



Inclusive learning disability research: the (nondisabled) researcher's role

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Summary

In this paper, the role of the nondisabled researcher who supports inclusive research in learning disability is explored. The author argues for more transparency about the role in order to highlight the challenges of working inclusively on research projects, the real contribution of people with learning difficulties to research, and the training/support implications of working inclusively.

Keywords *Inclusive research, learning disability, research roles*

Introduction

'no need to hear your voice when I can talk about you better than you can speak about yourself. No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my own. Re-writing you, I rewrite myself anew. I am still author, authority. I am still the colonizer, the speaking subject, and you are now the centre of my talk' (Hooks 1990, pp. 151–2).

The opening quotation sets the scene for a discussion of roles and relationships in research when people with very little power are the subjects of the research enterprise. This paper examines the role of nondisabled researchers who work with people with learning difficulties to develop inclusive research. In it, I argue that the roles such people play, although essential if people with learning difficulties are to fully engage in research, have been hidden and obscure, and that it is important, for a number of reasons, to examine what is actually involved, and to consider how the role might develop.

In writing this paper I own both to some self-interest, being one of those who argued for and pioneered inclusive methods and approaches (see e.g. Atkinson *et al.* 2000; Walmsley 1994) and some trepidation given the 'nothing about us without us position' (Aspis 2000; Harrison *et al.* 2002) adopted by many in what has been called 'the movement' (Chapman & McNulty 2004). Nevertheless, I would argue that without some honest reflection on exactly

what roles such people have played, the inclusive research agenda will be trapped in a cycle of sentimental biography or individual anecdotes (Finkelstein 1999; Goodley 1996).

Inclusive research in learning disability: the influence of disability studies

Inclusive research was a term coined to shorthand the various strands of research in which people with learning difficulties have been involved as active participants (Walmsley 2001), including participatory and emancipatory research. The impetus to inclusive research owes much to social model theorists, in particular Zarb (1992) and Oliver (1992) who argued for 'emancipatory' research, under the control of disabled people, and pursued in their interests. Proponents of the social model argue that disabled people must be active doers of research, rather than passive subjects, and that research cannot be value-free (Barnes 1996). The researcher is either on the side of disabled people, or one of the oppressors (Barnes 1996). Learning disability researchers in the UK particularly were challenged by this to find ways of moving the research agenda in directions, which enhanced the involvement and empowerment of people with learning disabilities. Rodgers (1999), for example, called a reflective critique of her own work on women's health 'Trying to get it Right' and reflected therein on the shortcomings of the research in terms of the emancipatory research agenda. Kellett & Nind (2001) also pondered on their own work with people with quite severe impairments in terms of the requirements of emancipatory research, and

found themselves lacking (although also baffled as to how they might empower such people to the extent required). To the voice of these nondisabled researchers has been added the voice of people with learning disabilities, also arguing for a greater say in research done about them (Aspis 2000; Townson *et al.* 2004). In short, ideas associated with the social model have undoubtedly influenced some types of learning disability research in the UK.

Much of what has been done in the name of inclusive research appears to have been inspired by a desire to redress wrongs, to show that we are not the oppressors described by Barnes, or the colonizers Hooks describes above. Proponents of feminism (Harding 1987; Hooks 1990), the social model (Barnes 1996), participatory action research (Freire 1970; Kemmis 1990; Zuber-Skerritt 1996), as well as self advocates (Aspis 2000; Harrison *et al.* 2002) have all added their voices to the demand that we, the researchers, discard our colonizing ways, drop the jargon, reject 'rejecting research' and put ourselves and our skills at the disposal of people with learning difficulties so that they might take their rightful place in charge of the research agenda.

The support role

There is no question that most people with learning difficulties need support to lead fulfilling lives, including participation in research. This is fully accepted by people with learning difficulties who will readily discuss and insightfully critique the nature of the support they need (see e.g. Central England People First 2001, unpublished data; Open University 1996). Arguably for people with learning difficulties a skilled supporter is as vital as a wheelchair is to a person who is unable to walk, or a BSL interpreter is to a deaf person taking part in a hearing person's event. As vital, and as unlikely ever to be discarded, although the nature of the support needed may alter as environments change, or as the person gains more skills and confidence. As Kiernan (1999, p. 46) observes:

'Given that the research process relies heavily on intellectual skills, it is less easily accessible to people with learning disabilities than to groups of disabled people who do not experience intellectual impairments'.

He goes on to argue that we therefore must take the role of supporter seriously if we are to make progress in terms of inclusive research. Riddell *et al.* (1998) similarly point to the need to confront the challenges if inclusive research is to be more than a stage-managed orchestrated performance.

