Inclusive learning disability research: The (non disabled) researcher's role

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> '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: 151-2)

Introduction

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 non disabled 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. 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, for example, called a reflective critique of her own work on women's health 'Trying to get it Right' (1998) and reflected therein on the shortcomings of the research in terms of the emancipatory research agenda. Kellett and 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 (though also baffled as to how they might empower such people to the extent required). To the voice of these non disabled researchers has been added the voice of people with learning disabilities, also arguing for a greater say in research done about them (Aspis 2000, Cumbria People First this volume). 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), 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.

In this paper I consider the roles that those non disabled people who have supported inclusive research have played. In doing so I own both to some self interest, being one of those who argued for and pioneered inclusive methods and approaches, (see for example Walmsley 1994, Atkinson et al 2000) 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 and McNulty in press). 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 (Goodley 1996, Finkelstein 1999).

The paper ends with a broad discussion of the relationships which will be needed if inclusive research is to move beyond its present rather individualistic approach

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 for example Open University 1996, Central England People First 2001). 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, though the nature of the support needed may alter as environments change, or as the person gains more skills and confidence. As Kiernan 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 people with disabilities who do not experience intellectual impairments

(1999:46)

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, non disabled people have an enduring role. Cocks and Cockram (1995) and Chappell (2000) see working together as a central component. Remarkably little has been written about what supporters (or non disabled researchers) do when supporting people with learning difficulties in a number of contexts, including participatory research. ~~However, my~~ 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 ~~a~~ passing and self effacing mention they often receive in the literature. Supporting inclusive research is a skilled activity. It needs be recognised 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 is 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. ~~First we look back, at the roles people have played as described in the literature to date.~~

What Roles do non disabled researchers play in Inclusive Research?

~~A new langua~~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.

~~One striking thing about i~~Inclusive research ~~is that it~~ 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 non inclusive research. ~~Language is used to indicate a change in power differentials between researcher and those who might have been researched upon, had the research not been deliberately framed as inclusive.~~ A whole range of terms has been coined to describe the roles of people engaged in inclusive research. So:

- March et al (1997) ~~a PhD student~~ 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'

- Kelley Johnson refers to research partners – interestingly also the term adopted in Citizen Advocacy circles for the person who enjoys the benefit of an advocate

- Knox and colleagues' (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 and Johnson's edited book (2000) 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, though 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 (Wolfensberger and 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 ~~supporter~~ 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 (Cooper 1997, Atkinson et al 2000), policy (Swindon People First 2002, People First 1993), safety and prevention of abuse (McCarthy with Anastasia, Pam and Deborah 2000, Walsall Women's Group 1999), service evaluation (Whittaker 1997, Flynn et al 1994), labelling (Williams 2002), history (Cumbria People First 2003), accessible information (CHANGE 2001, Ledger and Shufflebottom forthcoming).

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 ~~supporters~~ 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 1997, Atkinson and 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 and Cooper 2000). They resolved the question of authorship in this case through a joint attribution.

A contrasting example of a ~~supporter~~ 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). ~~Jean Andrews refers to the process of working together on a life story with Sheena thus:~~

~~How I wrote this chapter~~

~~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 ~~these~~ 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 text books such as Ken Plummer's (2001) on life histories and Paul Thompson's (1989) on oral history. But in inclusive research it has

become the convention to play down the skills of the researcher. ~~(or supporter), and to focus on the product, the 'story'.~~

~~In another chapter in the same book~~ McCarthy (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 contextualising 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 p. 48-49). ~~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 contextualising 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~~

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 To the supporter role was then added that of 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 … Serrvice 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 and Shufflebotham in press)

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 sub committee (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 and 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 and Trigler 2001 p. 58).

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.

Changing Relationships

Much inclusive research has been done through individual researchers working with individuals with learning difficulties they know, rather than through organizational relationships (though there are exceptions – for example Swindon People First's work on Direct Payments). Inclusive research has, for most people operating as researchers in this field, been driven not by organizational partnerships and goals, but by one to one relationships. Neither researchers nor people with learning disabilities have been selected for the work based on competencies and job descriptions. In most cases, people have been working with people they know on projects they themselves have set up. There is nothing inherently wrong with this – it's a classic way for change to start. But if we are to move the agenda beyond the realm of anecdote and story into research which develops theory, or promotes change on a larger scale, then this needs to change too. Zarb's original critique pointed to the importance of changing the material relations of research production (1992), and this should alert us to some areas for consideration in thinking about ways forward. If we were to focus, not on the individual skills of researchers (with or without disabilities), but on developing capacity for research within user organizations then some new avenues for developing inclusive research open up.

Moreover, to date, the methods used in inclusive research have been chosen in part because they are able to be accomplished by people with learning difficulties (Ramcharan and Grant forthcoming). Changing the relationships is necessary if inclusive research is

to expand its repertoire to methods which are inherently more complex, covering large data sets, requiring statistical analysis or knowledge of existing theory.

