
Including People with Learning Difficulties: Theory and Practice

By Jan Walmsley

INTRODUCTION

A major development of recent years has been the inclusion of people with learning difficulties in the Disability Movement. The application of ideas associated with the social model of disability to the situation of people with learning difficulties has the potential to be an empowering and energising development.

In this chapter I use my own experiences at the Open University to chart how such ideas have inspired change, a shift to inclusion of people with learning difficulties in a particular set of activities, teaching, research and publishing in the last 10 years. In 1986 I was a member of a team which launched a course, Mental Handicap: Patterns for Living, about people with learning difficulties, but neither for nor with them. In 1996 a replacement for that course, Working as Equal People, was launched. This course was different; it was made with, by and for people with learning difficulties as well - as about them. At least 25 people with learning difficulties were present at the launch, and this was neither charity or tokenism. All had contributed in some significant way to make Equal People.

Part of the paper, then, tells the story of how that came about, the nitty gritty practical things that made inclusion a reality, and shows some of the ways in which people with learning difficulties contributed to the final product, the course itself.

So far, so good, a positive example of theory into practice. However, I end the paper by questioning how far such strategies can take us.

THEORY AND PRACTICE

The inclusion of people with learning difficulties in ordinary, and indeed, extraordinary life has made great strides in the decade which this volume celebrates. It is the inclusion of people with learning difficulties in the rather extraordinary activities of research, writing and publishing that is the subject
of this paper. In 1984 Richards could identify only five British studies in the previous twenty years where people with learning difficulties had been informants in research projects. In 1996, such a list might well run into hundreds.

I was asked to contribute to the Disability and Society `Ten Years On' Conference on the strength of the work the Open University undertook in preparing a new pack `Learning Disability: Working as Equal People' which was an effort to move inclusion of people with learning difficulties onto a new plane, not only as students of the course, but as authors, contributors and critical commentators. The story of how this occurred, how we moved from making courses for to making them with people with learning difficulties encapsulates some of the shifts in practice that have occurred in the last decade, shifts which are in large part attributable to the work of self-advocacy organisations like People First, partners in making the course. So part of my task is to briefly tell that story, the practical issues which need to be addressed if inclusion is to be a reality.

But the chapter is not all descriptive. I also seek to set these developments in a broader context, of the relationship of people with learning difficulties to the wider disability movement, and of some of the particular challenges they face in being taken seriously as contributors to political and academic debate.

NORMALISATION AND THE SOCIAL MODEL OF DISABILITY

To begin, then a little bit of scene setting. The work of disabled people, including my colleague Vic Finkelstein, in developing a `social model of disability' dates from the 1970s and 1980s (see Finkelstein 1993, Oliver 1990 for overviews of the development of the social model of disability). These academics developed an argument that disabled people, through their shared experience of social and physical barriers to full citizenship, are a distinctive minority social group, with common experiences of oppression. There followed a vigorous period of analysis, political activity and self-identification as disabled people, the force of which can perhaps be seen in the success of the campaign to get the British Disability Discrimination Act passed in 1996. This Act is flawed and limited, but it does represent an acknowledgement that disability is on the mainstream political agenda, and a public recognition that disability may be socially created, and not just a personal tragedy.

At the time Vic Finkelstein, Mike Oliver and others were thinking through the social model, a very different ideology was the dominant force in learning disability, normalisation. Unlike the work in the disability area, this
`movement' was dominated by non-disabled people. Originating in Scandinavia, the arguments were that people with learning difficulties deserved to have opportunities to enjoy normal patterns of life, the rhythms of the day and the seasons, the separation of work and play, an ordinary life, even within segregated services (Nirje, 1980, p. 33). These ideas were developed and transformed by Wolf Wolfensberger and colleagues in the North American context as a strategy to reverse institutional models of congregation and segregation, and to promote integration with `valued' (ie non-disabled) individuals and institutions (Wolfensberger and Tullman, 1983). Normalisation, especially its North American strand, was at the time I became involved with learning disability in the mid 1980s, an incontrovertible dogma. Anyone who dared voice disagreement was labelled as dangerously illinformed, a heretic (for a fuller discussion of the history of normalisation see Chappell in this volume). Yet normalisation was very limited in its critique of the reasons why people with learning difficulties were devalued by society, basing it on labelling theory. The argument was that because learning difficulty/mental retardation/mental handicap/etc. were negative labels, services (not society as in the social model) should do all they can to offer people valued social roles and positive images. It was a movement which fostered integration of people with learning difficulties into mainstream society, which aimed to disperse people and help them develop relationships with non-disabled people because they are more `valued' as the terminology puts it, and to downplay difference, the very antithesis of the way the social model of disability critiqued social barriers and helped at least some disabled people learn to develop solidarity with one another, to revalue themselves as equal citizens, and to attribute their oppression and exclusion to social barriers, much broader than labelling.