It is, indeed, widely accepted that, in contrast to emancipatory research, in participatory research, nondisabled people have an enduring role. Cocks & Cockram (1995) and Chappell (2000) see working together as a central component. Remarkably little has been written about what supporters (or nondisabled researchers) do when supporting

people with learning difficulties in a number of contexts, including participatory research.

In contrast to the prevailing practice, which takes for granted the roles and skills of the supporter/researcher, I argue that these roles deserve more than just the passing and self-effacing mention they often receive in the literature. Supporting inclusive research is a skilled activity. It needs to be recognized as such because if it is not then researchers are silenced and are left almost ashamed of their skills. It also makes it very difficult to train people in this way of working if we describe it as 'just support' as some have claimed (Williams 1999). The power imbalances between people with learning disabilities and the researchers continue to be camouflaged by a rhetoric of participation. One of the keys to progress is to clarify what roles supporters of inclusive research, can play, and how we can develop our skills – and help new entrants develop theirs.

What roles do nondisabled researchers play in inclusive research?

In exploring the researcher's role in inclusive research the first difficulty is in terms of the language which is used to label the roles of different people in the research.

Inclusive research has spawned a new language. This language represents a struggle to find words to describe the work of the inclusive researchers (whether they have a disability or not) and those who would have been 'subject' to it in noninclusive research. A whole range of terms has been coined to describe the roles of people engaged in inclusive research. So:

- March *et al.* (1997) who studied the impact of self-advocacy on families, called themselves 'co-researchers'.
- Rolph (2000) described the people she worked with as 'life historians', she remained without a named role.
- Williams (1999) calls herself a supporter, the self advocates she works with are the 'real' researchers.
- Atkinson *et al.* (2000) refer to themselves as helpers, the women with learning difficulties became known as the 'disabled women'.
- Johnson *et al.* (2000) refers to research partners – interestingly also the term adopted in Citizen Advocacy circles for the person who enjoys the benefit of an advocate.
- Knox *et al.* (2000) informants were 'experts' the researchers were 'inquirers'.
- Van Hove (1999) describes research with people with learning disabilities in Belgium as 'cooperative research'.

Reading the reports of these projects, it is difficult to know if the writers are using the terms interchangeably or using them differently because there is little attempt to explore what these roles mean in practice or where the boundaries between roles lie.

This lack of clarity extends to co-authored papers where researchers work alongside people with intellectual

disabilities. Often it is difficult to work out who did what as with the chapter *Telling People What you Think* written by four self-advocates which is introduced thus

'This work was researched and transcribed by the Bristol self-advocacy Research Group which are people with intellectual talent' (Palmer *et al.* 1999, p. 33).

The supporter's contribution is not described, although her name is included as one of the authors.

Similarly, Janice Slattery's chapter in Traustadottir & Johnson's (2000) edited book is entitled *Family, marriage, friends and work: This is my life*, and is attributed to Janice 'with Kelley Johnson'. But Johnson's contribution is not explained. A reviewer of this book commented on this significant omission:

'I wonder how the other women worked together to produce the stories I read – not a minor detail considering that this is a rare attempt to publish the first person accounts of individuals who for the most part have difficulty communicating verbally and in writing; and their collaborators, apparently, were professionals' (Wickham 2001).

The arguments for hiding the role of skilled researchers behind the broad notion of supporter, co-researcher, partners, etc. are nowhere made explicit, although one is tempted to suggest that it is done with the best of motives, as a way of enhancing the image of the person with a learning disability as a competent adult, in other words social role valorization (SRV) (Wolfensberger & Tullman 1982). I have argued elsewhere that we researchers in learning disability are more influenced by a crude interpretation of normalization than we care to admit, an interpretation which attempts to deny difference (Walmsley 2001). Like the endless changing terminology in the field, the proliferation of terms to describe the researcher may be an example of what Sinason (1992) described as a manic desire to erase difference.

One of the interesting things to note here is the blurring of the boundaries between roles of 'researcher' and those involved in the research who are not by training or experience researchers in the formal sense. In at least some cases there is an effort through language to reverse the power roles. The researcher becomes an 'enquirer' and people with learning disabilities become 'experts', for example.

For this purpose, it is important to reclaim the word researcher as it is conventionally used. There may not be one label for the researcher doing inclusive research. Underlying the researcher's work is, almost invariably, a strong commitment to inclusion and to empowerment. However, the way this commitment is played out in a particular piece of research may be very different depending on the people involved and the nature of the project.

What does seem to be important is that there is clarity, and that inclusion brings added value to the research project.

