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Funding for Change : Translating emancipatory disability research from theory to practice

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INTRODUCTION

Like most of the people contributing to this book, I do so wearing multiple hats. Each has a strong influence on what I have to say about 'doing disability research' and, in particular, about how we can make it more emancipatory in practice; I want to start by saying a bit about each hat to put my contribution into context.

The first hat is as Programme Adviser on Disability for the Joseph Rowntree Foundation, the largest single independent funder of applied research and development projects in the fields of housing, social care and disability in the UK. Joseph Rowntree was a Quaker; his beliefs and values have a continuing influence on the Foundation and its work. His goal was to 'seek out the underlying causes of social evil' (by research amongst other things) and in this way 'to change the face of England'. In other words, he could see the importance of research, but only in so far as it provided the tools and the impetus for change towards a more just society, particularly for those most disadvantaged within it.

The second hat is that of Senior Research Fellow at the Norah Fry Research Centre at the University of Bristol. The Frys were also Quakers like the Rowntrees and the research and other work carried out at the Centre is similarly informed by a human rights perspective and geared towards changes in the support and opportunities available to people with learning difficulties as equal members of the society in which they live.

Finally there is the 'personal' hat, made up of multiple strands - past experience in community development and welfare rights work, in the women's movement and feminist research and teaching; personal involvement with people with learning difficulties and other disabled friends within the disability movement.

All these hats affect my understanding of, and involvement in, the development of more empowering disability research aimed at bringing about positive changes in disabled people's lives. In this chapter I want to draw particularly on recent experiences within the Foundation and the Norah Fry Research Centre to ask:

> 1. How far have we moved towards a more emancipatory disability research in practice over the last 5 years?

> 2. What progress has been made in involving people with learning difficulties in research that affects their lives?

> 3. What have we learned about ways of involving disabled children in projects?

> 4. What can we learn from all this about ways to promote positive change?

1. HOW FAR HAVE WE MOVED TOWARDS A MORE EMANCIPATORY DISABILITY RESEARCH IN PRACTICE?

Mike Oliver, in his contribution to this book, reviews progress in the funding policies and practices of the major funding bodies in this area: the Economic and Social Research Council (ESRC), the Department of Health, and the Joseph Rowntree Foundation. His verdict is that little has changed in reality even if superficially some gains appear to have been made. As far as the J Joseph Rowntree Foundation is concerned, he argues that 'little funding has gone to research which could generally be called emancipatory.' Not surprisingly, given the Foundation's key role in funding the seminal 'Researching Physical Disability' series, he views this as 'perhaps most disappointing of all' (Oliver, 1997, p24). I would agree with Oliver that progress remains frustratingly slow; but, as a pragmatist, I would point to a significant number of small steps which have been taken by the Foundation in recent years to ensure that the research that it funds moves closer to the criteria set out by him and others for more empowering or emancipatory disability research.

First, there is the avowed commitment to only funding research which locates itself within the social model of disability, a policy deriving from the inception of the Foundation's Advisory Group on Disability of which Oliver was an original, key, member, and significant resource and ally to

the author. N nowadays, an avowed commitment to the social model of disability is relatively commonplace (in principle if not in practice) but in 1988 this was far from true. As a major funding body, the Foundation was able to playa significant consciousness-raising role in firmly stating its commitment to the social model of disability and its expectation that those seeking funding would follow suit.

Second, with the advent of the NHS and Community Care Act and the official commitment to 'user involvement' came the requirement of the Foundation's then Community Care and Disability Committee that all proposals submitted to it should strive for appropriate user involvement at all stages of the research or development process. Thus the stage was set for searching questions to be asked of non-disabled researchers who had not sought partnerships with organisations of disabled people in putting forward their research proposals.

Third was the commitment to ensuring that at least one person on the Foundation committee handling funding proposals for disability projects should themselves be a disabled person (with relevant experience) involved with disabled people's organisations and the disability movement.

