

# Involving users with learning difficulties in health improvement: lessons from inclusive learning disability research

Jan Walmsley

School of Health and Social Welfare, Open University, Milton Keynes, UK

Accepted for publication 3 December 2003

WALMSLEY J. *Nursing Inquiry* 2004; 11: 54–64

## **Involving users with learning difficulties in health improvement: Lessons from inclusive learning disability research**

In this paper the author considers the lessons to be drawn from what is termed 'inclusive' learning disability research for user involvement around health improvement. Inclusive learning disability research refers to research where people with learning difficulties (intellectual disability) are involved as active participants, as opposed to passive subjects. There is by now a considerable body of such research, developed over the past 25 years. From the review, the author draws attention to areas which can inform practice in involvement of users in a way that adds value.

**Key words:** health improvement, learning disabilities, research, user involvement.

Considerable emphasis in current policy initiatives is given to 'user involvement'. This applies as much to health improvement for people with learning difficulties (intellectual impairments) as it does to any other area. In this paper, I discuss what can be learnt about involving people with learning difficulties in developing the evidence base for health improvement, drawing on lessons from what has been dubbed 'inclusive research' (Walmsley 2001; Williams 2002) in learning disability over the past 20 years. In brief, the article argues that there is added value to be derived from involving people with learning difficulties in projects intended to promote health amongst this group of people, but that careful consideration needs to be given to the methods for involvement and the time scale required, and that intellectual impairment does limit the degree to which people can be involved in certain activities which require a high degree of abstract reasoning.

Before developing the argument, it is important to clarify terminology which is enormously confusing and

contested. The term 'people with learning difficulties' adopted in this paper is that chosen by user groups in the United Kingdom (UK) as their preferred label to replace 'mental handicap' (Simons 1992; Goodley 2001). The UK Government prefers to use the term 'learning disability' (see, for example, Department of Health 2001a), whilst in Australia 'people with intellectual impairments' is the term with currency (Walmsley and Johnson 2003). In the USA 'mental retardation' continues to hold sway, regardless of efforts to dislodge it in favour of less offensive language.

## **THE HEALTH NEEDS OF PEOPLE WITH LEARNING DIFFICULTIES**

It is undoubtedly important to focus attention on health improvement for people with learning difficulties. All the evidence points to the fact that they are significantly disadvantaged in a number of respects. The UK White Paper on learning disability *Valuing people* (Department of Health 2001a) sets the following objective:

To enable people with learning disabilities to access a health service designed around their individual needs with fast and convenient care delivered to a consistently high

Correspondence: Jan Walmsley, School of Health and Social Welfare, Open University, Walton Hall, Milton Keynes, UK.  
E-mail: <J.S.Walmsley@open.ac.uk>

standard, and with additional support where necessary.  
(59)

Health issues for people with learning difficulties have been a neglected area, despite earlier initiatives in England (Department of Health 1995, 1998) and Wales (WHPF 1992) to focus energy and attention. People with learning difficulties experience significant barriers to accessing primary care (Langan, Russell and Whitfield 1993; Stein 2000) and preventive services (Espie and Brown 1998). They also experience significantly lower than average levels of health on a number of key indicators, for example, undiagnosed morbidity, psychiatric disorders, diet and exercise, management of menopausal symptoms, abuse (Cumella et al. 1992; Brown and Turk 1992; Rodgers 1996; McCarthy and Millard 2003). Basic knowledge of health amongst this population is limited, and absence of information appropriately geared to people who have very limited, if any, ability to read exacerbates the problems (Greenhalgh 1994; Curtice and Long 2002). The issues are clearly summarised in chapter six of *Valuing people*, and demanding standards are set, including an individual health action plan for everyone with a learning disability by June 2005.

Therefore, it is appropriate that work is done on developing an evidence base of good practice in health improvement with people with learning difficulties. If this is to be effective, and if the dangers of paternalism are to be avoided, some of the work must be done *with* people with learning difficulties. This is partly because policy is pointing in this direction — the creation of partnership boards, the introduction of person centred planning (Department of Health 2002) — and partly because research tells us that without this element, much well-intentioned activity will miss its target.

## THE DEVELOPMENT OF INCLUSIVE RESEARCH

We already know a great deal about inclusive practice in involving people with learning disabilities. The research has been developing for 20 years (Walmsley and Johnson 2003), and its fruits are to be seen in current policy initiatives — for example, the involvement of people with learning difficulties in developing the White Paper itself, and the commitment to accessible versions led by the Department of Health (Department of Health 2001b). However, although there has been considerable progress, a solid evidence base for practice in this area is underdeveloped. Much is at the rhetorical level, and some basic questions, such as ways in which people with learning difficulties can represent the views of others with the same label, the extent to which information can be genuinely made accessible (and the best means by

which to do so) and the nature of good practice in support and advocacy have not been examined critically. This paper sets out to tackle some of these quite fundamental issues, by drawing some lessons from the research which are applicable to user involvement in health improvement.