There has been a gradual breaking down of the distinctive differences these two contrasting sets of ideas represent, partly because people with learning difficulties have `found a voice' through self-advocacy, partly through bridge building between organisations like British Council of Disabled People and People First. There has been departure from strict normalisation principles to the extent that it is accepted practice for people with learning difficulties to appear on public platforms with a non-disabled supporter to prompt and advise them. However, the links between the disability movement and people with learning difficulties are often fragile, and most people with learning difficulties have not yet to my knowledge repudiated normalisation. The People First slogan `label jars, not people' owes much to normalisation whose analysis is that the labelling is the cause of the oppression. Research indicates that members of self advocacy organisations are notably more likely to own the `learning difficulty' label than other people with learning difficulties (Simons, 1992), but there is still a hesitancy in adopting the positive stance to
disability which characterises the broader disability politics. One of my arguments here is that thinking in learning disability is still dominated by normalisation.

Hence I would argue that there are still differences in the ways disabled people and people with learning difficulties and their allies, analyse the situation they find themselves in and differences therefore in practice. This is a theme I will elaborate upon below, before returning to the implications for the theory of inclusion of people with learning difficulties in the disability movement.

INCLUSION IN PRACTICE

To move, then, from policy to practice, I use my own experiences in the Open University to illustrate the how of inclusion. It's a neat story, spanning just over a decade from 1985 to 1996, and the production of four different open learning courses. Coincidentally, it is also the decade which this volume celebrates.

The UK Open University, founded in 1971, was dubbed the University of the Second Chance, offering an opportunity for higher education to those many people who had been unable to qualify for university entrance through the usual route of `A' levels (in England, Wales and Northern Ireland) or `Highers' (Scotland). It has a completely open access policy on university entrance. Anyone who could obtain a place, and afford the modest fees was eligible to become an Open University student. In theory, this includes people with learning difficulties, though few availed themselves of the opportunity.

The OU also produces `packs', open learning training materials for use by anyone interested enough to purchase and study them. In 1985, when I joined the OU, production of a new `pack' was in full swing, `Mental Handicap: Patterns for Living' made in collaboration with Mencap. In its day it was revolutionary, addressing as it did not only professionals and front line staff, but also family members and volunteers, the idea being to improve practice not only through information giving but also by bringing people from different backgrounds and in different roles together in mixed groups to study, discuss and debate. To a great extent it was successful. It sold well, and made quite an impact. It is estimated that in its ten year life at least 30,000 people made use of it.

However, revolutionary as it was in its day, its shortcomings are obvious with hindsight. It portrayed people with learning difficulties as human beings with real feelings, but did not include the `voices' of people with learning difficulties. They were anonymous, pseudonyms were used, and they were represented through line drawings, not photographs. They were not included in the target audience, nor were they involved in any way in its production or dissemination.
Very rapidly this omission was brought to the team's attention. We might not have envisaged people with learning difficulties doing Patterns for Living, but others did. Some imaginative and dedicated students set up learning partnerships so that people with learning difficulties could do the course, some getting as far as completing the computer marked assignments and gaining a Certificate of Course Completion. Letters began to come in urging the OU to produce a course for people with learning difficulties to study. The ideas in Patterns for Living were good, but the technology was wrong, almost entirely print based, too dense, too much reading.