Fourth, the Foundation's general commitment to only funding projects which have clear potential for bringing about policy and practice changes which will be positive for people's lives, and its commitment to 'staying with , projects funded {ensuring that their findings are promoted widely to a variety of different audiences and that questions are asked about 'what should happen next' to take things further) have been closely applied to disability projects. Thus, for example, a whole programme of work around independent living and direct payments has developed from the original work by Jenny Morris comparing disabled people's experiences of different kinds of community care services and how far they were facilitative of their independence (Morris, 1993); through Gerry Zarb and Pamela Nadash's work for BCODE comparing the costs and quality of services provided by local authorities as compared with those purchased by people through direct or indirect payments (Zarb and Nadash, 1994); to a continuing programme of work exploring how direct payments can be made to work for people with learning difficulties (Holman and Collins, 1997) and, in the future, perhaps, older people.

Foundation staff have also had access to some Disability Equality Training. As a result of all these developments the Foundation - officers,

Committee and Trustees - are all significantly more aware of disability research issues than they were 5 years ago. Traditional (positivist) research proposals will simply not get funded. Nor will research proposals masquerading as more emancipatory because of token references to 'consultation' with individual disabled people. Where proposals originate from non-disabled people and their organisations, then the assumption is that a proper partnership with organisations of disabled people should be in place. Where the Foundation commissions disability research then the means of involving disabled people and their organisations within the proposed is explicitly required to be outlined. Within our new Disabled Children's Programme (to which I return below) the involvement of disabled children as consultants, and in other ways is similarly expected. The experiences of disabled young people are placed centre stage. There are equivalent expectations of meaningful user involvement in research concerning people with learning difficulties (see below). There is increasing attentiveness to the need to support more appropriate and emancipatory research methodologies (as, for example, in the research on Deaf and hearing people working together, currently being undertaken at the Centre for Deaf Studies at the University of Bristol) and the need to ensure that. key messages from research are shared in ways which make them easily accessible to their intended audience, as, for example illustrated leaflets to disabled children and illustrated magazines and tapes for people with learning difficulties (see below) .Where the target audience is those involved with disabled people rather than disabled people themselves -as, for example, in a Foundation funded project to encourage people to 'hear the voice of people with dementia' - then imaginative strategies for disseminating ideas are being pursued - in this case via a card quiz game (Kindred and Goldsmith, 1997).

Clearly, there is still a long way to go. Not all of the disability projects funded by the Foundation meet all the criteria set out by Oliver (chapter 1 in this volume) but, I would suggest, that all of them address some. It remains true that the number of research projects conceived and undertaken by disabled people's organisations remains small but this is not surprising. Many organisations of disabled people would rather 'do' than 'research'. They are, moreover, almost always better equipped to do the former than the latter. Sometimes, the Foundation can have an important role in marrying up the separate and complementary skills and expertise of an organisation of disabled people which knows which issues need to be researched, with those of a consultant or non-disabled researcher, who has the skills required to ensure that the work undertaken

satisfactorily meets both the goals of the disability organisation and the requirements of methodologically robust research. Thus, the Foundation was instrumental in ensuring that the crucial research on direct payments for disabled people was undertaken by researchers with unarguable research expertise but working to the agenda of disabled people (BCODP) who knew what the appropriate issues were to be explored (Zarb and Nadash, 1994). Similarly the Foundation has been instrumental in funding consultancy to support REACT (Preston Research Action on Learning Disability), a group of young people with learning difficulties, to carry out a research project of their own.

Increasingly, the Foundation is able, through its privileged position in networks of researchers, professionals and disabled people and their organisations, both to learn how things might be done better and to educate others to act accordingly. In the wake of a substantial amount of work which has successfully involved people with learning difficulties in research we are now encouraging those who wish to undertake work with other marginalised and traditionally silenced groups to think of how they could do this in an empowering way within our 'Promoting voices and choices' programme.

Innovative projects on 'hearing the voice of people with dementia' (Goldsmith, 1996) and on issues confronting people with aphasia (being undertaken at City University) are to be joined by exciting work with children with autism, where research has almost exclusively been located to date within the medical model of disability. While there is still a long way to go before the work that the Foundation funds meets all the criteria of Oliver's ideal emancipatory research agenda, it is important not to overlook some of the significant progress that has been made. Below I look in turn at developments in research involving people with learning difficulties and research involving disabled children, as positive examples of change.

