# *Self-advocacy, Civil Rights and the Social Model of Disability*

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## *Final Research Report*

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# *Background*

This study examined the self-advocacy of people with the label of 'learning difficulties' as enacted within self-advocacy groups and accounted for in personal narratives. This very process illuminated a number of significant concerns in relation to the doing of disability research by disabled researchers. The theoretical, political and cultural background to this study can be broadly split into two areas.

## *The growing international self-advocacy movement*

The emergence of self-advocacy constitutes a new social movement (see Shakespeare, 1993; Boggs, 1996; Dybwad and Bersani, 1996). While a small body of literature has attempted to engage with this new movement, there is still uncertainty about the nature, meaning and significance of self-advocacy in the lives of people with 'learning difficulties' (Dybwad and Bersani, 1996). The accounts that did exist at the outset of this study included some limited theoretical accounts alongside the literature of self-advocacy groups themselves. Herein, were powerful arguments made by people with 'learning difficulties', and their allies and commentators, that self-advocacy is an important development in terms of the opportunities it offers for developing individual and collective confidence to speak out for human rights and challenge oppression in disabling society. Hence, the clear importance of self-advocacy to people with 'learning difficulties' justified the need for this study. Three specific political, professional and policy concerns formed a background to our study. First, the politics of identity immersed within moves towards cultures created by and for disabled people, and the challenges these pose for disabling society, highlighted the potential of self-advocacy (Finkelstein and Stuart, 1996). Second, questions have been consistently raised about the organisation of self-advocacy groups, nowhere more obvious than in the rise of service-sponsored and / or professionally led collectives (Worrell, 1988; Crawley, 1988; Simons, 1992). Self-advocates have consistently treated the rise of service-based self-advocacy with suspicion. In particular, the role of health and social welfare service professionals in the emergence of disability politics has long been perceived as actually undoing the potential of disabled people to organise their own collectives. Oliver's (1990) seminal text conceptualises such professional involvement as always threatening to usurp the radical nature of self-advocacy: replacing it with a politics of enforced normalcy and centring concerns on service issues rather than wider disabling practices (Chappell *et al*, 2001). Third, our study was

undertaken in a climate of reaction to recent changes in policy and legislation that were shot through with the rhetoric of 'promoting civil rights' and 'empowering services' for disabled people. The 1995 Disability Discrimination Act (see Gooding, 1995) combined with a new government's attempts to challenge social exclusion (see Blair, 2000), ensured that our study of self-advocacy was timely. Our overarching aim of exploring the contemporary significance and impact of self-advocacy on the lives of people with 'learning difficulties' was reinforced by a mixture of developments in professional practice, policy making and disability politics.

## *The developing social model of disability*

The theoretical importance of our study was consistently reinforced by a variety of emergent debates in British disability studies writings. First, our research has been carried out against a background of critique in relation to the lacking place of people with 'learning difficulties' in disability studies (Chappell, 1998; Goodley, 2001; Chappell *et al,* 2001). Second, this critique has turned attention towards the absence of sociological analyses of impairment in social modellist thinking (Hughes and Paterson, 1996; Barnes and Mercer, 1996; Corker and French, 1998; Thomas, 1999). Increasingly apparent is the unease of many disabled people at the lack of consideration being given not to impairment per se, but to the ways in which social modellist thought leaves impairment in the realms of medical discourse. Instead, and here 'learning difficulties' is crucial, it would seem that research needs to engage with and develop theoretical notions of 'impairment' that emphasise the cultural, political and social origins of meanings, experiences and treatments that are assigned and attached to such 'impairment-labels' as 'learning difficulties'. Third, the relationship between disability research and disabled people / activists – such as self-advocates – remains a tricky issue in need of exploration (Barnes, 1997; Shakespeare, 1997; Goodley and Moore, 2000). Issues to explore include the ways in which disabled participants are involved in research – in either participatory or emancipatory ways (Oliver, 1992, 1996; Zarb 1992; Barnes and Mercer, 1997) – and the ways in which research practices physically, politically and culturally include disabled researchers (March *et al*, 1997; Barnes and Oliver, 1997;). Finally, the growing use of various qualitative research approaches, such as ethnography and narrative inquiry, are receiving some intensive analyses in terms of how they how contribute to theoretical understandings of self-advocacy (Goodley, 1999), resilience

(Booth and Booth, 1998), impairment (Thomas, 1999) and disablement (Stone and Priestley, 1996).