Inclusive research with people with learning difficulties has developed alongside the imperative to include ‘users and carers’ in service development and evaluation. The move in the UK to include people with learning disabilities in research as more than just objects of study can be traced back to the mid 1980s when two British researchers, Margaret Flynn and Dorothy Atkinson, included direct testimony from people with learning disabilities in their research and subsequently published articles on the methodological implications (Flynn 1986; Atkinson 1989). From then on the pace has quickened, so that by the early twentieth century the number of studies which include people with learning disabilities as grant holders, advisors, researchers, authors and disseminators has proliferated (Walmsley and Johnson 2003), and a number of significant grant-giving bodies, such as the Department of Health itself, and the Joseph Rowntree Foundation insist on inclusion of users/carers as a major prerequisite for funding.

## The traditions of contemporary inclusive research

One can roughly split inclusive research into two methodological traditions: participatory and emancipatory (Kiernan 1999; Chappell 2000). Whereas participatory research entails a commitment to researchers working alongside people with learning disabilities as allies, in emancipatory research the stakes are higher, the requirement being that disabled people control the research agenda, a development associated with the UK disabled people’s movement (Zarb 1992), but which has been embraced by some people with learning disabilities, and those working alongside them (Townsend 1998; Atkinson, McCarthy and Walmsley 2000; Williams 2002; Walmsley and Johnson 2003). The slogan ‘Nothing about us without us’ (People First 1993) epitomises the moral imperative to include people with learning disabilities as active shapers of the research. Of particular interest here, given that it is associated with health, is Jackie Rodgers’ work on the health needs of women with learning disabilities. Carried out in the early 1990s (Rodgers 1996), it could be called ‘participatory’ because it included an advisory group of users and carers. Reflecting upon the research some time later, Rodgers, in a paper significantly called ‘Getting it right’ Rodgers (1999) took herself to task for the limited extent to which the project had involved women with learning difficulties. She should, she reflected, have made a far greater

commitment to inclusion if she was to have met the ideals of emancipatory research. Significantly, she does not argue that this would substantially have improved the findings, rather that this would have somehow meant she was 'getting it right' within the framework of emancipatory research.

Most research to date has been participatory, like Rodgers' original study, in which researchers seek to work alongside people with learning difficulties in a variety of roles. Some very useful work has been done which highlights major areas of health improvement, for example on women's health (the work by Rodgers referred to above), sexual health (McCarthy 1999), menstruation (Rodgers 1999), the menopause (McCarthy and Millard 2003), the importance of accessible information (Greenhalgh 1994; Ros and Cindy with Nightingale 2000), parenting (Booth and Booth 1994, 1998). Most of this has been done through interviewing people with learning difficulties, and some, such as Rodgers' study, has been participatory to the extent that an advisory group worked alongside Rodgers to help shape the research. The degree of ignorance people with learning difficulties have about basic health is one of the overwhelming messages from this body of research. The other is the importance of health professionals' attitudes as a determinant of the success of interventions.

These messages are important, and illustrate how vital it is for health improvement that practitioners get alongside people with learning disabilities, and, as far as possible, get a sense of the way they look at the world, if treatment is to be effective. However, the findings themselves, valuable though they are, are not the main subject of this paper. Rather, I am looking at process, at the issues involved in that very process of getting alongside, and at some of the pitfalls research has fallen into, as well as some good practice pointers.

Researchers in the inclusive tradition in learning disability have set themselves demanding goals. We (for I count myself amongst them) have set out to demonstrate that people with learning difficulties can interview (Williams 1999), frame research questions (Atkinson, McCarthy and Walmsley 2000), manage grants (Swindon People First Research Team 2002), author papers (Walmsley and Downer 1997), analyse data (Rolph 2000), theorise (Williams 2002), indeed do all the practical and cognitive tasks associated with research if given the right conditions and the right support. This has been a worthy aim, but has some very real drawbacks. The rest of the paper goes on to examine these.

## THE TENSION BETWEEN CONTENT AND PROCESS

Inclusive research is dogged by an unavoidable tension between content and process. If research is to be genuinely

inclusive, then as much, or more, attention and resource has to be devoted to *how* you do it as to what you might find out.

One of the hallmarks of inclusive research to date has been a near obsession with process. This is particularly the case with emancipatory research, but also applies to participative research. The goal of including people meaningfully at times threatens to engulf the very real need for significant content and outcomes. As Braye observes of user involvement:

Three things are clear. First, the language of participation is complex: the same thing means different things to different people, and the same concept may be known by a number of different terms. Second, the apparent consensus that participation is a good thing masks major differences of ideology between different interest groups. Third, ends and means are confused; participation is presented both as a means to an end, and at times the purpose and the process appear indivisible (Braye 2000, 9).