2. INVOLVING PEOPLE WITH LEARNING DIFFICULTIES IN RESEARCH

The research process - relying heavily as it does on intellectual skills -is, by definition, less easily accessible to people with learning difficulties than it is to people with other kinds of, non-intellectual, impairments. But the debate about the emancipatory research paradigm which was fuelled by the seminar series on researching physical disability has largely ignored the particular issues which arise in relation to research involving

people with learning difficulties. Those actively pursuing more empowering research strategies as allies of people with learning difficulties have yet to add their experiences to the emancipatory research paradigm debate, though they have clearly much to contribute (e.g. Rodgers, 1996). Nonetheless, there has been a positive sea change in ideas and expectations about appropriate ways of understanding and undertaking research involving people with learning difficulties (at least in some quarters) which seeks to respect and further their agenda for empowerment.

The most basic and fundamental change has been the recognition that people with learning difficulties, like non-disabled people and people with other kinds of impairments, might appropriately be involved in research as participants and respondents. While Oliver and others have, quite appropriately, commented on the negatives associated with research which 'rips off' disabled participants, by simply using them to obtain information without involving them in constructing or implementing the research agenda, for people with learning difficulties the recognition that they are appropriate respondents in research about their lives and the services that they use is a victory won only in the last 10 years. Before that 'user views' if sought at all were solicited from parents or professionals rather than people with learning difficulties themselves. In the intervening decade or so significant progress has been made in recognising that people with learning difficulties are the best commentators on their experiences and that it behoves researchers to acquire and develop innovative research skills which can access the views of people with learning difficulties who may only have limited verbal communication skills or may communicate in other ways entirely (see, for example, Atkinson, 1988; Beresford, 1997; Marchant and Page, 1993; Minkes et al, 1995; Simmons, 1994; Ward, 1997a; 1997b). Of course, there is real scope here for inappropriate exploitation of people with learning difficulties by seeking their views in the 'rip off research tradition appropriately condemned by Oliver, which is of primary benefit to researchers and professionals rather than people with learning difficulties themselves. But there are positive signs of funding bodies, like the Foundation, and researchers (e.g. McCarthy, 1997 amongst others) paying careful attention to ensuring that research undertaken is potentially empowering and, certainly not disempowering or exploitative of the participants with learning difficulties involved.

But beyond this basic right - to be consulted in research which affects your life - there have been more important gains. The Foundation, in its

expectations about research involving disabled people, states clearly that they should be involved in all stages of the research process. We now have positive models of practical ways in which people with learning difficulties can, and have been, involved in research in a variety of ways: as originators of the research idea; as advisers or consultants to a research project; as research workers or interviewers; and as disseminators of research findings (see Ward (1997a))

ORIGINATING RESEARCH IDEAS

A recent project funded by the Foundation and undertaken by researchers at the Norah Fry Research Centre originated in the concern of people with learning difficulties in the Bristol area about the extent to which they were involved in the recruitment of staff in their homes and day centres. The local self-advocacy group had written to the Social Services Committee about the importance they attached to this. Through a small survey of 11 local day centres, they found that opportunities for involvement in recruiting staff existed in principle but in practice were limited. Researchers at the Norah Fry Research Centre were alerted by them to this issue. The researchers sought funding for a more substantial research project on user involvement in recruitment with a view to encouraging better practice in the area. The research workers were non-disabled but were advised throughout by four panels of people with learning difficulties. They gave advice on the content and design of an accessible leaflet about the project; tested out the materials for the pictorial interview schedule for people with learning difficulties in the study and gave their own experiences of involvement in staff recruitment to guide the researchers in their formal interviews. Outputs from the project included a resource pack for supporters working with people with learning difficulties on how to facilitate involvement at all stages of the recruitment process (Townsley et al, 1997) and an accessible leaflet with factsheets giving clear ideas for action for people with learning difficulties themselves (Townsley and Macadam, 1996). The Foundation has now supported further work to help implement developments in this area in a variety of local organisations.