Role clarification

In order to progress in terms of inclusive research it is important to use everyday language to clarify roles. Inclusive research covers many different kinds of research – life stories and autobiography (Atkinson *et al.* 2000; Cooper 1997), policy (People First 1993; Swindon People First Research Team 2002), safety and prevention of abuse (McCarthy with Anastasia, Pam and Deborah 2000; Walsall Women's Group 1999), service evaluation (Flynn with Liverpool self advocates 1994; Whittaker 1997), labelling (Williams 2002), history (Townson 2004), accessible information (Change 2001; Ledger & Shufflebottom 2003). Where there has been clarity over the respective roles, there are evidently different approaches, and skills needed by the researchers, with or without disabilities.

The differences in the roles researchers need to play can be illustrated through examining some examples of inclusive research projects where roles have been explored. One of the most common forms of inclusive research has been the life story. Here some researchers have been explicit in describing what is involved in assisting people in telling their stories. Atkinson, for example, describes in a series of papers, some co-written, how she worked with Mabel Cooper to create Mabel Cooper's life story (Cooper 1997), and subsequent autobiographical accounts (see Atkinson *et al.* 1997; Atkinson & Cooper 2000). An interesting paradox is that Cooper's original 1997 account, a much-quoted chapter, is attributed to Cooper alone. Formally, Atkinson's role is not acknowledged, although in her account of their joint work Atkinson does mention Cooper's suggestion that her name should be included (Atkinson 1997). In subsequent work, Atkinson's skills as a researcher were brought very explicitly to the project when she assisted Cooper in locating her hospital records, and helped her to make sense of what was written, including what seemed initially very hurtful language such as 'imbecile' (Atkinson & Cooper 2000). They resolved the question of authorship in this case through a joint attribution.

A contrasting example of a researcher facilitating an autobiographical account is Sheena Rolph's work with Jean Andrews. Jean 'writes' of her experience in writing her story in the following terms:

'Sheena came here and saw me about it and we got together, didn't we. And I got to write the story, because I told the story. I told the story into a tape. Then Sheena types it out. Then we read it together, and I took bits out and put bits in' (Andrews with Rolph 2000, p. 35).

Much is presumably hidden behind Jean's words – the processes of building trust, prompting, skilful editing of an

oral account into something which flows easily in print, the stuff of qualitative methodological textbooks such as Plummer's (2001) on life histories and Thompson's (1988) on oral history. But in inclusive research it has become the convention to play down the skills of the researcher.

McCarthy with Anastasia, Pam and Deborah (2000) describes a different role. She worked with women from Powerhouse, an East London organization for women who have been abused. McCarthy set herself the task of exploring the published research on abuse of women with learning difficulties with the three women, themselves with some claim to expertise given the function of Powerhouse, and, as it transpired, their own experience. The process of this research is described as follows:

'This chapter is the result of a number of conversations between four women three of whom have learning disabilities. All conversations were taped, then transcribed by Michelle, who also edited them, adding some structure and contextualizing comments and references. A draft of the chapter was put on tape for Anastasia, Pam and Deborah to listen to. They were then able to comment on it and thus also contribute to the editing process. When research findings on sexual abuse were discussed, Michelle presented these in as accessible way as possible, including using pictorial forms to represent percentages' (McCarthy with Anastasia, Pam and Deborah 2000, pp. 48–9).

This process is a significantly different one to that employed with Mabel Cooper and Jean Andrews. McCarthy was not setting out to tap into and record direct personal experience. She was attempting to enable her collaborators to compare their own experience as project workers with what the academics have to say. This involved summarizing a complex literature, making it accessible as far as possible, and facilitating discussion, before assembling into written form, and re-editing with the involvement of the three co-authors. This is a very different activity to tapping into someone's own experience and recording it.

A further example is an innovative approach to reviewing a book designed to be accessible to people with learning difficulties. Sue Ledger (a researcher) and Lindsay Shufflebottom (a service user with learning difficulties) worked together to review the British Institute of Learning Disabilities' publication 'Easy Guide to Physical Interventions for people with learning disabilities, their carers and supporters' (2002). In setting out to do the review they showed the book to a variety of people with learning difficulties, and enlisted their comments on what they understood to be going on. What emerged is a very useful critique of an 'accessible' publication, and shows the value of this type of work in terms of developing an evidence base for writing accessible publications:

'The quality and relevance of the illustrative material was questioned by all our reviewers... Whilst care has been taken to represent a diverse user group the pictures are often not positioned alongside the relevant text. Different pages of the guide are headed in varying colours but it is not clear what this represents... Service users commented they found it difficult to elicit what was going on from the text and found the line drawings 'too faint and too busy'. ... Some service users, particularly those who relied heavily on the pictorial content thought the document was about bullying' (Ledger & Shufflebottom 2003).