To illustrate this in the context of inclusive research, I describe a project in which I was personally involved in the late 1990s, the task being to coedit and coauthor a book *by* and *about* women with learning difficulties *with* women with learning difficulties. The output was an edited volume *Good times: Bad times. Women with learning difficulties telling their stories* (Atkinson, McCarthy and Walmsley 2000). The long list of coeditors in itself tells a story. The book was put together over 5 years through a lengthy process of meetings of the advisory group, generously supported financially and practically by the Open University, where three of the non-disabled editors were employed. The coeditors were assembled through informal networking — we non-disabled academics invited women with learning difficulties whom we personally knew to take part, a point worth noting when accountability is at issue, given the desirability of some kind of constituency. We had consciously set out to demonstrate that women with learning difficulties had something important to communicate about their lives, and that the process could be enhanced by an inclusive process in which the power of the academic gaze was at least tempered by sharing it with some people who were usually gazed upon. I believe that the book successfully demonstrated that women did have a perspective which was worth hearing. However, the opportunity to draw conclusions which might guide policy, practice or even research was lost because our disabled coeditors were able to help collect the 'stories', and determine editorial policy. What they were unable to do, and what we non-disabled women refrained from doing, was to draw out the implications. The reasons for this were ethical. The entire project had set out to subvert the traditional 'researcher/researched' relationship, by working alongside women with learning difficulties. Our inability to share with the coeditors the high level skill of abstraction of themes

from a dense mass of anecdotal evidence meant that the stories had to be left to speak for themselves, if we were not to undermine the commitment to partnership. It is the methodological issues, the processes, which have been analysed, as here, rather than the findings.

Although perhaps an extreme example, this is not especially unusual in inclusive research (see Walmsley and Johnson 2003 for a more extensive review). The process is what interests the academics, and the process is largely what is written about. Analysing the content, and developing a body of knowledge fully informed by current academic debates in, say, gender studies is left for another day, and, so far, has been barely attempted (see Johnson and Traustadottir 2000 for an exception).

From the point of view of health promotion, the lesson to be drawn is that it is possible to develop constructive and productive relationships between 'experts' and disabled people, given time and resource; yet, importantly, that the nature of intellectual impairment makes some activities requiring high levels of abstraction less amenable to inclusive practice.

## ACCOUNTABILITY AND REPRESENTATION

I commented above on the accountability issues. The fact that in *Good times: Bad times* the disabled coeditors, and the story tellers, were involved through informal networking, rather than through collaboration with representative organisations of people with learning difficulties, meant they could only really speak for themselves as individuals. Although not especially problematic in a book which made no claims to be representative, this is a real challenge for user involvement in service development or evaluation. 'Users' who become accustomed to working with academics, service providers and the like can acquire the status of pseudo professionals, and lose touch with the realities of life for people who have not been co-opted into involvement. I was taught this lesson quite sharply during the course of compiling *Good times: Bad times* when I travelled to Birmingham to meet with an Asian women's group with a view to their contributing to the book. The women barely knew what a book was and could not grasp what I was proposing, so far was it from their experience. The comparison with the book's very sophisticated coeditors was indeed stark. The accountability issues are exacerbated in the learning disability context because of the fragility of many user organisations which can easily be swamped by demands to participate (Aspis 1997), and because the type of communication devices most organisations can take for granted (newsletters, e-mail circulation lists, telephone trees) rarely operate effectively for a population that has low literacy skills and is overwhelmingly poor (see Booth and Booth 1994 for a discussion of access).

There are, of course, particular challenges when one considers that the group which may have the most need for health improvement and interventions, people with severe and profound learning difficulties, often literally do not have a voice, and, according to Jackie Downer, herself a well known self-advocate, are highly unlikely to find their more able peers giving them one:

I'm so used to saying 'my needs, tough luck about the others'. They're somewhere else. I think it can work but it takes time. And we, as people with learning difficulties, we got no time (Walmsley and Downer 1997, 44).

If the intention is to include all people with learning difficulties, including those with the most severe impairments, then careful attention has to be paid to ensuring that they are included. Reliance on more able people with learning difficulties may not be the best route to reaching the least advantaged.

## ADDED VALUE

It is important to ask about the added value of user involvement, given the high cost of doing it well. What Braye termed as 'the apparent consensus that participation is a good thing' (Braye 2000, 9) has meant that it is at times attempted for its own sake, rather than where it demonstrably adds value. Time and resource are important variables which need to be considered. *Good times: Bad times* took much longer to produce than comparable edited volumes where inclusion is not the goal, and required far more resources for meeting rooms, travel expenses, producing and photocopying accessible minutes. Inclusion is far more costly than more traditional approaches to researching a particular phenomenon, because of the need to allow more time, to employ support workers, and to train the user researchers.