UNDERTAKING RESEARCH AND ACTING AS ADVISERS

The last few years has seen a gradual increase in the number of research projects which have been undertaken by people with learning difficulties themselves, not just as advisers or consultants (see, for example, Whit taker et al, 1991; Whit taker, 1997). In Bristol, for example, a group of

people attending a local day centre were approached by a local NHS Trust to find out where gender issues were particularly significant in service provision. The group of 11 men and women and their supporter took responsibility for deciding the questions to be asked, the format in which information would be collected and the design of the illustrated questionnaire, with support from a member of staff at the Norah Fry Research Centre. The researchers divided up the work involved in mailing out 400 copies of the questionnaire and analysing the material returned. They agreed the rates of pay for the work involved and were involved in disseminating the information they collected (see Minkes et al, 1995; and Townsley 1995, for further details).

In London, the organisation of people with learning difficulties, People First, was involved, with the support of the Joseph Rowntree Foundation, in a study of the experiences of people with learning difficulties moving from long stay institutions into homes in the community. With support from an adviser from Charities Evaluation Services, two interviewers from People First were trained to undertake the evaluation from carrying out the interview to analysing and presenting the material in a report, a summary and a tape (see People First, 1994). Elsewhere, the Nottingham-based Advocacy in Action group has helped the Notting Hill Housing Trust survey the views and experiences of tenants in their supported housing, including those tenants who could not respond to a written survey but could contribute their views with the aid of pictures, sounds, symbols and audio tapes (Notting Hill Trust, 1994). Other examples of service evaluation by people with learning difficulties are given in Whit taker (1997).

In other projects people with learning difficulties are increasingly playing a crucial role as consultants and advisers. At the Norah Fry Research Centre it is becoming the norm for research projects involving people with learning difficulties to recruit an advisory panel to help researchers formulate their projects appropriately. Thus, for example, in a recent Foundation funded project on the impact of legislative changes on opportunities for adult education for people with learning difficulties a group of six students with learning difficulties met during the lifetime of the project to design the letter which went out to self-advocacy groups with a tape inviting their views and experiences and guiding the questions which were used by interviewers in visits to particular colleges. Their involvement highlighted significant aspects of adult education (for example bullying by non-disabled students) which might otherwise not have been included in the research (Macadam and Sutcliffe, 1996a;

1996b). In another research project on the impact of changes in the law on registered homes for people who lived with other families - adult placements - the consultants with learning difficulties were able not only to advise on key words and important topics to include, and to test out the pictures which were used to enable people with learning difficulties to the part in the study, but also to articulate to the researchers the positives and negatives of adult placements from their perspective: often very different from those of the practitioners and policy makers involved (Robinson and Simmons, 1996a; 1996b).

As a funder of research involving people with learning difficulties, the Foundation would now expect all research projects in this area which were not undertaken by people with learning difficulties themselves to demonstrate firm evidence of partnership with their organisations and their involvement as interviewers or consultants and advisers with appropriate payment of fees (with due attention being paid to the method of payment so that rights to state benefits are not affected).

DISSEMINATION

The Foundation, because of its commitment to ensuring that the findings from the projects it funds become part of a process of change, places an enormous emphasis on dissemination. Traditionally, this has been aimed at policy makers and practitioners, who were seen to be in a position to bring about change. Now, however, there is recognition that people with learning difficulties are effectively disempowered by research if its findings are not accessible to them. As a result, the Foundation has funded an ongoing series of short, illustrated magazines (accompanied by tape) conveying key messages for people with learning difficulties from projects which it has funded. These are sent free to 1,100 self-advocacy groups and day centres in the UK and are also available on a subscription basis to other organisations and individuals. An evaluation of the pilot series was overwhelmingly positive; ideas for further improving the series on the basis of comments received from people with learning difficulties are now in hand and a guide for others on producing information in a simple and illustrated form is now available (Townsley and Gyde, 1997).

The development of the series has been aided by an advisory group of people with learning difficulties and the expectation is that every researcher producing a draft Plain Facts will test out the appropriate key findings or messages to be included within it with people with learning

difficulties in their local area. This is critical. Experience shows that even those most committed to making information accessible can unwittingly produce information which is not. Andrew Bright, of People First, London, for example, found in his evaluation of information produced by Southwark Inform (which was set up to provide accessible information to people with learning difficulties) that posters with photographs were best understood by people with learning difficulties and that video also worked well. However, information using symbols did not because people with learning difficulties did not understand them. His conclusion?