This led to `Patterns for Living: Working Together' (1989) an adaptation of the original course, particularly for people with learning difficulties. The content and ideas remained unchanged, but the technology was transformed. Eight of the main case studies were recorded as audio dramas, accompanied by a cartoon style workbook, and assignments to test comprehension of the dramas. This was for people with learning difficulties, but it again excluded them from the production. Ordinary actors were used - no efforts were made to employ people with learning difficulties - and one criticism was that these actors relied too much on speech impairments to convey learning disability. However, in promoting the course the people who tested it were invited to speak of their responses to the course, and some were extremely effective ambassadors. The message that people with learning difficulties could lead groups of students as facilitators, either alone or in partnerships, was one that was vigorously promoted in publicity, and widely taken up.

In 1988 the Patterns for Living team began work on an undergraduate level course about learning disability, `Mental Handicap: Changing Perspectives'. The challenge for the team was to find ways of including people with learning difficulties in a course which they were unlikely to be able to study - if the learning difficulty label means anything, surely we believed that it meant an OU degree is beyond most people so labelled (an issue I will return to below). The solution to this was to compile a book, an anthology of contributions by people with learning difficulties, entitled `Know Me As I Am' (Atkinson and Williams, 1990). The book is the heart of the course. Students are consistently asked to refer to it, and are expected to use its content as a reference point in their written work. Thus the voices of people with learning difficulties are fully represented, - though the analysis of what they say/write/draw was left to the course team and the students, and this is another important point.

Finally, to `Equal People'. By 1992 the original Mental Handicap: Patterns for Living was clearly out of date. As chair, I regularly fielded letters objecting to `Mental Handicap' in the title, there was precious little of self-advocacy, and too much about hospital life. It was time to consider its replacement. However,
as such packs have to be entirely externally funded, the challenge was to persuade funders that a `remake' was a worthwhile investment. Mencap's support was secured for the project, but how was it to be `different'? The answer to move forward the ideas that had been around in all three courses we'd made previously:

- to develop partnerships with people with learning difficulties to make the course, as had been done with `Know Me As I Am' in producing `Changing Perspectives'.
- to include people with learning difficulties in the audience, alongside staff, parents, relatives, volunteers.

At the outset, the means by which either was to be done were rather vague. I describe only the partnerships to make the course here, though the inclusion of people in other roles is equally important.

PARTNERSHIPS TO MAKE THE COURSE

Initially ideas about partnership focused on an advisory group. To put this into effect I and a colleague made an appointment with People First (London Boroughs) to discuss. It is to the credit of the people we met on that day that they immediately noticed the tokenism of an advisory group. In response to the rough diagram I produced to illustrate the production process, Lloyd Page, People First volunteer, asked `where's all the decisions made?' I pointed to the `Course Team' at the centre. His response was `That's where we want to be'. Indeed, that's where they ended up, though not without doubts on the part of the existing team that this was manageable or even desirable! There followed a letter from People First setting out the terms and conditions on which they would work with the OU and Mencap.

Including Lloyd Page and initially Anya Souza (later Desmond Coker-Davies) as People First representatives on the team turned out to have been an excellent decision. People First (London Boroughs) had the resources and the trained personnel to make the partnership work - efficient telephone and fax service, back-up for the representatives particularly Lois Robinson, who was the supporter throughout, a good network of contacts and on-going work on which we could draw. Questions were asked `why London?' The answer was that it is geographically convenient for Milton Keynes, but more importantly, People First (London Boroughs) provided the organisational infrastructure with which we could engage. For example, it was possible to pay the course team members for their work without threatening benefits because the money went to the organisation, not the individuals.
On the part of the OU it was important to pay attention to the means by which our new colleagues could be helped to engage with a complex and often stressful production system. Some of the steps we took were:

- to kick off with a two-day residential planning meeting. This helped us to get to know one another, build trust, share ideas about how to proceed, all those old cliches which are nevertheless important ingredients for a successful team
- to send out material for meetings and comment in good time for Lois to support Lloyd, Anya or Desmond in making sense of what was said, at least a week in advance
- to write minutes with careful attention to language
- to prepare explanations of technicalities like schedules, assessment (including Vocational Qualifications!), ways of publishing, etc. in advance, and presenting the information at meetings
- to train colleagues who visited the Team meetings (from marketing, editing, and design) to take account of speed of delivery, sophistication of language and paperwork
- to ensure that all meetings included agenda items which everyone could make a contribution to. We called this ‘Reports from everyone’, and it was a good opportunity to exchange experiences and ideas which most agendas do not permit
- to include breaks to help concentration. In principle this meant we worked for a maximum of 1 hour 15 minutes at a time, though we did not always manage to keep to this when pressure of work was too great.

We had been successful enough in raising money for the course to be able to afford to pay the additional costs of extra staff, and a supporter. However, without the partnership commitment it is unlikely we would have raised the cash, so it could not be called merely fortuitous.

Apart from giving credibility to the course, People First's contributions were:

- definitions of what was important to include, particularly learning materials on bereavement and the stresses of moving house
- access to on-going projects, and people
- the group work exercises which they co-authored, based in part on People First training materials and experience
- instant feedback on what was and what was not clear language
- opportunities to test materials on the spot - for example, in the audio drama the script moved straight from the star character's sister expressing
concern that she should remember to administer her sick father's medicines to his funeral. Desmond said he thought this meant she was responsible for his death - the script was amended • extra people to help fulfil the commitment to visit all 15 groups who tested the course in draft, groups which were geographically spread across the UK and Ireland • because the process was less rushed than usual, I think we all found it a good team to be in. For one thing, we learnt to listen to one another, to savour what was said, rather than struggle to be heard.

Space does not allow me to go into detail about the other side of the coin, the involvement of large numbers of people with and without learning difficulties, in making video, audio, contributing to case studies and advisory groups, testing and providing feedback, featuring under their real names with photographs, not under pseudonyms and in line drawings as was the case in 1986. The course has been on sale since March 1996, and will play its part in persuading others to take inclusion seriously, and show ways in which it can be done.

So, in the decade we are considering, the OU moved from making courses about people with learning difficulties to making courses in partnership with them. It's indicative of the shifts in attitudes, knowledge, technology and the efforts of people with learning difficulties to get others to take them seriously.

THEORY AGAIN

So far so good, a positive story of inclusion. But it will not have escaped your notice that it is I, not Lloyd, Anya or Desmond who writes this account. Indeed, there were no speakers at the Ten Years On Conference who call themselves people with learning difficulties, and a quick scan through recent Disability and Society editions leads me to tentatively say there have been no articles written by people with learning difficulties. This must be significant. As far as the Equal People team goes, Anya and Desmond are unemployed at the time of writing, whilst Lloyd and Lois have moved onto other projects. The barriers to inclusion were only temporarily dismantled, now they are back in place.

How does this relate back to theory, and the disability movement?

I will argue from here on that there are very particular issues for people with learning difficulties in taking control of analysing their own experience, issues which are less pressing for other groups of disabled people, and which the
broad disability movement must take on board if there is to be a genuine alliance, based on mutual trust and respect.

One important point is that the way people with learning difficulties contributed to `Equal People' was based on personal experience, who they are as people with learning difficulties, and the often unique insights they have to offer from that perspective. Those skills have not been transferred to other courses as they might have been had people without learning difficulties spent two and half years contributing to an open learning project. It is important to ask whether this is due to attitudinal prejudice, lack of opportunity or to the limitations imposed by the impairment itself.

A second related point, and one made by Simone Aspis, a woman with learning disabilities, to whom I am indebted for some of the ideas aired here (Aspis, 1997), is that the contributions made by people with learning difficulties are personal - they contribute their personal experiences, their life stories, and others take on the job of interpreting them. This critique can be applied to `Know Me As I Am', the anthology at the heart of the Changing Perspectives course referred to above, and, perhaps to a lesser extent, to the contributions made by people with learning difficulties to `Equal People'. Again, it is appropriate to ask whether this represents a failure on the part of people like myself to enable people with learning difficulties to contribute in this way, or whether we must accept this as a result of the impairment itself.