The additional investment can be very worthwhile, but clarity is needed about where inclusion brings added value. Ward and Simons (1998) point to some very obvious areas such as an advisory group to advise researchers on what words to use to ensure they are understood when questioning people with learning difficulties. Whittaker (1997) asserts with some justification that employing people with learning difficulties as the people who helped formulate and ask the questions in evaluating services in the London Borough of Hillingdon meant that a more accurate picture was obtained than would have been achieved by interviewers who lacked direct experience of life in residential care or day centres. Williams works alongside a colleague with learning difficulties to devise 'Plain Facts', a medium to convey research ideas in a format as accessible as possible to people with limited literacy skills (Williams 2002). A particularly innovative and constructive example of added value is the work by Central

England People First to network and to run focus groups to inform the English government's post White Paper investigation into what matters to people with learning difficulties (BRMB 2002, unpublished report). This People First organisation has also been engaged by a university to assist it in ascertaining what statistical data should be collected in order to support effective planning. It would not be practicable to ask this user organisation to do the basic research into what data sources exist — but to ask them to comment on the findings, and the gaps, seems a good use of informed user expertise (Learning Disability Research Initiative Newsletter 2003).

There are, however, many instances where inclusion appears to be undertaken for its own sake, and where it can actually detract from the research achieving its primary goals. There has been little reporting of this nature in the UK literature. However, in a US example, the researchers reflected that they had been mistaken in leaving their co-researchers with learning difficulties to devise the questionnaire.

The sub committee 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, 58).

What these, and a number of other enthusiastic researchers have done in the name of inclusion is to fail to identify what skills people with learning difficulties have, and what extra skills they might need to be effective researchers, or where the work is better done by trained researchers (Walmsley and Johnson 2003). It is as if being a person with the label confers some special properties which enables him or her to do things for which others have had to undertake extensive training. This has led to some, frankly, poor research which adds very little to our knowledge, and risks undermining the reputation of inclusive research.

Similar caveats apply when the framing of research is in question. It is, self-evidently, desirable that research takes place on issues which matter to people with learning difficulties (Ward and Simons 1998). A number of projects have set out to enable people with learning difficulties to determine what to research, and how to do it, for example *Good times: Bad times* (see above), Williams (1999), Swindon People First (2002), Williams (2002). This can work well in exploring matters which are already on the agenda generally. For example, Williams' co-researchers in her 1999 project chose to explore labelling, transport, jobs and work, and set out to interview other self-advocates about these topics. These are

all areas where a fair amount of research has been carried out in inclusive ways, for example have all been covered by Plain Facts (Townsend 1998). What this approach does not do is open up areas which are little known to people with learning difficulties, or which matter only to a subset of the population. McCarthy and Millard's (2003) work on the menopause illustrates this well. They found an abysmally low level of awareness even of what the menopause is when they set out to interview women in a funded project. It is hard to imagine the menopause coming to the fore if only people with learning difficulties are determining the topics which need to be researched. The research itself can and should contribute to a heightening of awareness of this as a health issue, particularly as, through close work with some of the participants, the researchers devised means of conveying information about the menopause to people without sophisticated literary skills. Johnson (Walmsley and Johnson 2003) argues similarly about the Australian project in which she was involved, 'Living Safer Sexual Lives', which examined through life story interviews people's sexual lives. She argues that because talking about sexuality is, in many instances, a taboo which people with learning difficulties have internalised, such a project needed to be sponsored by people with a greater degree of detachment. What she did do through working with a reference group is involve people throughout, and seek advice on key ethical issues, such as how to present the 'stories' and how to address the circumstances which gave rise to the often distressing findings.

Kellett and Nind (2001) make a similar point about their research with people who are 'pre verbal'. In a challenging paper (2001), they ask whether adhering to inclusive principles means that such research should be abandoned because its subjects are virtually powerless to make even their most basic needs known, let alone frame research which might benefit them. They conclude that abandonment of such research would not be helpful.

The idea of 'added value' is a useful one when considering inclusive work to develop the evidence base for effective health promotion. To ask people with learning difficulties to contribute information as to how to word questions, how to make ideas accessible, what to look out for, what practices in services need to be taken into account, and how to disseminate good ideas makes eminently good sense. There are also a number of instances where employment of people with learning difficulties as observers or interviewers will heighten the likelihood of obtaining insights unavailable by other means. Self-advocacy organisations can helpfully be approached to run consultations or gather information in focus group type activities. It is also important that people with learning difficulties advise on dissemination strategies.

But the lessons from research practice suggest that we should not ask people with learning difficulties to carry out tasks relating to research (or health improvement) for which they have had no training or preparation. Thus, to ask self-advocates to choose the topic, devise the methodology, manage the budget, analyse the data and write up the findings is likely to lead to so much time and effort expended in teaching and supporting that little will emerge from the project in terms of contributing to an evidence base which can inform further work, or contribute to improved health outcomes.