'We felt that people with learning difficulties should have been involved from the beginning, both in the day-to-day running of the project and in testing out the materials. This could have resulted in more people understanding more of the information' (Bright, 1997: 44).

It is, of course, also important that people with learning difficulties should be actively involved in the dissemination of research findings, as well as being enabled to have access to them. Over the last few years, there have been increasing, often powerful, examples of people with learning difficulties playing a key role in seminars and conferences based on project findings and in generating material in non-traditional or printed ways. Thus, for example, a Foundation funded project on crime against people with learning difficulties resulted not only in a report aimed at policy makers and practitioners (Williams, 1995) but also, as a result of pressure from the people with learning difficulties involved in the project, in a video in which they participated and a skills pamphlet to accompany it (Gyde et al, 1995). More recently, the messages from that project have been shared even more widely with people with learning difficulties as the Strathcona Theatre Company of people with learning difficulties have embarked on a nation-wide tour of their play 'Error of Judgement' and accompanying educational workshops.

INVOLVING DISABLED CHILDREN AND YOUNG PEOPLE IN RESEARCH

Just as people with learning difficulties have, traditionally, been liable to exclusion even from voicing their views in research which affects their lives, so too have the voices and experiences of disabled children and young people been ignored and silenced. The Children Act 1989 and the UN Convention on the Rights of the Child have slowly begun to change this in their embodiment of key principles that demonstrate respect for the views of children and paved the way for them to be consulted about

decisions which affect them (Lansdown, 1995; Alderson, 1995). Organisations like The Who Cares? Trust have successfully promoted the perspective of young people themselves and their right to participate in policy and practice decisions affecting their lives. Other key organisations like the Save the Children Fund, have started to involve children and young people as partners in research affecting them (West, 1995). More relevantly for this paper, there is now a small, but growing body of work on ways of involving disabled children and young people in research studies (see, for example, Children and Society, 1996).

The Joseph Rowntree Foundation, in embarking on its Disabled Children and Young People's Programme, decided that it would, so far as possible, ensure that the principles embodied in its Disability Programme (whereby disabled people should be involved as partners in all stages of the research process) should be extended to research and development projects affecting disabled children and young people. Our expectation is that disabled children and young adults will be active participants in all projects concerning them, though we recognise that the involvement of some children, including those with profound and multiple impairments and those who do not communicate with speech or conventional signs will pose particular challenges. Involving disabled children in projects means paying careful attention to safeguards and strategies to maximise their participation and well-being. To facilitate this, we have drawn together resources, issues and strategies for guidance. What follows is a brief summary of key roles that disabled children and young people can playas partners in projects drawn from the guide by Ward (1997b).

PARTICIPATING IN RESEARCH

The first -and most basic step - is to recognise disabled children and young people as appropriate respondents in research which is about their lives. This involves both careful attention to issues of meaningful consent (see especially Alderson, 1995) and also to appropriate and imaginative techniques for working with children who may not read or speak (see Beresford, 1997 for a valuable review of the literature in this area). Encouraging participation in research, means paying attention to the right of disabled and young people <u>not</u> to participate or to change their minds about doing so. It involves the preparation of accessible, illustrated leaflets or material in other forms, which will give them some idea of what involvement will mean. For the researcher it requires adequate preparation, proper attention to relevant approaches and techniques, plus careful thought about how to bring interviews or other

research encounters to a close while enabling the young person to express any issues of concern which may have arisen. Strategies for dealing with any distress which might have been aroused; arrangements for appropriate payment of fees where relevant and strategies for feeding back information both to participants and the wider groups whom they might represent are all necessary ingredients for a successful - and ethical -involvement (Ward, 1997b).

PLANNING AND CONSULTANCY

Research projects which may not originate from disabled children and young people themselves will, nonetheless, be greatly strengthened by consultation with them at the planning and subsequent stages. Sarah McCrum and Paul Bernal (1994) in their pamphlet aimed particularly at journalists stress how valuable consulting with children at an early stage of planning research (in their case for articles or programmes) can be:

> 'You could try to find out what issues are particularly important from their perspective (often surprising), what kind of children might take part or be interviewed, where you can find the right children, etc. These are all the same areas you would research for any interview but journalists often only ask adults, even when the subject concerns children It is important to remember that children, like adults, talk best about subjects they are interested in' (p. 9).

