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Vorwort

Inclusive Research: a remarkable journey

As 'grandmothers' of inclusive research, we are honoured to write the preface to this remarkable book. Reading it marks a coming of age for a movement (and we use that word consciously) which began long before it was named in the early 2000s. It was part of the swing to optimism about the potential of people with intellectual disabilities which characterised the later twentieth century. Inclusive research went alongside and was part of the recognition of people with intellectual disabilities as fellow citizens, not people to be feared or pitied, but people who could speak for themselves, and take their place in many spheres of life, including research. As grandmothers, like parents, we have watched inclusive research grow and develop since we wrote a book trying to document both its origins and methodologies in 2003 (Walmsley & Johnson 2003). From small beginnings inclusive research has now become a diverse movement involving researchers in many different countries across the world. Sometimes there is a hesitant first step towards it by academic researchers, who for the first time, seek the views of people with intellectual disability. Sometimes the research is controlled by people with intellectual disability and sometimes they are involved as paid community researchers.

But while inclusive research is a great movement, it is also a confusing one. We believe this is because the reasons for doing inclusive research are quite diverse, and it's not always about the best methodology to address the research questions. It is sometimes done for other, possibly equally valid reasons. This is because it is part of a movement, not just another research methodology.

The key thing about inclusive research is that it seeks to enable people with intellectual disabilities to be more than just subjects for professional researchers. This is well illustrated when we consider very early research in which people with intellectual disabilities were witnesses to their own lives. Arguably this started with US sociologist Robert Edgerton. He interviewed people who had left the Pacific State Institution in California in the early 1960s. Edgerton has been criticised because he viewed what people said to him through a particular lens, that their primary task was to overcome stigma, following Goffman (1963). Nevertheless he gathered some fantastic first person testimony, worth reading today if you can get hold of his early books, particularly *Cloak Of Competence* (1967). He was followed

by two more US sociologists, Robert Bogdan and Steven Taylor, who published life stories of two formerly institutionalised people, *Inside Out* (1982). They used these stories to argue that intellectual disability (mental retardation then) was a social construct, and that their informants were as normal as any of us, but that being labelled had forced them down a particular life path. Whichever lens you prefer, what these two seminal publications have in common is that the researchers assumed the right, even the duty, to interpret what people said to them. The stories and testimonies were used to make an academic argument, and it was an argument which belonged to the researchers, not to the informants.

Inclusive research has sought to get away from the idea that people's stories and insights are material for the academic gaze. It was in the later 1980s, with the UK in the vanguard this time, that a number of people, unconnected and in different parts of the country, began to look for ways for research to truly represent the authentic voices of individuals labelled as having an intellectual disability. One of the authors (Jan) remembers this vividly. Being part of a team at the aptly named Open University who had produced learning packages called *Patterns for Living*, first for staff, family members and advocates, and then for people with intellectual disabilities, our next task was an undergraduate course. We subscribed in principle to 'nothing about me without me', but how to get the voices of people with intellectual disabilities at the heart of student learning was a challenge. We hit on an anthology. Over 200 people contributed stories, art, poems, reflections, vignettes. The editors tried hard to stand back and let people's voices and ideas speak through the pages of the book. An advisory group comprised of people with intellectual disabilities advised on issues like whether to correct spelling and grammar, how to manage confidentiality, what titles to give each chapter, and what to call the book. It was called 'Know Me As I Am' (Atkinson & Williams 1990). And it marked a turning point.

Things moved on from there. The ambition became, not just to 'hear' and share people's voices as untainted as possible by the academic gaze, but to enable people to be researchers. Since that time, the validity of 'inclusive research' has gradually been recognised by some funders, some academics and some people with intellectual disabilities, including those contributing to this book. Inclusive research has taken its place alongside other research epistemologies. It has achieved a great deal in terms of acceptance. One of the authors (Kelley) has seen the development of inclusive research as a national movement in the Republic of Ireland. Initiatives in the UK and Australia have led to special journal issues which have documented the research undertaken inclusively (*British journal of learning disabilities* 2012; *Journal of applied research in intellectual disability* 2014). But there remain questions about its purpose, and about its impact, many of which this book explore. We can trace the impetus for inclusive research to a diverse range of influences. Depending which you choose, the emphasis and the purpose changes.