# *Aims and objectives*

Against this background a number of aims and objectives concerned the research team:

1. To examine self-advocacy as it is experienced and practised by people with 'learning difficulties';
2. To develop a theoretical understanding of the concept of 'learning difficulties' informed by the experiences and perspectives of those involved with self-advocacy;
3. To critically re-evaluate the social model of disability with reference to the experiences and perspectives of those involved in self-advocacy and the larger disability movement;
4. To use evidence and insights generated by the study to inform and support the self-advocacy movement;
5. To investigate how self-advocacy can be understood and supported within policy making contexts;
6. To develop links between ethnographic and narrative methods and self-advocacy in action.

An additional and significant aim emerged immediately when two disabled researchers joined the research team:

7. To devise a series of recommendations for doing disability research and supporting disabled researchers.

# *Methodology*

The research team consisted of two half-time research assistants (Kath Sutherland and Linda Laurie) supported by two project directors (Dan Goodley and Derrick Armstrong). The research schedule was set from September 1998 to September 2000 (though a number of unforeseen barriers threatened to delay the research as we detail below). This study adopted two complementary qualitative research methods: ethnography and narrative inquiry. The former was conducted to examine the workings of four self-advocacy groups; the latter allowed researchers to explore the lived experience of self-advocacy.

### *Ethnography of four self-advocacy groups*

In order to probe the workings of groups we turned to a methodology that has a long tradition in the disability studies field (e.g. Edgerton, 1967;

Braginsky and Braginsky, 1971; Vlachou, 1997). Self-advocacy groups have until recently (see for exception Goodley, 2000a), been absent from accounts of disability culture and the emergence of the disability movement (Campbell and Oliver, 1996). Our research groups were identified from a postal survey of British self-advocacy groups (from Goodley, 1998a) and through contacts made by researchers in their previous work. The four groups were chosen to capture divergent types of group, varying advisor roles and affiliations, and to reflect some of the differences in the social and personal lives of self-advocates. The groups were:

(1) *Service-sponsored Group* – a Day Centre-based self-advocacy group supported by members of staff attended by representative users of the Centre;
(2) *Advocacy-supported Group* – set up by local citizen advocacy scheme, though meeting in a local Day Centre and supported by a Day Centre Officer from the Centre;
(3) *Independent Group* – met in a local community hall and were supported by a volunteer;
(4) *Organisational Group* – this fourth group had some coalition links with local organisations of disabled people, was based in its own offices and offered self-advocacy training to local services and professionals.

Group membership ranged from eight to 23 though these numbers fluctuated. These groups met with our original aims to capture the characteristics of different types of group that make up the international self-advocacy movement (People First of Washington State and University of Oregon, 1984). For example, the Organisational Group straddles the typologies of independent (from services) and coalition groups (links with the Independent Living Movement). Researchers were involved with groups in a variety of contexts such as weekly meetings, social events and trips to the Day Centre. Researcher assistants spent time both with the groups and individual members. The latter were largely self-selecting as they offered their time to the researchers. Field notes were taken after every meeting, shared with the research team and provisional analyses were made throughout the study at a number of regular team meetings. These sessions allowed us to distinguish between theoretical, methodological and empirically informed field notes (see for example Glaser and Strauss, 1967; Schatzman and Strauss, 1973; Charmaz, 1995).

### *Narrative inquiry with self-advocates*

We aimed to capture the storied nature of self-advocacy. Stories are particularly important in capturing novel or hidden cultures (Sparkes, 1994). They combine subjective positions which reference wider socio-cultural backgrounds (Bertaux, 1981). Furthermore, they have the potential to contribute to disability research in ways that emphasise the significance of the voice of disabled people while providing contextual frameworks for deep analyses of disabling and disability cultures (Barnes and Mercer, 1997; Finkelstein, 2001). There were four parts to our narrative inquiry. First, we wrote up the detailed life stories of 17 key informants, drawing upon in-depth interviewing (Parker, 1992; Taylor and Bogdan, 1984), including 9 women and 8 men of which two were from 'black / ethnic' communities. The greatest number of interviews held with a single participant was eight, the least was two. Participants' ages ranged from 20 to 63. In two cases, two informants were interviewed together though their stories were written up separately. Second, in addition to the life stories, we collected a number of what we termed 'accessible narratives'. These included the lifelines of a further 30 self-advocates (see *Appendix 3*) and the collection of 16 'circles of importance' (see *Appendix 4*), including 20 men and 26 women. This turn to other accounts invited the use of accessible methods and displayed the variety of a narrative approach – a point explored later in point 6 of key findings. Third, group interviews were carried with each of the groups, with advisors often leaving the context so as not to stifle any conversation. Fourth, four supporters across the groups were interviewed a number of times. One of these supporters had been given the label of 'learning difficulties' and so allowed for an interesting analysis of contrasting identities of 'disabled' and 'supporter'. A lot of time was allocated to research relationships: explaining the research, building up trust and rapport, not least in dealing with the disclosure of sensitive material and promoting collaborative narrative construction (Ferguson *et al*, 1992; Taylor and Bogdan, 1984). All narrative sessions were extended and held in addition to the many hours spent with participants that were not audiotaped. All participants were members of the research groups and were normally approached if they showed particular interest in the research. Participants were involved in the editing of their accounts and a number of them raised interesting issues in relation to working with uncommunicative or inarticulate people.

