

Developing Empowering Research Practices with People who have Learning Disabilities

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ABSTRACT

In this paper we report an exploratory attempt to design a practice that facilitates the extent to which 'researched-upon' and 'researcher-on' can be cooperatively involved in the planning, data collection and interpretation of research in the field of learning disability and community living. The informants were four people with learning disabilities who had been residents of long-stay mental hospitals but, at the time of the study, had all been living in the community for at least 1 year. After an extended period of informal familiarization, the research had three main phases. The first phase consisted of five individual, non-directive, depth interviews over a 2-month period. The second phase consisted of a meeting in which each participant became a paid co-researcher involved in the design and planning of the next phase of the research. The third phase consisted of three 1-hour guided neighbourhood tours led by the participants who had become co-researchers. Over the course of the three phases, the role of the researcher gradually became more a 'newcomer-learner' as he adopted the role of co-researcher and the role of participants with learning disabilities gradually became more 'expert-teachers' as they adopted the role of co-researchers. As the research progressed, the balance of power shifted, although modestly, in favour of those with learning disabilities. This led to an improvement in the quality and effectiveness of communication and understanding and an increase in the satisfaction with and enjoyment of the research process for all those involved. © 1998 John Wiley & Sons, Ltd.

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BACKGROUND

In 1993–4, we began research into the experiences of life in the community for people with learning disabilities. The research was framed in the context of our concerns over social policy on community care based on the UK governmental White Paper early in the 1970s (Department of Health and Social Security, 1971). This social policy initiative gathered momentum early in the 1980s and concerns were being

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raised in the literature over its implications for people with learning disabilities (Renshaw *et al.*, 1988; British Psychological Society, 1984). Such a policy alluded to a reintegration of people with learning disabilities into the community. Yet, by the late 1980s this population continued to occupy a marginal, devalued and disadvantaged role in society (Renshaw *et al.*, 1988). We were further concerned over the lack of qualitative research found in our literature review of this area and the disempowered role people with learning disabilities often occupied in social science research. There was very little evidence that this population was offered a voice through, or had any control over, the research being conducted into their lives. Conspicuous to social science research into disability issues are research processes that appear to oppress rather than liberate a population who already occupy a disempowered position in society (Kerruish, 1995). Typically it is the researcher who decides the problems addressed, the questions that are to be asked, and to whom and in what manner they are asked.

We conducted our research in central Scotland over a period of 5 months. The research project involved four individuals with learning disabilities. Each research participant had a mild level of learning disability and was screened to have sufficient verbal communicative skills to take part in research interviews. The decision to exclude individuals who lacked verbal communication skills was one we did not take lightly. The use of non-verbal, projective techniques had been originally considered but was rejected because that would have increased the emphasis upon the interpretative powers of the researcher rather than the communicative powers of the participants, and this was perceived as in conflict with the redistribution of power in the research relationship being here sought. We therefore decided to rely on verbal interviewing in our initial research method, although we concede that the exclusion of participants who may have been verbally less articulate was far from satisfactory.

All our research participants had previously been resident in a long-stay mental hospital but had been living in the community for at least 1 year before the research began. Our research project consisted of an extended period of informal familiarization, followed by the researcher and each participant meeting on nine occasions to explore participants' experiences of living in the community.

Our research began with participants and fieldworker getting to know each other through weekly, informal social contact. We followed this with five non-directive, 30-minute depth-interviews conducted individually with participants over a period of 2 months. In the next phase of the research, each participant was employed for 1 hour as a co-researcher. We concluded our collaborative fieldwork with a series of three 1-hour tours of each participant's neighbourhood over a period of 2 months. The tours consisted of each participant guiding the fieldworker around his/her neighbourhood.

The research resulted in qualitative insight into the lives of four individuals with learning disabilities as they were living in community settings. The implications of community care practices for our research participants' housing and employment circumstances and the confusion such practices created in our participants' social lives were explicated. We disseminated these implications to research participants, care workers and to a section of the local voluntary services involved in community care for people with learning disabilities. Further details of the research design and discussion of research results are reported in Duckett (1994)—copies available upon request.

