Research and 'Disability': Accounts, Biographies and Policies

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Abstract
This article reviews and re-evaluates a qualitative research project carried out in England in the late 1990s. The project was informed from its inception by the social model of disability, and explores how 'disability' is conceptualised within the accounts of participants defined by others as disabled. It also examines participants' views of community care services. As part of this discussion, notions of collaborative and emancipatory research are appraised. The implications of the findings for policy and practice in the field of social work and social care are also discussed.

Introduction

When first considering undertaking a qualitatively orientated research project focusing on how those regarded as disabled by others both view and understand disability, the main researcher, Barbara Fawcett, wrote a research funding proposal for a major health board in England. The proposal was turned down and the reason given was that 'disability' has a clear and universally applicable meaning. Despite being advised to conduct randomised controlled trials into the functional aspects of disability; instead, the decision was made to continue with developing the original idea of a qualitatively oriented research project. This course of action was influenced by discussions with disabled colleagues. It was also informed by a commitment both to the social model of disability as a political focal point, and to exploring issues of difference and diversity between and amongst disabled people.

The social model of disability clearly defines 'disability' as "the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (UPIAS, cited in Oliver, 1996: 22). This political definition is of immense importance. However, in the research project emphasis has been placed on the 'personal as political as personal'. That is, political challenge is seen to be key, but individual perspectives are also emphasised.

As highlighted, this article explores understandings of disability with participants regarded as disabled by others. The participants' views of 'community care' services are also examined and linked to policy and practice considerations in the field of social work and social care. However, this article begins by discussing notions of collaborative and emancipatory research and by locating this research project within current debates.

Emancipatory and collaborative research

In recent years increasing numbers of disabled researchers have emphasised that all research in the field of 'disability' has to have an emancipatory and/or collaborative focus and are scathing of research projects which objectify the participants (e.g. Morris, 1993; Barnes and Mercer, 1997; Barnes, Mercer and Shakespeare, 1999). Whilst there are many good reasons for espousing this view, there are also problem areas.

Proponents of 'emancipatory' research, for example, make it clear that research should be orientated towards challenging oppressive social and economic conditions and empowering research participants. The combination of research and political action is undoubtedly attractive – for epistemological, political, moral and even psychological reasons. However, as those engaged in emancipatory feminist research projects in the early 1970s and 1980s found, problems can often emerge, in terms of whose agenda should be seen as pre-eminent. Difficulties can also be encountered when the more technical requirements of the research project and political directives come into conflict. Additionally, with regard to the 'empowerment' of participants, different understandings and thus different strategies can jostle for supremacy (Fawcett, 2000).

Collaborative research arguably is less contentious than emancipatory research, but problem areas still remain in that collaboration can be taken to mean many different things. To draw a parallel with Arnstein's (1969) 'ladder of citizen participation', collaboration can vary from full participant 'control' to 'therapy'. It is also important to acknowledge that the experience of 'disability' does not in itself qualify an individual or group to speak on behalf of others. There is a growing critique from many different perspectives of crude versions of identity politics (see, for example, Ardill and O'Sullivan, 1986; Adams, 1989; Gilroy,

2000). Humphrey (2000) points to the danger of "demarking sameness from otherness" in such a way that everyone is potentially misrepresented. She maintains that even if a researcher experienced the same impairment as the research participant, the researcher would have to be cognizant of the "otherness of the other" as presumptions of sameness would affect the validity of the research (Humphrey, 2000: 79). In addition, experience of 'disability' does not in itself necessarily ensure that matters of reflexivity and methodological rigour are appropriately addressed.

While there is much work that needs to be done in order to make collaborative research partnerships a reality (see Stone and Priestley, 1996; Priestley, 1997; Moore et al, 1998), it also has to be borne in mind that for a whole variety of reasons, not all research projects can be fully collaborative. Nonetheless, research projects which cannot be fully collaborative have to pay full attention to issues of informed consent and confidentiality, with detailed discussions taking place about the aims and objectives of the research project and the personal implications for the participants. Research projects also need to be anti-oppressive and anti-discriminatory in orientation with full attention being paid to both ethical and process issues.

In order to ensure that the research process is anti-oppressive, key questions can be formulated which the researcher has to address. These include: 'Why is the research project being undertaken?'; 'Can it be a collaborative venture?'; 'What is its purpose (s)?'; 'How might the values and belief systems of the researcher influence the project?'; 'How can appropriation of the project and participants be avoided?'; 'What are the likely short-term and long-term effects of the project?'; 'How can key findings be used to influence and change policies and practices?' But these may still be the researchers' questions, so a more far reaching issue may be the extent to which the setting and the answering of questions about the research process is itself collaborative and negotiable.