## *Participation, accessibility and giving back*

Throughout the study, we critically engaged with a participatory research philosophy (see Zarb, 1992). In the early stages of access we made reference to accessible introductory leaflets that outlined the research (*Appendix 1*), gave examples of how participants might like to present their stories in a life story workshop developed by one of the researchers (*Appendix 2*) and clarified difficult concepts such as 'rights' and the 'social model of disability' through the further use of prose and illustrations (*Appendix 5*). This philosophy ensured that the research process was to some extent steered by research participants. One researcher worked with a self-advocacy group who requested that she help them disclose their stories over the course of a number of meetings. The researcher consequently developed the imaginative strategy of constructing 'circles of importance' (*Appendix 4*). Our introductory leaflets were appreciated by participants, mirroring their stance against jargon (see People First London, undated) and enabling us to tackle informed consent through recourse to accessibility. Gaining consent, maintaining confidentiality and ensuring anonymity concerned us and the participants throughout the study: as Tiger Harris put it in relation to anonymising his life story, 'Things are private and I can say what I want but no one can take offence!' It was therefore decided that the material produced from ethnographic field notes, interview transcripts and narratives remained within the research and would not be made available to other parties, for example, via the ESRC Archive database. In terms of what groups gained from their involvement, the research team strove to give a variety of things back to the groups. For example, the Advocacy-supported Group asked for support in accessing the views of users of the local Day Centre. Many of the members attended this Centre and had strong opinions on the good and bad practices within it. Consequently, a questionnaire was devised and a report written through engaging with self-advocates and other users during a number of meetings (See *Appendix 6*). Indeed, this report led eventually to the Centre being awarded a Charter Mark for Innovation.  The Independent Group felt that they wanted more than a collection of stories or summary report from their involvement and so asked the researcher to work with them to present a performing arts piece that captured their group history and explained the meaning of 'learning difficulties'. This is ongoing at the time of writing. Our final analysis of the stage of access, fieldwork, feedback and dissemination highlights how the disabled researchers of our team succeeded in spite of a variety of disabling institutional barriers. Yet, as a

research team, the experiences of the researchers also became important recurring concerns (Goodley, 2000b)

## *Disabled researchers and doing disability research*

The research team itself became part of the narrative of self-advocacy following the appointment of two research assistants who are themselves disabled. Zarb (1997) has discussed the issues surrounding the employment of disabled researchers in his ESRC funded work on 'Measuring Disablement in Society'. Zarb argues that many of the practical problems experienced – accommodation, working arrangements, additional expenditure, etc – reflect wider issues about the contradictions between the social and material relations of research production. Yet according to Finkelstein:

> As long as disabled people avoid, or are discouraged from, participation in research into their own affairs they will remain passive and dependent upon others. This means that the "subjectivity" of disabled people should be regarded as an "objective" asset, to be cultivated in the research setting (Quoted by Zarb 1997:59)

In relation to the difficulties we faced in our research, three particularly challenging areas emerged.

- *Institutional preparedness* – We did not know in advance that we would be employing disabled researchers. However, we underestimated the implications of our decision for our institutions. Considerable delays were experienced in both institutions before appropriate access and facilities were provided. These occurred despite the obligations placed on universities as employers under disability legislation. Unfortunately our institutions were reactive rather that proactive and this inevitably led to difficulties and delays. One consequence of this was that neither of our researchers felt fully included in the life and research culture of the departments.

- *Working arrangements* – The University of Sheffield did provide home Internet access that was of some assistance, though the library had to be accessed through a support worker. It was three months, however, before access to the designated University workspace was possible. These difficulties at both Sheffield and Bolton (Dan Goodley's original location) created particular problems for research supervision and

research training. Challenges also arose in respect of fieldwork when it was discovered that one of the groups met in a building that did not allow disabled access. This challenge was taken on by the group concerned and alternative arrangements made but further delay and stress were created for the researchers who were trying to keep to deadlines. A third challenge arose when one of our researchers was forced to take extended leave due to an impairment-related illness. The ESRC were kept fully informed of this circumstance. Although confined to hospital and later to a lengthy period of home convalescence, our researcher continued to maintain contact with the self-advocacy groups with which she was working and to produce material that was of great value to the project. We were nonetheless concerned that anxieties about continuing employment and successful completion of the project were having a damaging impact upon the long-term health of our researcher.