### Accessible information

It is axiomatic that inclusive practice or user involvement requires the dissemination of information in accessible ways. People with learning difficulties are one of the most challenging groups to work with in this respect. Some have reasonable literacy skills — and it is frequently the people who are the most fluent communicators who come to the fore in self-advocacy groups. However, many have very limited ability to benefit from the written word; and some people, such as those who are deaf and blind, are severely disadvantaged.

It needs to be recognised that to date there are no modes of communication which can reach people with severe and profound disabilities except at an intensive one-to-one level. There has been some excellent work done with people who are at first sight unpromising communicators (see for example Goode 1989; Sanderson 1998), and there are some techniques, such as facilitated communication, for which major claims are made (see, for example, Rubin et al. 2001). However, few would contest that communication of sophisticated information to such individuals requires intensive one-to-one work — and that the effectiveness is hard to evaluate.

This does not obviate the need to attempt to make information as accessible as possible. Numerous findings show that lack of information — whether it is how often to take the pills or what constitutes healthy diet (Greenhalgh 1994) — is a critical limiting factor to health improvement, so making information as accessible as possible is vitally important.

So far, there is no clear consensus on how best to develop accessible information, though there are instances of good practice to draw on. One of the commonest strategies is simplified language plus illustrations. A good instance is The White Paper 'Valuing People' accessible version which uses plain language and cartoon type pictures, and audio taped versions are also available. The Joseph Rowntree Foundation's *Plain Facts* series is one of the best established mechanisms for dissemination of research findings. This also uses plain text with illustrations, alongside carefully crafted audio tapes (Townsend 1998). The Open University's *Equal People*

course (1996) employed a slightly different technique, using 'Story So Far' boxes to summarise at regular intervals in what is an otherwise standard prose text. Such summarising techniques have also been employed by Trausadottir and Johnson 2000) and in *Good times: Bad times* (Atkinson, McCarthy and Walmsley 2000). Videos, such as *The shampoo set* (Open University 1996), have their supporters, as do IT solutions. Some people with learning difficulties use sign language (Makaton), and this can be used to develop illustrations to accompany text.

However, surprisingly little rigorous evaluation of the different methods has taken place. A great deal of effort is expended in sourcing illustrations, without any clear evidence of whether they enhance communication directly, or merely break up the text. In a review of the British Institute of Learning Disabilities' publication 'Easy guide to physical interventions for people with learning disabilities, their carers and supporter's (2002) Sue Ledger and Lindy Shufflebotham (the latter a service user) comment:

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 and Shufflebotham 2003).

It is healthy to see such reviews appear in print (and an excellent example of inclusive practice), but the critique of what are now quite standard approaches to making information accessible should give us all cause to consider.

A key message is that different people will benefit from different strategies. But perhaps the most important thing to remember is that few people with learning difficulties will access information without some human support. In producing accessible information, the researcher/practitioner may well be providing the supporters with the tools to communicate, rather than attempting to communicate directly.

I would argue, also, that there are limits to the extent to which complex information can be conveyed in plain language or through cartoons. In the translation, subtlety and complexity are invariably lost. Take, for example, the following extract from the *User's guide* (accessible version) to *Valuing people*:

We do not get good equal health treatment or good health services.

What we plan to do

We want to make sure this does not happen in future.

We want to tackle the problems so that you can have better health (Department of Health 2001b, 22).

This is the nearest equivalent in the *User's guide* to the objective set out on earlier in this paper:

To enable people with learning disabilities to access a health service designed around their individual needs with fast and convenient care delivered to a consistently high standard, and with additional support where necessary. (Department of Health 2001a, 59).

Whether better or worse at getting its message across is perhaps not for me to say. But it is certainly different, and is enough to alert to the challenge of conveying abstract ideas effectively in a way that at least some people with learning difficulties can understand.

The question of accessibility has been debated in the disability literature without particular reference to learning disability. Despite some stern admonitions from leading exponents of the social model of disability that access is vital (Barnes 1996), in practice scholars have retreated from this position as papers in the leading journal *Disability and Society* demonstrate. Tom Shakespeare put it elegantly:

Make everything as simple as possible, but no simpler (1996).

From the point of view of the practitioner, there is a key message — there are no easy prescriptions for making information accessible. Large print, tapes, plain language can all help convey simple ideas. But when it comes to ideas which are more complex, there is unlikely to be a substitute for working alongside people who know the individual well and can draw on experience of what works with him or her.

### *Roles of supporters*

One of the most complex areas to consider when working alongside people with learning difficulties is the roles played by non-disabled people. Almost all inclusive research is supported in some way by individuals without a learning difficulty, though exactly what such people do is often obscure.

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. Authors 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. A whole range of terms has been coined to describe the roles of people engaged in inclusive research. So:

- Mitchell (March et al. 1997), who studied the impact of self-advocacy on families, called her colleagues (and by implication herself) 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, McCarthy and Walmsley (2000) refer to themselves as helpers, the women with learning difficulties became known as the 'disabled women';
- Knox, Mok and Parmenter's (2000) informants were 'experts', the researchers were 'inquirers';
- Van Hove (1999) describes research with people with learning disabilities in Belgium as 'cooperative research'. It is difficult to know if the writers are using the terms interchangeably or using them differently because there is little attempt to actually explore what these roles mean in practice or where the boundaries between roles lie.