Although the questions highlighted above were addressed throughout the project, with regard to the second question, it became clear at the outset that the project could not be a collaborative venture. This was because the project evolved over time and disabled respondents participated as the research progressed. It was also undertaken without mainstream funding, making it impossible to pay disabled researchers/collaborators. However, the project did generate a considerable amount of information relating to how a collaborative venture could be developed. Key aspects here relate to funding; the initial forming of a core group of researchers, disabled researchers and disabled participants; the negotiation and structuring of a clear research agenda; the formulation of an ethical statement highlighting roles, responsibilities and operational procedures incorporating mechanisms for addressing problem areas; and agreement about how the research findings are to be effectively disseminated and used to influence policy and practice.

The Research Project

Settings
The research project involved participants from four different settings. The first setting was an 'innovative' residential centre, where staff were employed to be the 'arms and legs' of disabled residents. The second was a 'traditional' residential centre which had gradually moved away from being a centre for older people to being a resource for disabled people. The third setting refers to those living either alone or with family members in the community who were known to social services departments, and the fourth setting was a day centre for disabled users. All the three centres were operated by social services departments, while those living in the community received services arranged by social services and health trusts, but did not attend a day centre.

All the twenty-five participants gave their informed consent to take part in the project. All were offered taped or written transcripts of their interviews and as part of the interview process were asked their views on 'community care' services so that these could be fed back to social services departments. Fourteen of the participants were women and eleven were men. Four of the participants came from Black or Asian communities. The low numbers of participants from Black and Asian communities reflected the ethnic composition of the settings.

28

Research process and analytical considerations

All those who agreed to participate, after being fully informed about the nature of the project, were interviewed. The participants were encouraged to generate their own accounts, rather than answer a series of questions, by initially being asked: 'Can you tell me what you understand by 'disability'?' or 'What does 'disability' mean to you?' Many of the participants then went on to develop their own account without further prompting. When a participant did not develop an account, prompts, relating to whether they regarded themselves as disabled, how they felt they were viewed by others, the impact that 'disability' had had on their life in relation to their gender and impairment, were used to promote discussion and generate the account. Within the interviews, the participants also related their views of 'community care' and the effect which current arrangements were having on them.

With regard to the analysis of the accounts, a five step analytical process was designed for the purposes of this research project. This process was informed by the work of among others Rosenthal (1990), Rutledge Shields and Dervin (1993), Miles and Huberman (1994), and Mason (1996). In step one, a biography taken from the account and comprising details which the disabled participant chose to give about their life in the context of the interview, was compiled. In step two, data was identified relating to key areas (i.e. material which in the context of the account was being particularly emphasised). In step three, key quotes/phrases and material related to the varying aspects of each specific key area were re-stated and re-grouped on a separate sheet. The analyst's interpretation of what was being said was also given at this point for checking in relation to other areas identified. In step four, themes related to the key areas were identified from the groupings of key phrases/ quotes and associated material. In step five, themes emerging from the accounts of each participant in relation to key areas were compared and contrasted with each other.

It is also important to state that individual accounts were not seen as unproblematic or transparent descriptions of experience, but were viewed in terms of how an individual made sense of their experiences at a particular point in time. Drawing from the work of Rutledge Shields and Dervin (1993) this could be seen as a way of enabling participants to theorise from their experiences. It was also regarded as a way of valuing the contribution made by people often marginalised by social systems and enabling voices frequently ignored or silenced to be heard (Opie, 1992).

Considering the accounts

It is not possible to focus on all of the accounts generated by the research project in this article. Emphasis has been placed on a comparative overview which explores how gender and impairment influenced understandings of 'disability'. However, the accounts provided so much thought-provoking and informative material that the key themes which emerged from one account have been presented.

An individual account

Participant E is a white man in his early twenties. He has cerebral palsy. He is a permanent wheelchair user and has limited use of his right arm. He does not have a degenerative condition and has been disabled since birth. E is a strong supporter of the social model of disability and has lived at the 'innovative' residential centre since it was opened ten years previously.