- *Resources and timescale* – Some 6 months before completion of the project it became clear to us that the circumstances described above necessitated an extension to the project. This was supported by the ESRC. However, even with this extension it became necessary to buy-in some additional research support, particularly to assist with the preparation of material for analysis. This was an unanticipated expenditure, though our staffing budget was not exceeded. In retrospect, it would have been better for this two-year project to have been undertaken over three years. In the event, with the permission of the ESRC, it has been completed in two and a half years.

It is perhaps inevitable that a discussion of disabling barriers has the potential to present a problematic picture of disability research. However, it is essential to remind ourselves of the (continuing) positive involvement of (disabled) researchers in this project. The delay to the research has meant that one of researchers is still working with her two research groups. Indeed, these groups asked the researcher to become involved with them as their supporter. This may be because of commonality and the unique nature of having a fellow disabled supporter. While disablement threatens to extinguish the self-advocacy of researcher and self-advocates alike, these very conditions also encouraged the development of activism and resistance that was so crucial to this project's emergent understandings of self-advocacy, civil rights and the social model of disability.

# *Key findings*

The analysis of data is ongoing but a number of themes are emerging which suggest that an understanding of self-advocacy, civil rights and the social model of disability will be enhanced by the perspectives of self-advocates represented in this study. In this section we have identified seven provisional themes relating directly to our original aims and objectives.

## *(1) Living and experiencing self-advocacy*

Narratives situate self-determination in the life course (Cohler, 1991) and ethnography clarifies the variable impact of different cultural contexts (Edgerton, 1967). Crucial to emergent understandings of self-advocacy is to note that it is a phenomenon created in direct relationship to a variety of (lacking) opportunities and chances. It does *not* just emerge as a direct consequence of self-advocacy group membership but often has wider familial, cultural, social and historical origins. This illuminates what Corker (2001) means by the centrality of life experiences to any understanding of disability politics and identity: self-advocacy is not something that can be artificially pinned onto those who need it but something organically and culturally created by enabling and, paradoxically, disabling environments (see Page and Aspis, 1998). This takes further a point of our planned contribution to theory detailed in the original proposal - that self-advocacy occurs in and outside of the self-advocacy movement. This raises issues about how we understand disability politics. Indeed, perhaps the most oft-cited reason for attending self-advocacy groups was that it was a chance to form and maintain friendships. The profound significance of this can be comprehended in light of the lack of opportunities to meet with friends in a context and at a time that is self-determined rather organised by others:

> I still see my friend Shirley. We went to school together. Now I see her when we go swimming. The boss organises the swimming - the boss of the Centre (Andrea Simons, life story)

> I sometimes go out to the club, which is on a Friday night. It's a working men's club and ladies are allowed to go as well. I do go, but not anymore, because my Step-Dad's not been out (Tiger Harris, life story).

Members of the group should go out together more, perhaps even on holiday together: socialising and that (Heather Parrot, life story)

When self-advocacy groups were alluded to this was often made in direct contrast to other cultural contexts that were viewed as limiting. Andrea Simons' story contrasts the meaningful nature of being a self-advocate with the emptiness of 'work' in the centre; 'I work on the reception in the Centre. Well, just pretending you're writing in a diary or something' (Andrea Simons, life story). Self-advocacy groups therefore have the potential to offer a stable, safe context for the development of meaningful cultural capital which are self-created in contrast to community care settings designed by others:

I've lived in lots of places. Group homes, with my mum, with lots of people. I find it hard to make friends. I stayed in places for 6 months at the most. Then the teenagers started. I have had loads of cares, support workers and the like. At night, I pack my bag for the morning. Up at 7.30 and off to the group (Heather Parrot, life story)

I'm always seeing the same people every day too. Some of the people at the Centre went to the same school as me and now they're at the Centre. I would really like to meet other people because I see the same people at the Centre, at the clubs that I go to and just about everywhere I go … you run out of things to talk about after a while (Gary Hargreaves, life story).

When I go out, I go out with someone, not on my own because it's not safe – I think that other people have told me its not safe. If I go out on my own, I get worried and I get a bit frightened (Dorna Mack, life story)

Nevertheless, we should be careful not to artificially contrast service (read as 'disabling') and self-advocacy group (read as 'enabling') cultures. A number of self-advocates emphasised the importance of friendship even in the most disabling contexts, while their stories oozed with resilience. Aled Thomas told us about a life time of rejection, sexual and physical abuse and lack of security as he was moved from one family member to another. Even so, he remains resolute:

The final thing I'd like to say is that any time you find yourself in a position that I've been in, just don't give up! If anyone feels how I feel about being lonely, I'd say, 'Don't feel alone and give up'. Keep going, because there's hope out there. There's a life. There's someone for you. (Aled Thomas, life story)

Interestingly, Aled does not mention the self-advocacy movement once in his account, though he clearly displays the characteristics so often associated with this movement. Victor Moon reminds us of the variability of life experiences, reflecting on the solitary past from a relatively culturised present (Thompson, 1988):

I made my own games too. I made them up for me. When it was raining outside. I stayed inside and played them. I made the ball hit the back door and it came back to me. I did that all the time (Victor Moon, life story).