RESEARCH VALUES

Our initial research aims were to promote the understanding of community integration from a perspective of individuals with learning disabilities, to respect their rights as individuals and to prevent the research procedures from negatively intruding into their lives. In particular, our research was designed to redistribute power between researcher-on and researched-upon in the latter's direction. The participants were, as fully as possible, involved in the planning, data-gathering, analysis, interpretation and in the conclusions finally drawn in a cooperative enterprise. As psychologists adopting this position, we aimed to learn collaboratively with participants as persons rather than to attempt to achieve understanding through manipulating 'subjects' into contrived situations in order to reject null hypotheses. These values have similarly been emphasized by other researchers working in the field of disability (Morris, 1992; Oliver, 1987, 1992) and social science research in general (e.g. Fryer and Feather, 1994), who argued that '... the extent of informants' control over the research process should be maximized rather than minimized wherever possible ... the relationship between researchers and informants should be developed and enhanced ... as a means of information enrichment rather than minimized as a source of data pollution' (Fryer and Feather, 1994, p. 231).

THE LOCUS OF EXPERTISE

Research into people with learning disabilities living in the community has been prolific. The field has been characterized by the use of a wide variety of methods, ranging from surveys (e.g. Bayley, 1973) and attitude questionnaires (e.g. Pittock and Potts, 1988) to qualitative interviews (e.g. Gollay *et al.*, 1978). Researchers' questions have been framed for and posed to a wide variety of informants, including the general public (e.g. Hagan, Powell and Adams, 1983; Wilmoth, Silver and Severy, 1987; Pittock and Potts, 1988), staff and support workers (e.g. Thousand, Burchard and Hasazi, 1986) and family members of people with learning disabilities (e.g. Bayley, 1973; Garth and Gumley, 1986). The content of the questions asked in relation to community care has also been broad. Topics have ranged from housing (e.g. Campbell, 1968), education and training (e.g. Lane, 1985; Jahoda, Cattermole and Marková, 1989; Griffiths, 1989), employment (e.g. Innes, Johnson and Miller, 1978), money matters (e.g. Sigelman *et al.*, 1980), leisure activities (e.g. Schalock, Harper and Carver, 1981) and social relations (e.g. Mitchell, 1969; Edgerton, 1967).

We strongly believe that those who themselves have learning disabilities know the topics that are important to them and have an insufficiently appreciated wealth of expertise regarding what it is to live with a disability in the community. Our values are similar in this respect to those of Carl Rogers, who wrote prolifically on the overriding value of acknowledging the expertise people have in understanding their own experiences. Kirschenbaum and Henderson (1990) expressed Rogers's reformulation of the locus of expertise in psychology, written with clinical practice in mind although of relevance, we feel, to general research practice: '... it is the *client* who knows what hurts, what direction to go, what problems are crucial, what experiences have been deeply buried. It began to occur to me that unless I had a need to demonstrate my own cleverness and learning, I would do better to rely upon the client for the direction

and movement in the process' (Kirschenbaum and Henderson, 1990, p. 13) (authors' emphasis).

The experiences, thoughts and feelings of people who have learning disabilities can be accessed through qualitative methods (e.g. Edgerton, 1967). Indeed, qualitative methods offer opportunities for people who lack the communicative abilities required by many standardized, quantitative techniques of data collection to have a voice. This is especially so when the use of standardized quantitative techniques, such as attitude questionnaires, may appear mystifying, manipulative or even humiliating, or when the research topic is one that involves social stereotyping, stigma and the tendency for research participants to acquiesce to the researcher's agenda rather than their own. As explored by the work of Edgerton (1967), stigma and stereotyping are rife in the social phenomenon of learning disability. Further, acquiescence has been a problem identified by researchers working with this population (e.g. Rosen, Floor and Zisfein, 1979; Rapley and Antaki, 1996). However, valuable as qualitative techniques are, we believe that simply adopting a qualitative approach is not enough. There is still a danger that participants' inputs may be limited if the qualitative research methods do not allow them to demonstrate their expertise fully and to address their own agendas. The ability of people with learning disabilities to express their own thoughts and feelings has perhaps been most poignantly shown through the writings of these individuals themselves (e.g. Stanovich and Stanovich, 1979; Hunt, 1982). Where researchers become involved in facilitating a voice for this population, it is important the methods they use *do not* compromise the autonomy of this voice and *do* empower the participants in order for their voices to be truly heard.