How might this change be accomplished? There are some possible avenues to explore. One is to place the researcher in the position of expert advisor to people with learning difficulties. There is no reason (other than financial) why academics should not be employed by organizations of people with learning difficulties to bring their specialist skills to the research task, thus making him or her a consultant, or employee, whose work is directed, but not carried out, by people with learning difficulties. Direct Payments are a service based analogy to this. No one argues that if people with learning difficulties employ a personal assistant they also need to learn how to carry out all the tasks that person is employed to do. The same could apply to research, given the inevitable difficulties most people with learning difficulties will have with questionnaire design, sampling frames, data analysis and writing up. Thus people with learning difficulties could control the research in terms of determining what questions are to be asked of whom, and the dissemination, without necessarily attempting to acquire specialist skills which take career researchers many years to acquire. Significant projects in the disability field which have a claim to be emancipatory, like Priestley's work on community care (1999), were not emancipatory because carried out by disabled people, but because *controlled* by an organization of disabled people. A modest, but important start has been made to this in the research commissioned by the English government following the publication of the 2001 White Paper *Valuing People*, given that two people with learning difficulties are part of the commissioning group (Grant and Ramcharan 2002, BJLD in

conversation piece), but a lot more will need to be done to move this from commissioning to ongoing supervision of the project and outputs.

Similarly, if capacity within user organisations were to be developed systematically, then partnerships between universities or other commissioners of research and organizations of people with learning difficulties are potentially a way forward. BRMB worked with Central England People First (CEPF) in 2002/3 to ensure that the questionnaire they were preparing to find out what matters to people with learning difficulties as part of the follow up to *Valuing People* covered the major topics, and was accessible. CEPF did this by holding consultation events with people with learning difficulties, accessing information which non disabled researchers would find difficult to acquire, thus adding a particular value to the research enterprise through partnership (personal communication). In terms of developing capacity it is important to acknowledge that people with learning difficulties will need training if they are to carry out research, other than research which asks them to record their own personal experience and memories. If they are to work within a social model framework, for example, then knowledge about what the model says is important. As Spedding et al noted in relation to support of self advocacy:

> In tracing the history of individuals and a group with its members, opportunities arise to make open and clear these shifts from the personal to the political aspects of advocacy work. This then provides a wider framework for supporters to act within which links to the social model of disability …. If this link is not made then advocacy will remain locked into an ever revolving wheel of personal issues so wider challenges to the service systems and government will fail to be made

(2002 p. 150)

Although some argue cogently that theories need to change to incorporate the experience and perspective of people with learning difficulties (Goodley 2001, Williams 2002), it is also arguable that people with learning difficulties need to know the theory in order to be able to challenge it. Failure on the part of non disabled academics to share their expert *knowledge* as well as their skills indicates, not respect, but disempowerment.

If the impetus for developing research is to move from an elite of people who have developed relationships with individual researchers to representative organizations of people with learning difficulties, then questions about how such organizations can develop the skills and people to commission and manage research will also need to be considered. Precious few self advocacy organizations have that capacity at present, and may well not be in a position to prioritise research (Ramcharan and Grant forthcoming), given all the other calls on their time.

There is no one right answer to the who should do what and how questions. But a commitment on the part of inclusive researchers to some clear information on what was done and by whom; an openness to consideration of the types of relationships between researchers and organisations of people with learning difficulties; and a recognition that people with learning difficulties (and the organizations which represent them) will, like others, need education, training and resources to become effective researchers, or commissioners of research, all of these are vital.

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, the belief that to serve the interests of people with learning disabilities all research needs to actively include them has led to a preoccupation with looking for ever more inventive ways to enable people with learning disabilities to 'do' research. 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 non inclusive research centers. The inclusive enterprise is marginalized, left to a few (mainly women) to pursue, while the well funded prestigious centers 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, opportunities for organizations controlled by users to learn about research, how it's funded and carried out, and how to manage it; and the necessity for organizations which carry out research to learn how to partner organizations of people with learning difficulties.

I have also argued for an alternative approach, namely to seek ways of enabling representative organizations of people with learning disabilities to control or influence research projects which they have identified as being relevant to them, rather than to do them. That is a big agenda in itself, given the precarious financial position many user controlled organizations experience. But it is, I would contend, important if people with learning difficulties are to influence the policy driven research agenda. A start has been made with the post White Paper commitment to including people with learning

difficulties in the process of commissioning Government funded research in England. But there is plenty more to do in this area. If we genuinely want to support inclusive research, then people with learning disabilities and their organizations will need investment of time and money to develop their capacity to commission and manage research. Few such organizations have this sort of capacity at present.

Finally we also need another sort of language. We struggle with the language. The binary divide, the polarizing of 'the non disabled' 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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