## *(2) Deconstructing 'learning difficulties'*

Our original aim to explore the (de)construction of 'learning difficulties' was met particularly through the stories and accounts that we collected. Indeed, an interesting exercise developed in the research team was to tackle independently the writing of one informant's story (Armstrong et al, in preparation). Differing frameworks from which we approached storytelling illustrated shifting understandings of 'learning difficulties' (see also Goodley, 2001). When asked what they understood about the label 'learning difficulties', informants drew upon various notions of 'impairment':

I think I was happy when I was small, but on some days, I weren't. I don't know about when I was a baby ... I know that I couldn't walk then and I still can't. Its because I was born early - I was premature - and my brain had low oxygen... My Mum said to the nurse, 'This baby's passed. He's got took'. The hospital made a mistake and I was there for two weeks (Victor Mason, life story).

What I want to say about what its like having a learning difficulty, and how people treat you is it sometimes can be a bit awkward, if you know what I mean? Because people seem to stare at you and things like that but I just try to ignore them by not looking at them. Nobody's

perfect! Everybody's got problems in different ways. We should all look after each other. That's the way it works! The other thing is that I don't have anything to do with psychologists. They don't try and help people they just tell them they're not normal. People who can't do things like tests and things (Tiger Harris, life story).

I were bullied a bit at school ... because I was classed as slightly different and not one of the crowd. I had my hair cut and in a quiff with big thick glasses, like Buddy Holly. I used to get the rise taken out of me for that and I wasn't that confident. But it's nice not being one of the set crowd and it's their ignorance. I saw this girl in the pub the other night and she said 'Sorry for taking the rise out of you (Steve Grundy, life story).

Apparently, Mum had a difficult time when I was born (John Coltrane, life story).

Essentialist, medicalised and educationalist discourses entered the fray. Indeed, Victor Moon's relationship with his mother influenced negotiations of (in)capacity:

My mum used to make a lot of decisions for me. She used to get me all my clothes and things like that. But when I was older, I had to tell my mum what to do because her mind was going.

Perhaps common to many of the informants' perspectives is the idea that impairment, in relation to 'learning difficulties', is relational and distributed (see Booth and Booth, 1994). Members were keen to draw their attention to peer support:

Tony: I'm helping Heather if it's alright.
Heather: Thanks Tony.
Interviewer: That's fine yeah.
Tony: I'm helping Heather.
(Organisational group, field notes)

I try to be kind to everyone and help them if I can. I like most people and get on with them because that's what you should do. Lots of people like me too. I always try to give people a chance … We all

listen to each other and we help each other and things get done (Gary Hargreaves, life story).

It's helped me being in a self-advocacy group because my friends help me to stick up for myself. When my friends are down, I help them and when I am down, they help me (Dorna Mack, life story).

As Bob Healy puts it, one of the key aims of self-advocacy groups is to provide peer support: 'to support each other as well. That's the group in a nutshell'. Dis/abilities within self-advocacy are often considered in terms of interdependence:

I met my fiancé about two and a half years ago, at the Day Centre ... I don't want to get married too soon, though. I'm waiting until we get all our support workers sorted out because I'd rather take it slowly and easy to make sure everything's okay (Aled Thomas, life story)

When me and my boyfriend get married we can't have children, I've no where to put them … We want to live together but we don't want staff. We'll manage to get on and I'll get him to do the cooking and the cleaning. I'll get him to do it all, but if he can't I'll have to do it! (Dorna Mack, life story).

An interesting observation was that none of the members of the groups had extensive notes written about them like they had when they attended services. Perhaps, self-advocacy allows a trajectory out of constant surveillance to a place of hopeful privacy. Paul Newton, a supporter, argued that the most important issue in relationship to membership of the Organisational group was that members had chosen to come rather than being shoehorned into existing day services. Consequently, the interpersonal origins of meanings associated with 'learning difficulties' illustrate the potential of self-advocacy groups to offer what Vincent (1998) calls 'alternative frameworks of sense'.