One of the interesting things to note in these definitions is the negation of the researcher role or 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.

There may not be one label for the researcher doing inclusive research. The way the role 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 a clarity about roles which is understood by all those taking part. Sometimes this is fully explored (see, for example, the chapter called 'The helpers' story' in the work of Atkinson, McCarthy and Walmsley 2000), but frequently it is not, or is referred to only in passing. Williams, for example, reduces her role to such activities as driving the car (Williams 1999). Although one cannot overstate the importance of such practical supports, without which few self-advocates could aspire to do much research, to be effective, researchers need to do a great deal more than merely provide these practical services.

To illustrate this, it is helpful to consider some examples. One of the most common forms of inclusive research has been the life history. 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, a former patient at St Lawrence's Hospital, to create Mabel Cooper's life story (Cooper 1997), and subsequent autobiographical accounts (see Atkinson 1997; Atkinson and Cooper 2000).

At first, Atkinson merely recorded Mabel Cooper's memories; in later work (Atkinson and Cooper 2000) she assisted Mabel in locating her case files, thus enabling her to understand what had happened in her past, and why. In making her professional skills as a researcher available to Mabel, she enhanced Mabel's understanding of her life. Another example of a researcher facilitating an autobiographical account is Sheena Rolph's work with Jean Andrews.

Jean describes 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, 35).

Much is 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 Ken Plummer's (2001) on life histories and Thompson (1988) on oral history. But in inclusive research it has become the convention to play down the skills of the researcher.

McCarthy (2000) describes a different role. She worked with women from Powerhouse, an East London organisation 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, 48–9).

This is a significantly different approach to that employed with Mabel Cooper and Jean Andrews. McCarthy was not setting out to tap into and record direct personal experience. Rather she was sharing with the Powerhouse volunteers as fellow experts her knowledge of an area of academic knowledge hitherto unknown to them, and pooling ideas with them on the accuracy of the research vis-à-vis their own practice derived knowledge. This involved summarising 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 coauthors. Here is an instance where the researcher is overtly sharing her own knowledge and expertise as an academic in addition to the facilitating skills implied in the previous examples. This model is one which might usefully be adopted in health improvement, for it brings the expertise of the professional to bear, whilst allowing people with learning difficulties to bring their own experience to the table, and make comparisons, which should be enlightening for both sides.

This example is relatively rare, or at least its acknowledgement is. Most inclusive researchers claim, at least in public, to be merely aids to recording and writing for publication — the concept of the 'writing hand' (Peckat Well College quoted in Open University 1996 Workbook One).

The arguments for hiding the role of skilled women researchers behind the broad notion of supporter, co-researcher, partner, inquirer, 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 valorisation (Wolfensberger and Tullman 1982). 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, a pretence that with the right intentions the impact of the impairment can be minimised.

This coyness about what is involved in inclusion is unhelpful to practitioners (and others) trying to work with users. The research reports can make it sound as if things went smoothly. Who did what, and how, can be hard to discern — thus learning from good practice more difficult than it should be.

Some pointers can be derived from this body of research: clarity over roles and expectations; the need for professionals to be prepared to give information as well as listen to people's views; a recognition that people will have practical needs that need to be met, as well as having regard for the particular expertise they bring; and the need for plenty of time to build rapport, and to take things slowly.

## CONCLUSION

In this paper I have sought to derive lessons from developments in inclusive research which might usefully be used in working with people with learning difficulties to promote health improvements. After more than a decade, it has begun to be possible to critique inclusive research, and build some pointers for professionals seeking to work inclusively. The naïve belief that if conditions are right somehow the effect



of the impairment will disappear continues to be evident in some quarters. But a more detached perspective allows a recognition of the positive value of such approaches, and some of the limitations. Working alongside users and carers is just too important to improve practice, and improve lives. People with learning difficulties do have pressing health needs. It is important to draw out the best practice from research to support this, whilst not being distracted by overstated claims about what is both possible and achievable.