In some places groups of disabled young people already exist and adult researchers (whether disabled or not) need to consult with them to check that any work proposed addresses issues they consider worth pursuing. Partnership can be very productive: the group of disabled young people may know the important issues to address and will have relevant insights and contacts. The other parties to the partnership can bring additional research skills to the process. Obviously, projects conceived and run by disabled young people are particularly important; building in specialised advice and support from others (for example, on research techniques) where this is welcome, may strengthen their endeavour. Experience at The Who Cares? Trust suggests that where young people complain of bad experiences of involvement it often centres on 'not knowing what's going on': involvement at the planning stage should avoid this and make it more likely that participating children and young people are given clear information on their role in the project and proper preparation and training as required.

Disabled children and young people are likely to have different perspectives from those of disabled adults. Research projects undertaken by adults will benefit from employing disabled young people as consultants to advise as the project progresses, with, of course, appropriate payment being made for involvement. Research projects also benefit from the ideas generated by advisory groups. Where projects concerning disabled children and young people are concerned, then it is probably better to set up a separate consultative group of disabled young people focusing on aspects of the project of particular concern to them, rather than having them involved in a larger group where they might feel outnumbered and overwhelmed by professionals and other adults. In some cases, it has become clear that it is more appropriate to involve disabled children and young people as consultants on an individual basis than to bring them together as a group: project workers need to be sensitive to both possibilities.

UNDERTAKING RESEARCH AND PROJECT WORK

The idea of involving young people as interviewers and project workers is still relatively novel. Alderson (1995) reports on the Barnardo's Young Interviewers project and includes copies of materials used together with a report on the young interviewers' experiences and views. Significantly, the young interviewers were uncertain about their competence to undertake the work beforehand but were subsequently confident enough to suggest that in future they should be involved in the interviewer training process!

McCrum and Bernal (1994) also stress the value of letting children have a say at the editing and analysis stage of the project, perhaps looking at early drafts and making comments or even having a fuller involvement. Where disabled children or young people cannot easily read then alternative means of sharing this process, perhaps via a group meeting or through using audio or video tapes, needs to be followed.

DISSEMINATION

Disabled young people also have a useful role to play in suggesting what the key messages from a project are for other disabled children and young people and how these messages can best be got across in terms of both content and of format or medium. They may be able to help with illustrations or by contributing to audio-tape summaries. Clearly it is vital

that key findings from projects which are relevant to disabled young people are made available to them in appropriate and accessible ways whether this is via illustrated leaflets, cartoons, audio or video tapes. Some disabled young people may also wish to playa role in contributing to conferences or workshops, as the three young interviewers involved in the Barnardo's project did at the launch of Priscilla Alderson's report. Where disabled children and young people are involved in this way then careful preparation and skills training may need to be provided. The Who Cares? Trust gives useful advice for both journalists and young people in this area (The Who Cares? Trust, 1993).

CONCLUSION: FUNDING FOR CHANGE

The title I chose for this contribution was 'Funding for Change'. I have tried to show how a funding body which is idealistic in its original goals and values, pragmatic in its operational style, can do a good deal to begin to shift the balance of power in disability research and to help change the face of what is seen as acceptable, desirable or feasible within it. Of course, funding bodies like the Foundation have multiple missions, programmes and agendas, of which the movement to a more emancipatory disability research is only one. Inevitably, this means that not all that commentators like Oliver feel should be done, will be. Nonetheless, those changes that are publicly advocated and instituted (like those discussed in this chapter) have the potential to influence both other researchers (through their exposure to the Foundation's expectations) and other funders (as, for example, the National Lottery Charities Board in the research strand of its recent Health, Disability and Care grants round). The unifying characteristic of all the hats I mentioned in my introduction was the desire for positive, practical and empowering change for disabled and other marginalised and disadvantaged people. Debate and dialogue between the disability movement, disabled and non-disabled researchers and funding bodies has a critical, if necessarily sometimes uncomfortable, role to play in moving forward that agenda for change.

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