FIELDWORK

Phase I: Familiarization and depth interviews

The research procedure began long before the first set of interviews, with a period of familiarization between the fieldworker and participants. The fieldworker developed a genuinely friendly relationship with each participant through a social club for people with learning disabilities. The fieldworker had been a club member for 5 years and participants had been club members for between 1 and 7 years. The club ran weekly activities, including visits to the cinema and meetings in a local bar for a drink and a chat. Through these activities, a relationship developed between the fieldworker and club members who were later to become first a researcher-on and researched-upons and then collaborating, participative researchers in the study reported here. This initial relationship had not been initiated for research purposes but its existence was a foundation for the development of a trusting and open research alliance between fieldworker and participants.

The research continued with five individual, non-directive depth-interviews. All interviews were held in a university office and each lasted half an hour. The interviews were conducted in a way designed to create an informal, relaxed atmosphere. This included a protocol that restricted the fieldworker's input to comments that encouraged and/or clarified, a role that facilitated rather than directed the interview. Indeed, the course and content of the interview were controlled as far as possible by the interviewee. The fieldworker sought to establish equity in the interviewer-interviewee

relationship. Thus, participants were, as far as possible, ascribed a role of equal status to that of the fieldworker.

Topics explored during each interview included housing, employment and social aspects of living in the community. Each participant was encouraged to talk about his/her day-to-day living experiences. This included anything from feelings about television programmes to aspirations for employment. Attention was paid throughout to the developing relationship between the interviewee and interviewer, in particular, to where the locus of power appeared to reside, i.e. who appeared to control the course and content of the dialogue during interviews. Attention was also paid to the extent to which emotional disclosure occurred. The interviewer recorded both of these aspects in field notes taken immediately after each interview. We associated a high level of emotional disclosure with the existence of an open and trusting relationship between the fieldworker and participant. All interviews were audiotape-recorded and transcribed in full. Qualitative analysis was carried out by cognitive mapping. Cognitive mapping is 'a method of modelling persons' beliefs in diagrammatic form . . . developed in the context of action research' (Jones, 1985, pp. 59–60). During the analysis stage, we directed our attention to cases of possible acquiescence to the researcher's agenda on the part of the participants and to communicative breakdowns during dialogue.

Phase II: Participants became co-researchers

In phase II, participants were encouraged to voice criticisms and to discuss their general level of satisfaction/dissatisfaction with the interview procedure. The planning of the next stage of research was undertaken in the spirit of colleagues working collaboratively towards a common goal, i.e. portraying accurately each participant's experience of living in the community. The method evolved through ideas concerning the possible setting, format and duration of subsequent research contacts, discussed by and worked through with people who had effectively become co-researchers. Participant co-researchers chose between several options concerning each possibility, e.g. verbal or non-verbal communication, 30- or 60-minute interviews, etc. and were encouraged to take an active role in planning the next stage of the research procedure. The co-research strategy thus reappraised the interview method used in the first part of the study. Its purpose was to discuss research issues with each participant and to work together to decide how research was to progress. Each participant was paid a wage for his/her input. This wage was set at a rate of £5.00/hour, a rate that 2 years following completion of the research was still above the hourly rate for a national minimum wage called for by the UK Trades Union Congress.¹ Moreover, this was a rate of pay that was significantly higher than that to which these participants were accustomed.