The aim of the innovative residential centre was facilitation and at the outset staff, who were recruited on the basis of not having nursing or social services backgrounds, were employed to respond to the wishes of the disabled residents. It was envisaged that the centre would run in a participative way with residents and staff being fully involved in decision making processes. However, paradoxically at the time when the interviews took place, considerable changes were underway in relation to the aim, philosophy and operating principles of the centre. The new manager, with the backing of the social services department, had a clear brief to re-settle people from the centre into the community, to implement a care plan system for each resident specifically designed to facilitate independent living in the community and to clarify the groundrules as to which demands by residents were acceptable and which were not. The manager was also given the task of improving the marketability of the centre as it was running at a loss, increasing the number of short breaks offered, upgrading the emergency care

service and facilitating the greater use of the centre as a day resource. These changes were clearly in contradiction with the 'full involvement' model. They also provoked a variety of reactions from residents, many of whom had regarded the centre as their home for as long as they wished to remain there. One resident made it clear that he felt the wishes and feelings of particularly the longer term residents were being disregarded and that 'others' were once again deciding what was best for them with resulting implications for their self autonomy and control. Another saw the introduction of care plans as a retrograde step, a means of re-asserting the 'care and control' agenda, much criticised by proponents of the social model of disability.

In E's account, the meanings associated with 'disability' are presented as being multiple. 'Disability' means having to be assertive in terms of having personal needs met. This for E relates to wanting the workers at the centre to do things for him as he would do them himself if he were able. This has led to some workers seeing him as "fastidious and obsessive" and feeling that he treats them "like slaves". 'Disability' for E is also about ensuring that people talk to you rather than to the person you are with. It is about adopting a view which asks others to focus on the person within, rather than one that rests on external impressions. It is also about perceived privilege, for example, as a wheelchair user, E obtains admission to concerts early, to the assumed envy of other concert goers. It is about having ongoing practical problems in terms of getting around. It is about finding it hard to establish sexual relationships. It is a hindrance, causing E to have to fight harder to achieve what he wants. It is about being the subject of ongoing scrutiny, with questions being posed about sexual abilities and having to fight off being regarded as a "charity case". It relates to always being regarded as different and having people not know how to respond to you. It refers to wanting to be in control of your life and to making your own choices. It also involves redefining masculinity (cf. Gershick and Miller, 1995). This is double edged, on the one hand it provides freedom from the restrictions of stereotypical conceptions, on the other it is frightening as it exerts pressure to forge personal definitions of identity. In the account, E adopts a positive and at times combative stance

towards 'disability', although the strain of always being different and having to fight your corner are clearly apparent. He values attending meetings of disability activists, but also admits to some anxiety about not being fully accepted as part of the group and being left without a point of focus or a social position to occupy.

With regard to 'community care', E sees it as being about cutbacks. He exclaims: "It's money, money, money all the time, and they're making it harder and harder ... because no matter what they promise you now, next year will be different because of the cutbacks." E is critical of the changes taking place at the centre but feels that he has no option but to accept a move into the community. However, he finds the prospect "scary". He is concerned about having to rely on services where contracts are negotiated and re-negotiated centrally and which are continually being rendered more restrictive. He feels that he will have less autonomy and independence in the community because he will only have restricted access to 'care' staff. He also worries about being lonely and about the possibility of being viewed as abnormal and subject to hostility by local residents.

E's account highlights that 'disability' is multi-faceted and that his views and perceptions are significantly affected by context. Wendell (1996) talks about valuing disability as difference. E's account emphasises the ways in which he is different from an able-bodied counterpart and the value that can be attached to this. However, similarities, particularly in relation to psychological and sexual insecurities and needs are also apparent and these aspects often fail to be sufficiently acknowledged. E makes it clear that 'disability' as defined by the social model is important for him but fuses 'disability' and impairment. 'Disability' is about social challenge and change. It is also about managing an impairment that has made him what he is.

A comparative overview of key themes
This is a qualitative research study and as such it has to be borne in mind that the accounts cannot be regarded as representative of accounts that may be given by other disabled people. Another aspect that has to be highlighted is that, like participant E, none of the participants separated 'disability'

30

from impairment. For all of the participants, 'disability' and impairment were indivisible. As a result, in the context of the accounts, impairment has to be seen as being inextricably connected to disability.

Gender, biography and conceptions of 'self'

As has been pointed out (e.g. Hearn and Morgan, 1995), assumptions of difference between male and female participants in research studies have to be viewed cautiously. There can be seen to be many differing masculinities and femininities. However, with regard to the themes emerging from the accounts of the female participants, a key point of note is that just over half, unlike the majority of male participants, conceptualised 'disability' in terms of 'personal biography' or regarded 'disability' as an integral part of their conception of 'self'. This theme relates to notions of self and personal identity being deeply imbedded in the histories or biographies of the women. As 'disability' featured significantly in their histories, their views of disability were intricately linked with personal understandings of who they were.