## REFERENCES

- Andrews J with Rolph S. 2000. Scrub, scrub, scrub ... bad times and good times: Some of the jobs I've had in my life. In *Good times bad times: Women with learning difficulties telling their stories*, eds D Atkinson, M McCarthy, J Walmsley et al., 31–42. Kidderminster: BILD.
- Aspis S. 1997. Self advocacy for people with learning difficulties: Does it have a future? *Disability Society* 12(4): 647–54.
- Atkinson D. 1997. *An auto-biographical approach to learning disability research*. Aldershot: Ashgate.
- Atkinson D. 1989. Research interviews with people with a mental handicap. In *Making connections*, eds A Brechin and J Walmsley. Sevenoaks: Hodder and Stoughton.
- Atkinson D and M Cooper. 2000. Parallel stories. In *Crossing boundaries: Continuity and change in the history of learning disabilities*, eds L Brigham et al. Kidderminster: BILD.
- Atkinson D and J Walmsley. 1999. Using autobiographical approaches with people with learning difficulties. *Disability Society* 14: 203–216.
- Atkinson D, M McCarthy J Walmsley et al. 2000. *Good times bad times: Women with learning difficulties telling their stories*. Kidderminster: BILD.
- Barnes C. 1996. Disability and the myth of the independent researcher. *Disability and Society* 11(1): 107–111.
- Booth T and W Booth. 1994. *Parenting under pressure: Mothers and fathers with learning difficulties*. Buckingham: Open University Press.
- Booth T and W Booth. 1998. *Growing up with parents who have learning difficulties*. London: Routledge.
- Braye S. 2000. The language of participation. In *User involvement and participation in social care*, eds H Kemshall and R Littlechild. London: Jessica Kingsley Publishers.
- Brown H and V Turk. 1992. Defining sexual abuse as it affects adults with learning disabilities. *Mental Handicap* 20(2): 44–5.
- Chappell A. 2000. The emergence of participatory methodology in learning disability research: Understanding the context. *British Journal of Learning Disabilities* 28(1): 38–43.
- Cooper M. 1997. Mabel Cooper's life story. In *Forgotten lives: Exploring the history of learning disability*, eds D Atkinson, M Jackson and J Walmsley with Rolph S. Kidderminster: BILD.
- Cumella S, J Corbett, D Clarke and B Smith. 1992. Primary healthcare for people with learning disability. *Mental Handicap* 20: 123–5.
- Curtice L and L Long. 2002. The health log. *British Journal of Learning Disabilities* 30(2): 68–72.
- Department of Health. 1995. *Health of the nation: A strategy for people with learning disability*. London: HMSO.
- Department of Health. 1998. *The healthy way*. London: HMSO.
- Department of Health. 2001a. *Valuing people*. Norwich: The Stationery Office.
- Department of Health. 2001b. *User's guide to valuing people*. Norwich: The Stationery Office.
- Department of Health. 2002. *Planning with people: Guidance for partnership boards*. London: HMSO.
- Espie M and M Brown. 1998. Health needs and learning disabilities. An overview. *Health Bulletin* 56(2): 603–11.
- Flynn M. 1986. Adults who are mentally handicapped as consumers: Issues and guidelines for interviewing. *Journal of Mental Deficiency Research* 30: 369–77.
- Goode D. 1989. The world of the congenitally deaf-blind: Towards the grounds for achieving human understanding. In *Making connections: Reflecting on the lives and experiences of people with learning difficulties*, eds A Brechin and J Walmsley. Sevenoaks: Hodder and Stoughton.
- Goodley O. 2001. Learning difficulties, the social model of disability and impairment: Challenging epistemologies. *Disability Society* 16: 207–31.
- Greenhalgh L. 1994. Well aware: Improving access to health information for people with learning difficulties. Anglia and Oxford: NHS Executive.
- Johnson K, P Frawley, D Holopainen, L Hillier and L Harrison. 2000. *Living safer sexual lives. Workshop evaluation*. Melbourne: Australian Research Centre in Sex Health and Society, La Trobe University.
- Johnson K, R Strong, L Hillier and M Pitts. 2002. *Screened out. The experiences of cervical screening for women with disabilities*. Melbourne: The Cancer Council of Victoria.
- Kellett M and M Nind. 2001. Ethics in quasi-experimental research on people with severe learning disabilities: dilemmas and compromises. *British Journal of Learning Disabilities* 29(2): 51–5.
- Kiernan C. 1999. Participation in research by people with learning disability: Origins and issues. *British Journal of Learning Disabilities* 27(2): 43–7.