## (3) Informing the social model of disability and disability politics

Simone Aspis, a well-regarded British self-advocate, has argued that self-advocacy is often separated from the wider disability movement:

> People with learning difficulties face discrimination in the disability movement. People without learning difficulties use the medical model when dealing with us. *We are always asked to talk about advocacy and our impairments as though our barriers aren't disabling in the same way as disabled people without learning difficulties.* We want concentration on our access needs in the mainstream disability movement (Quoted in Campbell and Oliver 1996, p97, Our italics).

Our research suggests that there are indeed differences but also commonalities between self-advocacy groups and the wider disability movement. First, difference and the search for independence. Many of the research groups celebrated increasing independence from affiliations with other organisations. For example, the Organisation group saw their movement away from local organisations of disabled people as an incredibly positive development. This recognition of independence may superficially be viewed as against the collective aims of the disability movement: emphasising impairment-specific groupings over wider disability politics (see Oliver, 1990). Alternatively, it may be seen as an essential aim of self-advocacy: to demonstrate that people with 'learning difficulties' are capable of working for themselves without the interventions of 'more capable' others:

> It could be argued that whilst the disability movement has fought the colonisers of disability (e.g. the medical and allied professions) for the right to define disability on their own terms, the fight against the colonisers of learning difficulty is of a different order; it is a fight against the denial of humanity itself; hence, this group' insistence on being perceived as *people first* (Gillman *et al*, 1997, p690, italics in original).

Hence, the self-advocates represented in this study often cited their abilities: challenging demeaning notions of handicap and disabilities in relation to 'learning difficulties'. This accentuation of the positive (see Booth and Booth, 1994) can be understood not as a denial of difference or disability but as a specific aim of self-advocacy to rephrase disablist and pathological definitions of 'learning difficulties' which dominate others' definitions of people so-labelled. Hence, self-advocacy can be seen as contributing to current debates about the contestable notion of dependency

in social modellist thinking (see Shakespeare, 2000). Dependency on others and a lack of ability are dominant constructions assumed to exist amongst the 'learning difficulties population'. Yet, they are challenged by the aims of self-advocacy groups. Second, a commonality with the wider movement was a recognition of diversity and difference. Barnes (1998) argues that disability politics is much more than just disability and must embrace a whole gambit of inter-related forms of oppression. Similarly, Bob Healy (a supporter and self-advocate of the Organisational Group) told us:

> The aim of the Organisational Group is to stamp out all forms of discrimination and to encourage people with 'learning difficulties' to speak up for themselves and to take up services but only if they have been changed. To encourage people with 'learning difficulties' in everyday life

Indeed, the Organisational group had strong, established separate men and women's groups, thus illustrating a sensitivity and awareness of diverse experiences and needs within the wider collective aims of self-advocacy.

## *(4) Supporting self-advocacy and conceptualising rights*

> I could see my Dad sat on the chair. I thought it was a dream but he spoke to me. He told me how he loved me and that I was lucky to survive such a bad accident. I saw him again for a few nights, and one night, he said, 'I'm going now. You won't see me for a long time'. It was weird because although he'd passed on, he came back to watch over me. A guardian angel (Aled Thomas, life story).

Self-advocacy groups are constantly under threat. One of the researchers had been meeting with a group for a number of weeks, at the outset of the project, when it suddenly folded; leading her to develop links with another similarly organised group. Some groups reflect the unstable nature of the voluntary sector, while other affiliations impacted upon opportunities. For example, service-sponsored groups faced particular difficulties, supporting previous appraisals (Simons, 1992; Goodley, 2000a). In her life story, Edna Richardson drew attention to a conflict of interests (Hanna, 1978) faced by the group's advisor. Meeting in a Centre meant that their advisor (who was keyworker to a number of clients) was often called away during

meetings to attend to other users' needs. Similarly when the Centre Group chose to meet outside of the Centre this created further issues of control:

> I had arranged to meet with members if the group. When we arrived we were told that the group had already been taken to the college. We were give directions to the college and eventually joined the meeting ... At 3pm, the transport (segregated coaches funded and organised by the local social service department began to arrive to collect people and transport them home. The time that the group begins and ends its meetings are determined by the routine of the day centre and the availability of transport (Centre Group, researcher field notes)

This contrasted with the Organisational Group's equal opportunities plans: 'some people need support to get to meetings by bus. People can meet and travel together for support but still be independent'. Similarly, the Independent Group requested that one of the researchers work with them to produce an evaluation report entitled 'What we did and didn't like about our previous facilitator'. As with Oliver's (1990) typology of organisations of and organisations for disabled people, we were drawn to the difficulties faced by self-advocates to enact basic choices in service settings. Yet paradoxically, these constraints enabled the development of some rather expert critiques of professionalism:

> The Day Centre hasn't changed much ... as for the manager, he has actually done a management course, but I think he needs to go back and do his course again because he won't take any responsibility for some of the things that were going on (Tiger Harris, life story).