If, for example, the driving force is self advocacy, enabling people with intellectual disabilities to speak for themselves, then we would expect that inclusive research would be about researchers supporting people to tell their stories and let others know who they are, and what they want. We would expect the result to be that there will be a more positive view of people, looking beyond the label to see the unique human being, and a clearer view of how best to support people to lead a good life. We might also expect that inclusive research itself would be used by self advocates in asserting their rights and in attempts to change policies and practices. If the driving force is social role valorization, then the emphasis would be more on the process, on research as a route to valued social roles for people at risk of devaluation. Doing research, being researchers gives people new roles and skills. People who are seen as able to do socially valued things like research will gain respect and inspire others. The result should be that perceptions of people with intellectual disabilities change and that the people engaged in the research gain in confidence and self esteem.

If the social model of disability is the conceptual framework, then the purpose of inclusive research is to identify how to get rid of the barriers to full participation in society. 'Nothing about us without us', the powerful slogan of the disability movement, applies also to research. It is unthinkable to return to the bad old days when Miller and Gwynne (1972), non disabled researchers, pronounced the disabled people they researched as 'socially dead' and inspired Paul Hunt, one of the people so described to become a leader of the disabled people's movement. If disabled people had been in charge, goes the argument, this insulting distancing would never have happened. This is a rationale for Experts by Experience to be involved in inspecting services and for ensuring the State takes responsibility for removing barriers for participation. Success for inclusive research in this paradigm would be that it finds solutions which reduce barriers to people being treated with respect, including finding jobs, getting better health care, education, and a better life. And if improving the quality of services is the aim, then the emphasis would be on partnerships between professionals and disabled people to find out how to make services work better. This is the idea behind co-production. The result should be that professionals learn to work in partnership, services really do meet people's needs, and these 'co-produced' solutions might even be less expensive.

Finally, we may do inclusive research for the reason that this is the best way to get the answers to unanswered questions. Like the stories people have told about living in long stay institutions; or what makes a good supporter; or how to better understand how people with intellectual disabilities experience sexual relationships or how to ask straightforward questions, and interpret the answers.

Is it a problem that inclusive research has had such a diversity of influences? No, but it does make it harder to pin down what it is and what difference it makes.

Take the question of impact. Mainstream academia remains impervious to including people with intellectual disabilities. It is only at the margins that inclusion is prioritized. And while inclusive research depends on particular academics rather than being embedded more strongly in academia it will be at risk. The strongest evidence of impact is that individuals who have worked as co-researchers gain in confidence and skills. However, this gain may be short-lived as the project ends, and other opportunities are lacking. It will be a challenge that the next generation of inclusive researchers will have to rise to, to demonstrate that inclusive research gives added value beyond symbolism.

There are also questions of who can be a co-researcher. Early examples frequently cite friends of researchers being co-opted into research projects, with no formal selection process. More recently, especially when funding is available to pay co-researchers, there has to be a selection. It is not enough just to be labelled as having an intellectual disability, however that is defined. Literacy skills, competence in interviewing or in data analysis may also be requirements. There is then the danger of creating an elite group who are no more in touch with the grassroots than academics. On the other hand research which includes the skill development of researchers with an intellectual disability and recognizes these skills once they are there is also important. There remain many more questions about inclusive research, many of which are explored in this excellent book. We leave you with one last question:

If current policies of inclusion in mainstream schools and use of the generic services succeed, if personalization and the development of much more choice and control by individuals with intellectual disabilities develop strongly, if self advocacy and other settings where traditionally people gather continue to decline, where will people with intellectual disabilities be found, and how will they be recruited to be 'inclusive researchers'?

Enjoy the book, and enjoy the inclusive research journey.

Literatur

- Atkinson, D. & Williams, F. (1990): *Know me as I am. An anthology of prose, poetry and art by people with learning difficulties.* London: Hodder Arnold H&S.
- Bogdan, R. & Taylor, S. (1982): *Inside out. Two first person accounts of what it means to be labeled mentally retarded.* Toronto: University of Toronto Press.
- British journal of learning disabilities (2012): Special issue. The research and work of learning disabled people with their allies and supporters, 40, 2.
- Edgerton, R. (1967): *The cloak of competence. Stigma in the lives of the mentally retarded.* Berkeley: University of California Press.
- Goffman, E. (1963): *Stigma: Notes on the management of a spoiled identity.* Englewood Cliffs, NJ: Prentice-Hall.
- Miller, E. & Gwynne, G. (1972): *A life apart. A pilot study of residential institutions for the physically handicapped and the young chronic sick.* London: Tavistock Publications.
- Walmsley, J. & Johnson, K. (2003): *Inclusive research with people with learning disabilities. Past, present and futures.* London: Jessica Kingsley Publishers.