Thirdly, the Equal People course does not tackle the politics of disability head on. It has a rights agenda, but does not set out to teach the social model of disability. I am again indebted to Aspis for this insight (personal communication 1996). She argues that it was a failure on the part of the Course Team. I am less certain than she that this is the case. My defence is that at the level at which we pitched the course, a basic training tool for people with learning difficulties, family members and untrained staff it was not appropriate. Certainly my own teaching skills are not up to that task. It was instructive to me to watch Simone expound her ideas on the limitations of self-advocacy to a mixed group of women, with and without learning disabilities. The women with learning disabilities, all of whom were active in self-advocacy and related activities, found her arguments hard to comprehend.

CO-AUTHORING AND CO-EDITING: A WAY FORWARD?

In order to overcome the many barriers to inclusion in academic and political debate, the idea of co-authoring and co-editing a book is an attractive strategy. Since completing work on `Equal People' I and some colleagues with and without learning difficulties have formed a group, known as Women in Learning Disability
(WILD) to co-write a book about women with learning difficulties to which women with learning difficulties will be editors and contributors. There is, I believe, a genuine commitment to make this more than tokenistic, and following Aspis's argument, more than the disabled women relating their `stories' for the non-disabled women to unpick, analyse and re-package. However, there are some contradictions deeply embedded within the project, which have impeded progress.

First, there is the question of access. For most of the non-disabled women, it is important to make this a book which will be taken seriously, which will help to re-orientate policy, and shift ideas. Therefore it needs to be more than a set of training exercises, a video, or an audio led package. The peculiar conjunctions of gender and learning disability give rise to unique issues, and these are as yet poorly understood and theorised. Those of us brought up in the academic world see print as the means by which ideas are worked through, tested and clarified. The disabled women, or at least some of them, disagree. For them, the main purpose is to reach women with learning difficulties - to do this will require, not a book full of ideas expressed in complex language, but a video, or a highly illustrated set of booklets, similar to those produced by, amongst others, People First (London Boroughs) (People First, 1994a,1994b), or indeed, `the `Equal People' pack (Open University, 1996). I am not sure whether these are mutually exclusive aims, but at the present state of my knowledge, I feel that they are.

Secondly, there is the issue of power, who controls the analysis. Not for the first time, I have been present as disabled women in this group re-live their disappointments, their very personal experiences of oppression, exclusion and discrimination in front of an audience. These are moving stories, yet I feel an acute sense of unease, and helplessness. It is almost like being a voyeur. The women are keen for the stories to be told, for the injustice to be recognised and the struggles acknowledged, yet I do not know how to support them in translating these experiences from the personal to the political without taking over. Nor is it yet clear how a book can represent women with learning difficulties without inviting - the reader to join in as a voyeur.

Thirdly, there is, as always, the question of resources. To write a book with genuine involvement will mean lots of meetings, time, writing partnerships and struggles. What publisher will finance such a project?

And finally, even if we answer these questions, there remains a danger of creating an elite, a group of women who, admittedly, can act as role models for others, but a group which excludes many, such as people without speech, and whose members may find it as difficult to represent and reach them as do the rest of us.
It is possible to counter all these arguments - we could aim for two outcomes, one a book, the other training resources, so that all possible audiences can be reached, for example. It may be that the group has to work through issues of personal and political, to separate them so that we all become interpreters of the experiences of women with learning difficulties, with the disabled women contributing their own experiences not as raw material but as an interpretative tool. We could, perhaps, obtain resources through special fund raising, setting up as a research project rather than only as book authors. And Mike Oliver is not the only disabled academic to make the point that disabled people can and must speak for others - it is not just a matter of being representative.