> I was living in a house with some staff but it was boring. They wouldn't let me do what I wanted to do … sometime when I do something wrong, like banging things on the table, they shout at me. When people shout at me, I get really angry with them and throw a temper (Dorna Mack, life story).

Bob Healy suggests that offering training packages, working on the computer and organising the group's money are all simply ways of gaining confidence 'to learn about being in charge instead of being told what to do'. Heather Parrot supported this point by suggesting that being a member of a self-advocacy group meant that she had to travel by public transport more often than before. Indeed, as Paul Newton, a support worker for this

group, puts it: 'self-advocacy is about being valued and valuing others'. A crucial part of this is public visibility, with self-advocacy groups being the antithesis of a history of incarceration and segregation (Potts and Fido, 1991). Supporters from the Centre Group suggested that 'valuing and respecting' were key attributes of receiving formal social care training as professionals. Convincing other members of staff not to underestimate self-advocates was a crucial part of their role as advisors. However, the collective conceptualisation and public contention of self-advocates' rights did, at times, cause problems. The apparent development of a relationship between two self-advocates in the Independent Group was picked up on by other group members to the apparent unease of these two people:

> The group members encouraged them to see each other, insisting Susie should tell her Mum about the relationship, 'You're not a kid, you know. You can have a boyfriend if you want – its you right'. Then Susie reacted, 'I'm fed up everybody telling me what to do. Since I was really little, everyone's been telling me what to do. I'm sick of it'. I followed Susie out of the room. 'I didn't know you were seeing Tony?' 'I'm not', replied Susie, 'that's the problem' (field notes).

In these complex dynamics of self-advocacy groups, it would appear that human and civil rights not only contrast in their focus (Hudson, 1988) but also in terms of how they are tackled:

> It's a bit hard for me to do something else that costs money, because I need my money for the Centre. I need to get a job so I can do the things I want to do … If I had a job and a girlfriend then I could look after her in our house and she could give me care and love. That's what I want from life – Its not too much to ask now, is it? (Gary Hargreaves, life story).

> I was with Pam. I couldn't get on with her mother. She wouldn't let Pam have a relationship. Of course, I used to meet her at night at the bottom of the lane. She knew me and Pam were going out, but it was like, you know, if we 'bumped into' one another. Pam' Dad was totally opposite. He was like, 'Let them get on with it' (John Coltrane, life story).

> I used to be a member of loads of committees fighting for rights and all that ... yeah, and the Disability Movement do some great stuff for

other people, but how's all that stuff on politics going to get me a girlfriend and a job (Tiger Harris, life story).

Tiger reminds us that basic choices are often so difficult to enact because of the prejudice and surveillance of others. Privacy and individuality may be ignored in the search for collective rights. This point has obvious consequences in a whole host of policy-making contexts. Rights for many self-advocates were associated with a variety of individual choices, the chance to take risks and emphasised adult roles (Mitchell, 1998). For people with 'learning difficulties', the most basic of rights are denied so often but there is a danger that we lose sight of them as we get caught up in the changing elements of policy and welfare (Means and Smith, 1994). As a supporter to the Organisational Group pointed out, one of the most articulate members of the group was the exact opposite when at home with his family.

## (5) Supporting and understanding self-advocacy in policy making contexts

When self-advocacy is understood as an abstract phenomenon to be taught and delivered to people with the label of 'learning difficulties', this may threaten their very right to self-determination. There is danger that self-advocacy becomes something owned by health and social welfare professions and that any policy that is meant to tackle rights is also working from this top-down stance. Indeed, when supporters from the Centre Group talked about members of the group during our interviews they often alternated between talking about them as 'self-advocates' they supported and 'clients' who were under their jurisdiction and care. This suggests that (some) professionals bring baggage with them that can confuse the aims of self-advocacy: to move away from passive client roles to active, self-determined self-advocates (Worrel, 1988). In contrast, a recent analysis suggests that professionals actually might be able to draw upon enabling discourses and interventions of support (Goodley, 1997; 1998b). Promoting self-advocacy in professional-client contexts and cultures obviously has potentially positive implications for user empowerment.

