the only way that research about issues relating to and influencing lives of people with intellectual disabilities can be conducted. While the importance of inclusive research is unquestionable, it is not a ‘dogma’ for research in the area of disability studies. There needs to be a clear rationale and added value for using this approach.

One of the aims of this special issue is to begin to conceptualize inclusive research. The variety of ideas and experiences included in the articles within this issue begin to do this. This issue also aims to disseminate research data about the effectiveness and impact of inclusive research. In addition to these aims, this special issue is a call for harder evidence for the claims about the inclusive research approach and its assertions of effectiveness.

Bigby, Frawley and Ramcharan open this special issue with a much-needed discussion about conceptualizing inclusive research. The authors have identified and illustrated three distinct approaches from both the literature and their own experiences. Their conceptual framework may well be used as a guide for future inclusive research, in addition to opening up the door for more debate on how to define, conceptualize and undertake this research approach.

Strnadová, Cumming, Knox, Parmenter and the ‘Welcome to Our Class’ Group discuss the need for research training for an inclusive research team and provide an example of what this might look like from

their research study on the coping strategies of older women with intellectual disabilities. Their paper highlights the importance of team building, peer mentoring and taking individual team member preferences into account.

There is only anecdotal evidence on conducting data analysis within an inclusive research approach (Nind 2011). Stevenson's paper documents the analysis of textual data made available from a participatory action research project involving young people who have Down syndrome. The author shares her experience and hence inspires and informs other researchers seeking to include people who have an intellectual disability (and who also have access to text), in the data analysis process.

Walmsley and self-advocate colleagues explore the use of inclusive research methods in telling the history of self-advocacy. Their paper describes the journey of a self-advocacy group in telling its history. This account also addresses the issue of co-authoring academic papers by non-disabled researchers and researchers with intellectual disability. The use of different font for each group presents one possible solution to the challenge of non-disabled researchers meeting the requirements of formal academic dissemination while still allowing the coresearchers' voices to be heard.

Chapman has contributed a paper that details the varied roles of self-advocacy support workers in UK People First movement. The paper reflects on some critical processes and experiences of undertaking collaborative research in order to add to discussion around developing inclusive approaches. The findings explore how in inclusive research teams researcher roles are fluid, especially when it comes to who is providing support and assistance to whom.

Bigby, Frawley and Ramcharan build upon the framework proposed in the first paper by examining the collaborative group approach to inclusive research. They identify the components necessary for the successful application of this approach, gleaned from the shared experiences of an inclusive research group.

O'Brien, McConkey and García-Iriarte present their inclusive research study conducted on a national level. One of the distinguishing features of this paper is the examination of the feasibility of inclusive research across all aspects of the research process. Suggestions for making the process more accessible are made, for example, that the advisory group should be cochaired by a university researcher and a coresearcher with intellectual disability and that recruitment strategies for coresearchers need to include a session for supporters to understand that coresearchers with intellectual disabilities have ownership over the research agenda.

In their paper, Johnson, Minogue and Hopkins focus on how inclusive research may contribute to social change. The authors address this issue by exploring the contribution of two examples of inclusive research in Australia and the Republic of Ireland to change in policy and legislation. The paper explores how the process of empowerment of both people with intellectual disabilities and advocates undertaking research and the use of research findings in which they have a heard voice can promote change.

The papers contained in this special issue address the wide range of questions that need to be resolved within inclusive research, ranging from the conceptualization of inclusive research, providing arguments for its added value and suggesting how inclusive research impacts the lives of people with intellectual disabilities.

References

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