In their accounts, all of the female participants also highlighted the importance of interdependence in terms of the nature of relationships with family members. They saw themselves as neither 'dependent' nor 'independent' but as interacting in a context where these states fluctuated and where they operated as care givers, care receivers and individuals who both cared about others and were in turn cared about. This particular aspect has been highlighted by Jenny Morris who emphasises the many interrelationships which operate for disabled women (Morris, 1993, 1996).

In contrast, the majority of male participants avoided a total identification with 'disability' and emphasised a particular aspect, or aspects of 'disability'. One participant, for example, stressed the personal importance of "fighting disability"; another looked at 'disability' in relation to having the pressure of work removed; and a further participant gave a definition of 'disability' which he then distanced himself from in order to emphasise his "abilities". It is also noteworthy that the importance of 'families' did not feature as

prominently in the accounts of the male participants. The majority of male participants also highlighted the significance they attached to independence rather than to interdependence.

It is also important to note that the full incorporation of disability into an understanding of 'self' and/or a personal biography, did not necessarily equate with the acceptance of a disabled identity related either to the positive revaluing of disability (social model) or a focusing on impairments (medical model). Proponents of the social model of disability view a disabled identity linked to social model frameworks as giving the individual the potential to challenge and change debilitating scenarios. However, the assumption of a disabled identity tied to medical model frameworks is regarded as leading to a negative self-image (e.g. Shakespeare, 1994, 1996; Silvers, 1995; Wendell, 1996; Morris, 1993, 1996). Shakespeare (1996), for example, details the key aspects of a negative disabled identity. These include the internalisation of grief and loss, a denial of disability and an emphasis on 'normality', and the adoption of a role which uses impairment to obtain sympathy and attention. Although some of the participants did verbalise a tendency towards some of these aspects, particularly a denial of disability and an emphasis on 'normality', there were considerable variations in terms of the understandings of disability conveyed. It is also worthy of note, that those participants who could be seen to relate their understandings of disability to medical model frameworks in accordance with Shakespeare's (1996) criteria did not, in the context of the interview, present a negative self image. It was rather the experience of deteriorating impairment which was linked to a negative self image. The majority of the participants understood and related to disability in a largely idiosyncratic manner which drew from social model, medical model, personal and social scenarios.

Community care services

With regard to discussions about physical assistance, 'care' is the key term used by the participants to refer to input from formal support services; that is paid, or in some instances voluntary, non-family assistance. Within each account, varying and often complex views were

31

expressed, but some similarities can be distinguished and it is useful to explore these further.

Only a small number of the participants were living in the community at the time when the interviews took place. However, of all those who participated in the project, a substantial number held very negative views about community care services. These views were related to experiences of, or concerns about services rather than to political critiques linked to social model of disability understandings.

It is interesting to note that those participants who viewed 'community care' services positively had developed good relationships with the workers allocated from local voluntary organisations and these strong relationships were viewed as important. The importance of relationships with 'care' workers can be seen to call into question the increasing practice of some social services departments to abruptly rearrange contracts with care provider organisations resulting in service users being subject to sudden changes in practices and personnel.

Many of those who viewed community care negatively were faced with the prospect of having to move out of centres for disabled people which they regarded as "home", and into the community which they generally regarded as unsupportive and potentially hostile. All feared a reduction in terms of the physical assistance that would be available to them in the community. Many also feared loneliness, isolation and the lack of emotional support. Indeed two of these participants, although regarding staff from the 'traditional' residential centre positively, viewed other professionals, particularly those who carried out assessments on them, as threatening. It is a point of note that the participants from the 'innovative' residential centre, despite a greater familiarity with the social model of disability, found themselves in the same position as their 'traditional' residential centre counterparts and felt that they had no control over the making of key decisions.

The remaining participants who viewed the reforms negatively lived in the community and experienced 'care' services generally as being inflexible, imposed and limited. They did not feel that their expressed needs were taken into account and they felt that little attention was paid to the outcomes which they felt were important. One participant expressed frustration because the one service she really wanted - psychological counselling - she found impossible to access. However, none of these participants specifically criticised their direct workers. They felt that senior managers and policy makers were to blame for imposing cuts, unworkable schedules and rigid task allocation which prevented care workers from focusing on those areas which were of particular concern to them as service users. Two of these participants expressed some concern about the operation of the Direct Payments Scheme in their area. Both felt that the help they felt they needed in order to manage their own care package would not be available. They also feared the possibility of exploitation if they had to take direct responsibility for employing personal assistants.