However, when professionalism usurps the wishes of self-advocates then the whole meaning of self-advocacy becomes tied up, yet again, in professional discourses. Interestingly, when we asked self-advocates about

their supporters they were, without exception, positive – regardless of supporters' affiliation or professional accreditation. At times, there were different interpretations of advisors' support between the narratives of self-advocates and the ethnographic field notes of researchers. Researchers picked up on the submerged dangers of professional engagement while narrators often emphasised the fact that there were some people (advisors) who happened to also work in the Centre (professionals) and were good enough to support them in their pursuits. The complexity of notions of support held by informants and researchers was further extended by the obvious dilemmas faced by all advisors. Indeed, Dowson and Whittaker's (1993) argument that advisors need to 'work themselves out of a job' and the obvious problems this faces a paid, professional supporter was evidenced even in the case of volunteer supporters. Bob Healy talked about 'twiddling his thumbs': knowing that as the group he supports works more and more for itself then this can be frustrating for supporters involved. Overall, it is crucial that any understanding of self-advocacy in policy-making contexts attends to the dynamic, shifting nature of power (see Lukes, 1986).

## *(6) Self-advocacy, narrative methods and ethnography*

Bowker (1993) argues that biographies are in a constant state of becoming. The same can be said about self-advocacy. For some of our participants, detailed life stories were embraced as a means for conveying their views on their lives. For others, circles of importance and the construction of lifelines were deemed more appropriate. We were encouraged by self-advocates to embrace various modes and means of communicating their stories. Indeed, self-advocates' emphasis on plain, accessible language ensured a big take up on the option of constructing lifelines and circles of importance (*Appendix 3 and 4*). While life stories provide detailed, wordy versions of life, circles and lifelines present immediate snapshots. Indeed, for some members who – to paraphrase (Booth and Booth, 1998) – did not have much talk in them, circles and lifelines allowed them to reflect upon the impact of self-advocacy and present their aspirations in ways that embraced symbols over text. In contrast to Plummer (1993), who maintains the need for articulate story-tellers in narrative research, our self-advocacy stories were varied in terms of their reliance upon the written and spoken word and reminded us of the need to adopt particular methods that emphasised self-advocacy rather than the articulate. This point was also taken further in our ethnographic writing. While we were driven by an

adherence to the perspectives of self-advocates, this partisanship meant that our ethnographies aimed to be responsible archives of the achievements of self-advocates. While our approach to research did not follow the tenets of emancipatory disability research, many of our ethnographic tales aimed to capture the self-emancipatory acts of groups and their members.

## *(7) Recommendations for doing disability research & supporting disabled researchers*

Our experience on this project has greatly improved our understanding of some of the issues surrounding the employment of disabled researchers and the absolute importance of conceptualising this within the broader framework of equal opportunities policies.  Policy frequently embodies broad statements of principle but is less effective in defining procedures for its operationalisation.  The importance of the latter must be recognised by all involved in the research process. Funding agencies who commission and support research activity should provide clearer guidelines for institutions and researchers relating to the employment of and support for disabled and other researchers who may experience institutional discrimination and disadvantage.  In particular, this guidance needs to be framed within the context of an equal opportunities policy that focuses attention on institutional barriers rather than 'personal problems'. Research institutions should be required to demonstrate compliance with anti-discriminatory legislation as a condition of funding from the ESRC and this issue should be specifically addressed at the approval stage for research proposals. We would recommend the addition of a section on the proposal form asking how equality issues have been addressed in the proposal, both in relation to methodology and institutional facilities. Finally, research teams should be more aware of the need for realistic project planning and funding to comply with 'good practice' in respect of equality issues and research timescales. More explicit procedures should exist for review of funding arrangements for projects where compliance with anti-discriminatory legislation and 'good practice' in this area gives rise to a reasonable case for additional funding and/or extension of the life of a project.

# *Dissemination*

- End of Project report – Research participants and 140 British Self-advocacy groups will be sent an accessible summary of this report - see Appendix 4 and 5 for previous examples by the research team;
- Launch of full report, summary and accessible versions on the Centre for Disability Studies website (http://www.leeds.ac.uk/disability-studies/) June 2001;
- Viewpoint magazine – MENCAP's national magazine have agreed to publish a summary of the research;
- Journal articles, conferences and seminars –including Goodley (2000b, 2001); Goodley and Lawthom (2001);
- Book in progress – under discussion with Dr Pat Sikes (University of Sheffield) series editor of *Doing Research in Educational Settings* with the Open University Press;
- Drama performance of self-advocacy – by one of the self-advocacy groups to various audiences is currently being prepared and rehearsed by one of the groups with the support of a researcher from our team.

## *Appendix* available on request (email d.goodley@leeds.ac.uk)

1) Accessible introductory leaflet
2) Introducing narrative inquiry
3) Lifeline – an example
4) Circle of importance – an example (Dorna Mack)
5) Clarifying difficult concepts – Introducing the social model of disability & Standard United Nations Rules
6) Giving back to participants – Extract from the Evaluation Report of Views of Centre Users - Produced in collaboration with Kath Sutherland and the Advocacy-supported group (Anonymised version)
7) Examples of published work emerging from the project

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