Being explicit in accounts of the work about who did what, and what was not straightforward, enables others to learn from experience, rather than make the same mistakes. The following is a useful US example of the sort of clarity that can help others who follow on later, writing in relation to some research commissioned by a People First group:

'The subcommittee (of people with learning difficulties) made all the final decisions on how to word questions, which questions to include in the survey, and the rating scale. Because this was their study we had decided that our role as researchers was to identify conceptual issues, highlight problems and state technical concerns about particular questions for discussion purposes only. Unfortunately, in our eagerness to give self-advocates control of the questionnaire we created methodological problems which compromised the results' (Ward & Trigler 2001, p. 58).

One of their conclusions is that 'role clarification at the beginning of the process, identifying areas of expertise, and establishing guidelines for the team process will mediate power and control issues' (Ward & Trigler 2001, p. 58). An overemphasis on getting the process right in terms of inclusion, can lead to mistakes being made in locating methods to answer the questions.

This brief review of the way different researchers have worked with people with learning difficulties in inclusive research projects demonstrates that a variety of approaches can work well, and produce important results. It also shows that clarity over who did what can assist those who come later to construct projects which are both ethically sound, and methodologically rigorous.

Education and training issues

One of the drawbacks of lack of clarity over the role people play in inclusive research is that it makes provision of appropriate training difficult – on both sides. Not only do (non-disabled) researchers need support and training if they are to work successfully in this mode, so do people with learning difficulties. Spedding *et al.* (2002) argue that it is

not enough to listen to people with learning difficulties recount their own stories, efforts need to be made to help them situate their experiences in a wider context. Here ideas can helpfully be borrowed from other areas where user led research has made inroads. In the DIY Guide to Survivor Research (Mental Health Foundation 2002) are some practical hints on how to get started on user led research in mental health. These hints are written in plain language, although not explicitly accessible to people with learning difficulties. Similar approaches can usefully be developed for researchers with learning difficulties – once the conceptual confusion about the skills needed for particular pieces of research are clarified.

The messages from the body of research discussed here reinforce the view that there is no one right way to approach inclusive research. Adjustments are needed according to the topic, the methodology and the skills of those involved. Inclusion can, quite appropriately, take different forms. Enough has been done now for people to be in a position to learn from a variety of inventive approaches, and develop a sophisticated pantheon of techniques, with appropriate training where necessary.

Conclusion

What has been termed 'inclusive research' has already made a major contribution to changing the way people with learning disabilities are viewed, and has revolutionized approaches to research in learning disability. Although there is some way to go before everyone working in the learning disability research field puts principles into practice, the case for asking researchers to consider the interests of people with learning disabilities in the work they do is irrefutable, thanks to the work of the pioneers. At the very least they need to consider demonstrating how what they do matters to people with learning disabilities and how they can help people with learning disabilities access the outcomes of their work.

Nevertheless, there are some real conundrums and challenges in the way inclusive learning disability research has been heading. Although it is difficult to prove, I would argue that inclusive learning disability research, like normalization/srv and many other developments in learning disability, has been largely driven by values – of social justice, redressing past and present wrongs, promoting valued social roles – rather than an evidence base. Often the people who have pioneered the work have done so because they want to change things, to show that in the small world of research we can do things differently, and better. This is essential to kick start change, and the commitment shown by a relatively small number of people has made a big difference. However, probably with the best of intentions people who have done inclusive research have not always explained what they do, and how they do it, when working

inclusively. This led to a mystification of the process. The myth can develop that somehow some people magically get it right, but how the magic works is obscure. The hard work, the finely honed skills, the self restraint researchers need to exercise have been camouflaged, as are the particular contributions made by people with learning difficulties. In the paper I have argued that it is important to change this, and to learn from what has been done. At present, 'big' research, the sort policy makers listen to, is still the preserve of the noninclusive research centres. The inclusive enterprise is marginalized, left to a few to pursue, while the well-funded prestigious centres carry on much as they have always done.

If a clarification of the process is not done systematically, if it is left unclear what precisely is the added value of inclusion, other than meeting rhetorical goals, then it will be difficult to move forward because, for inclusive research to penetrate beyond its present narrow confines there needs to be a focus, not on people with the right values, but people with the requisite skills to work on inclusive research. This goes for both sides of the binary divide – training courses for the career researchers, and for those people with learning disabilities who have the potential and the inclination to 'do' research.

Finally we also need another sort of language. We struggle with the language. The binary divide, the polarizing of 'the nondisabled' and the 'disabled' the 'researcher' and the 'co-researcher', the 'inquirer' and 'the expert' is perpetuated, not dissolved, through inclusive research. Only the excluded need 'inclusive' research. This is not to argue for difference to disappear; it is to argue for some clarity over language. People with learning disabilities have made and will continue to make valuable input to research. They do not need obscurantist language to prove that. Rather, they need the contributions they make to be named and described and recognized for what they are, not for what we wish they could be.

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