- Knox M, M Mok and T Parmenter. 2000. Working with the experts: Collaborative research with people with an intellectual disability. *Disability Society* 15(1): 49–62.
- Langan J, O Russell and M Whitfield. 1993. *Community care and the general practitioner: Primary health care for people with learning disabilities*. Summary of final report to Department of Health. Bristol: Norah Fry Research Centre.
- Learning Disability Research Initiative. 2003. *Learning disability research initiative research No 1*. Sheffield: University of Sheffield.
- Ledger S and L Shufflebotham. 2003. Review of BILD's easy guide to physical interventions *British Journal of Learning Disabilities* 31(2)103–105.
- McCarthy M. 1999. *Sexuality and women with learning disabilities*. London: Jessica Kingsley.
- McCarthy M. 2000. Sexual abuse and women with learning disabilities. In *Good times: Bad times: Women with learning difficulties telling their stories*, eds D Atkinson, M McCarthy, J Walmsley et al. Kidderminster: BILD.
- McCarthy M and L Millard. 2003. Discussing the menopause with women with learning disabilities. *British Journal of Learning Disabilities* 31(1): 9–18.
- McCarthy M with Anastasia, Pam and Deborah. 2000. Sexual abuse and women with learning disabilities. In *Good times bad times: Women with learning difficulties telling their stories*, eds D Atkinson, M McCarthy, J Walmsley et al. Kidderminster: BILD.
- March J, B Steingold, S Justice and P Mitchell. 1997. Follow the yellow brick road. People with learning difficulties as researchers. *British Journal of Learning Disabilities* 23(3): 94–7.
- Nightingale with Ros and Cindy. 2000. Good health. In *Good times bad times: Women with learning difficulties telling their stories*, eds D Atkinson, M McCarthy, J Walmsley et al. Kidderminster: BILD.
- Open University. 1996. *Learning disability: Working as equal people*. Milton Keynes: Open University.
- People First. 1993. *Oi! It's my assessment*. London: People First.
- Plummer K. 2001. *Documents of life 2*. London: Sage Publications.
- Rodgers J. 1996. Healthy Lives? How the lives of people with learning disabilities affect their potential for health. Unpublished PhD thesis, University of Bristol.
- Rodgers J. 1999. Trying to get it right: Undertaking research involving people with learning difficulties. *Disability and Society* 14(4): 421–33.
- Rolph S. 2000. The history of community care for people with learning difficulties in Norfolk 1930–80. Unpublished PhD thesis, Milton Keynes, Open University.
- Rubin S, D Biklen, C Kasa-Hendrickson, P Kluth, DN Cardinal and A Broderick. 2001. Independence, participation and the meaning of intellectual disability. *Disability and Society* 16(3): 415–30.
- Sanderson H. 1998. A say in my future: Involving people with profound and multiple disabilities in person-centred planning. In *Innovations in advocacy and empowerment*, ed. L Ward, 161–182. Chorley: Lisieux Hall.
- Shakespeare T. 1996. Rules of engagement: doing disability research. *Disability and Society* 11(1): 115–120.
- Simons K. 1992. *Sticking up for yourself. Self advocacy and people with learning difficulties*. York: Joseph Rowntree Foundation.
- Sinason V. 1992. *Mental handicap and the human condition*. London: Free Association Books.
- Stein K. 2000. Caring for people with learning disability: A survey of general practitioners' attitudes in Southampton and South West Hampshire. *British Journal of Learning Disabilities* 28(1): 9–15.
- Swindon People First Research Team. 2002. *Journey to independence: Direct payments for people with learning difficulties*. Report to BILD. Swindon: Swindon People First.
- Thompson P. 1988. *The voice of the past*. Oxford: Oxford University Press.
- Townsley R. 1998. Information is power: The impact of accessible information on people with learning difficulties. In *Innovations in advocacy and empowerment for people with intellectual disabilities*, ed. L Ward, 77–90. Chorley: Lisieux Hall.
- Traustadottir R and Johnson K. 2000. Finding a place.... In *Women with intellectual disabilities finding a place in the world*, eds R Traustadottir and K Johnson, 9–23. London: Jessica Kingsley Publishing.
- Van Hove G. 1999. Cooperative research with people with learning disabilities in Belgium. *Tizard Learning Disability Review* European Issue 3(2): 40–45.
- Walmsley J and J Downer. 1997. Shouting the loudest: Self advocacy, power and diversity. In *Empowerment in everyday life*, ed. P Ramcharan, 35–47. London: Jessica Kingsley.
- Walmsley J. 2001. Normalisation, emancipatory research and learning disability. *Disability and Society* 16(2): 187–205.
- Walmsley J and K Johnson. 2003. *Inclusive research with people with learning disabilities: Past, present and future*. London: Jessica Kingsley Publishers.
- Ward L and K Simons. 1998. Practising partnership: Involving people with learning difficulties in research. *British Journal of Learning Disabilities* 26(4): 128–31.
- Ward K and JS Trigler. 2001. Reflections on participatory action research with people who have developmental disabilities. *Mental Retardation* 1: 57–9.
- Welsh Health Planning Forum. 1992. *Protocol for investment in*

- health gain: Mental handicap (learning disability)*. Cardiff: Welsh Office.
- Whittaker A. 1997. *Looking at our services: Service evaluation by people with learning difficulties*. London: Kings Fund Centre.
- Williams V. 1999. Researching together. *British Journal of Learning Disabilities* 27(2): 48–51.
- Williams V. 2002. Being researchers with the label of learning difficulty: An analysis of talk carried out by a self advocacy research group. Unpublished PhD thesis, Milton Keynes, Open University.
- Wolfensberger W and S Tullman. 1982. A brief outline of the principle of normalization. *Rehabilitation Psychology* 27: 131–45.
- Zarb. 1992. On the road to Damascus: First steps towards changing the relations of disability research production. *Disability, Handicap and Society* 7: 125–38.