'Community care' services have been subject to much criticism over the past decade. Balloch et al (1999) in a retrospective review of the National Health Service and Community Care Act (1990) highlight ongoing difficulties associated with the identification of need, the continuing failure of community care services to equally and effectively involve service users, and the problems associated with rationing and charging. Recent reports from the Nuffield Institute for Health and the Kings Fund (1998) relating to older people, state that many public, private and independent organisations are still providing unreliable and inflexible services and failing to give older people a say in their 'care'. In this study 'community care' services tended to be viewed by those participants who had experienced them and those who felt that they had no option but to experience them, as unresponsive to individual needs, inflexible and imposed. It is noteworthy that with regard to both the 'innovative' and the 'traditional' residential centres, the residents' wishes were overridden with financial considerations, 'best interest' rationale and policy changes, inexorably taking precedence over individually expressed concerns. One participant said in her account that she was a member of a key committee overseeing changes. Her expectation

32

was that her views would be ignored, and she found this to be the case.

It is also interesting to note that the participants in the study blamed failings in community care services on senior managers and policy makers, not on individual workers. The ways in which social workers and social care workers have struggled to meet service users' needs against a backdrop of a lack of resources and continued re-organisations have to be emphasised. Fisher (1999) points out that in the rush to incorporate business principles into the operation of social services departments in the early 1990s, little attention was paid to the development of a human resource strategy for those operating in the field of social work and social care. Recruitment problems now being experienced by many social services departments can be related to adverse changes in career progression, increasing workloads, new contracts, fewer training opportunities, low wages and increasingly difficult working conditions (Huber, 2000). The impact of this on the organisation and delivery of services to service users cannot be underestimated.

Lindow and Morris (1995) highlight how the issue of social inclusiveness has been marginally attended to in the development of community care services. They stress that most community services for disabled people are still based on a medical rather than a social model of disability. Accordingly, in line with many others, it is a rights-based not needs-based model of community care that they advocate, with user-defined quality of life outcomes being prioritised.

It also has to be emphasised that the low proportion of Black and Asian participants in the project reflects the composition of the settings. This could be associated with the fact that despite claims made in the literature about service provision being multi racial and multi ethnic, with regard to operating practices and cultural norms, services and centres are predominantly white resources (Littlechild, 1996; Bokhari et al., 1996; Atkar et al., 1997). This raises issues about the relative importance of specialised and integrated resources and the final dispelling of myths about disabled Asian people in particular being fully supported by their families.

'Community care' or the more positively framed 'social care' services are very much part of the Government's modernising agenda, which, by means of a performance driven and prescriptive programme, aims to improve and standardise provision. As part of this programme, National Service Frameworks and the National Care Standards Commission have been put in place and Care Trusts, to jointly commission health and social care services, have been established. However, the perspectives of service users have remained surprisingly consistent. This could be associated with the reforms not being in place long enough to bring about the necessary improvements. It could also have something to do with an overarching focus on targets and outcomes marginalising process issues such as those relating to how 'care' is experienced and how the 'care' provided fits with what the service user finds useful.

Concluding remarks

Reflecting on the contribution that non-disabled researchers can make to disability studies and the disability movement, Drake (1999) makes it clear that non-disabled people cannot speak on behalf of disabled people. However, he maintains that it is appropriate for non-disabled people by means of research and investigation to highlight disabling policies and practices. This article focuses on this area using a reflective review of a qualitative research project which looked *with* disabled people at understandings of 'disability'.

The aim of the research project was to explore understandings of 'disability' held by people 'registered disabled' and often regarded by others, as comprising a categorised grouping referred to as 'the disabled'. Although there are some commonalities which can be identified, it is obvious from the accounts generated by the research project that understandings of 'disability' varied enormously and that the participants have different needs, expectations, hopes and aspirations. These findings in themselves are not surprising. What is surprising is that disabled people continue to be compartmentalised as a given category in relation to policy and practice in the fields of social work and social care.

Relating research findings to policy and practice is almost always fraught with difficulties. This is

33

particularly the case with qualitatively oriented projects, where findings can be dismissed as not being subject to the same internal and external reliability and validity checks as positivist research. Findings can also be disregarded because they refer to small numbers of people. However, in defence of this project, it is possible to argue that individual understandings are important in the field of social work and social care and that individual accounts have to be seriously considered and the policy and practice implications explored. A concentration on locally and nationally agreed targets and performance indicators without corresponding attention being paid to questions of process and qualitative issues presents only a partial picture. Perhaps in the twenty first century more service users will be able to fully contribute to policy and practice in the arenas of disability and community or social care and feel part of, rather than peripheral to, both the process and the outcomes.

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34

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35

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36