THE ROLE OF ADVISERS

The discussion of the WILD project inevitably gives rise to questions about the role people without learning difficulties play as advisers, supporters, co-authors and the like. People with learning difficulties are uniquely reliant on human intermediaries to gain access to the sort of complex ideas represented by academic and political debate, and indeed, to contribute to such debate. Whilst most disabled people rely on aids, human or technical, to enable them to participate in society on equal terms, the role of advisers to people with learning difficulties is one that is more complex then, say, a British Sign Language interpreter for a deaf person. The BSL interpreter has the relatively straightforward task of translating from one language to another. The adviser has a far more complex task both of enabling a person with learning difficulties to understand ideas, and at the same time task of enabling him or her to articulate a response.

The role of advisers and supporters in the lives of people with learning difficulties is a little researched topic. Other than some practical checklists for advisers (Values into Action, 1993) there is very little written, partly because people with learning difficulties rely on such people to enable them to get into print, and standing back from that relationship to reflect upon it, and communicate it to others cannot be easy. Issues such as the degree of affection and mutual respect required to make the relationship workable, and questions about the impact of gender, age, class or ethnicity on the relationship have barely been put on the agenda. Anecdotal evidence and personal observation are all I have to draw on to in trying to make sense of a very complex relationship, and loyalty to those people with learning difficulties who have confided their personal reservations about their advisers bars me from committing much to print here. Suffice it to say, there are precious few safeguards to protect people from learning difficulties from exploitation at the hands of their advisers, and I, in common with many people who spend time with self-advocacy groups, have observed both extremely facilitative and some
extremely questionable practice by advisers. It is a moot point whether the imbalance of power that is at the very root of the relationship between people with learning difficulties and their advisers can ever be remedied by better training, supervision and codes of practice. At present, none of these is in place, and the short-term funding on which most self-advocacy groups operate makes it difficult to visualise how that might happen.

CONCLUSION: UNANSWERED QUESTIONS

In the final analysis I am left with a series of questions.

What is the nature of learning disability? Is it, as normalisation theory has it, rooted in labelling?

How far can the environment be manipulated to solve the limitations learning disability imposes? Is it the nature and implications of the impairment which gave rise to the absence of speakers with learning difficulties at the Ten Years On Conference (to be replaced by people like me) or is it a failure of imagination on all our parts to enable them to contribute at the level of an academic conference, or in a volume of academic writings?

I ask whether, with all the time, technology and teaching skills in the world, it is possible for people with learning difficulties to learn the skills which will enable them to take part in such debates on equal terms?

The dice are loaded against such a development, not just because of poor opportunities for learning them, not just because we lack resources or have the wrong attitudes, but because it is ultimately a normalising agenda we are working to, an agenda which maintains that to take part in society on equal terms people with learning difficulties must heroically rise above the impairment and join in a conspiracy to deny that their intellectual limitations matter. Or maybe these limitations are not real, maybe they are socially created, and they can be undone.

Every form of disability gives rise to a particular set of restrictions on what the disabled person can do, and it is in the area of political and academic debate that people with learning difficulties will always be at a disadvantage. Even if they somehow rise above those limitations they will then run the risk of being relabelled as `normal', as not having learning difficulties at all, a development I have witnessed in relation to individuals with particular gifts which go counter to common-sense notions of what learning disability means. Having a degree is one such example. Another is being able to think, write and publish
without assistance. In a sense, there are two messages, both complementary and contradictory.

The first is that inclusion and partnership are possible. They require a will to make it work, money and time, and careful attention to detail. They require that the environment is carefully manipulated. It is work I am personally very proud to have been involved in as Chair of the Equal People course team, I'm proud of the process and proud of the product.

The second is a more mixed message. It is that including people with learning difficulties in academic and political debate will always be a struggle. Unlike other groups of disabled people with different impairments, it is unclear whether they will ever be able to engage on equal terms. It is not just a matter of time, resources, technology and positive attitudes. It is not just a learning difficulty, the sort we are too ready to say we share because we too have learning difficulties. It is where normalisation has not got all the answers. This is an area where oppression and exclusion take a distinct form for people with learning difficulties, and if they are to take their place alongside other disabled people, at gatherings like the Ten Years On Conference, for example, or in the pages of the journal, it's something that has to be addressed. This chapter is an attempt to place these questions on the agenda of people working with people with learning difficulties in this area, and of the disability movement. I look forward to a continuing debate.

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