Phase III: Participant-led investigative tours

The method used in Phase III of the project was a direct result of the collaboration between fieldworker and participants during Phase II. In Phase III each participant

¹ The legal minimum wage was abolished in 1992 in the UK, but if it was still in force it would today stand at £3.18/hour, according to the Director of the Low Pay Unit (Travis, 1996).

took the initiative by guiding the fieldworker on three separate hour-long exploratory 'tours' of the participant's environment; one of each participant's home and two of each participant's community neighbourhood. On each tour, the fieldworker accompanied the participant on foot, observing and noting what was shown and said by participants and asking clarifying questions. Most of the fieldworker's questions were generated through environmental cues, e.g. 'Do you do your shopping here?', 'That library who have just shown me, do you ever go in there yourself?' and 'Did you choose the picture hanging in your hallway yourself?'. The fieldworker also took opportunities to gain further insight into topics covered in Phase I. Tour data was recorded, both at the time by taking memos on a pocket sized audiotape recorder and retrospectively by taking field notes of the tour. During Phase III, the researcher's role was more passive than in Phase I. During the tours, the fieldworker became the 'newcomer-learner' while the participant became the 'expert-teacher'.

POSITIVE CONSEQUENCES OF OUR RESEARCH APPROACH

All participants reported enjoying their research experience and especially the wage received for their co-research input. The expressions on participants' faces, upon receipt of their wage packets, suggested that they experienced a great deal of satisfaction concerning this aspect of the role of co-researcher. Rather than being casually crumpled into a pocket, the brown envelope containing the money and wage-slip was grasped proudly with both hands. It also appeared that the co-research undertaken by each participant was a source of enhanced self-esteem, although this was not formally measured. Participants' degree of emotional disclosure was greater in Phase III. We believe this reflected a more open and trusting relationship between participants and fieldworker at this stage of the research compared to earlier stages, i.e. after adopting the role of co-researchers. Effectiveness of communication and participants' readiness to assert their own views were also greater in Phase III than in Phase I. For example, the incidence of communication breakdowns, misunderstandings and acquiescence was much lower in Phase III than in Phase I. Of course, this cannot be attributed entirely to the enhanced interpersonal relationship. Improved communication also occurred because Stage III took place in a context relevant to the topics under discussion, allowing participants to use non-verbal as well as verbal skills, e.g. pointing to features of the environment they wished to bring to the attention of the fieldworker. Furthermore, information expressed by the participants was frequently clarified by being contextualized during the tour. For example, one participant had talked in Phase I of having discos in his house almost every night. The researcher misinterpreted this to mean the participant had regular parties in his house. The researcher's misconception was highlighted during the Phase III tour of the participant's home. Here, the participant's use of the term disco was illuminated to mean listening to the radio in his living room in the company of his flatmate.

As researchers, we gained considerable satisfaction from being engaged in research we regarded as not only generating rich, authentic, applicable data, but also being research that was consonant with our personal value systems. The fieldworker's role, one that built upon and enhanced an existing social relationship with each participant, dovetailed in a satisfying fashion with the fieldworker's previous and future membership of a social club for people with learning disabilities.

NEGATIVE CONSEQUENCES OF OUR RESEARCH APPROACH

A drawback during the Phase II co-research stage was that we were less successful than we had hoped in empowering the participants to make informed choices, and this restricted the amount of their influence over the whole research process. Participants chose from a preselected set of options when deciding upon the progress of the research. These options were selected by the researcher and, as such, imposed a restriction upon the freedom of direction in which participants could take the research. However, participants appeared to be more comfortable and confident in choosing from a set of preselected options than in making their own suggestions. A further drawback of Phases II and III was that there were clearly consequences and responsibilities of establishing relationships of trust and openness that do not cease with the end of the research project. In this study, the fieldworker had a commitment to a continuing friendly relationship with each participant. In cases where no such continuing relationship is planned, careful consideration should be given to the responsibilities entailed by using methods such as those used in this study. Finally here, we draw attention to the fact that the names of the four co-researchers with learning disabilities in this study do not appear as co-authors of this paper. Their involvement in the research process genuinely led to their joint responsibility for the method that was developed. However, we felt that co-authorship had to be distinguished from co-research. The need for, and value of, publication seemed to us irreconcilable with the requirements of confidentiality and anonymity of informants in cases like this where the roles of informants and co-researchers overlap.

CONCLUSIONS

The replacement of Phase I data collection techniques by those of Phases II and III involved us as researchers forfeiting our orthodox social scientist roles. The nature of and the manner in which questions were asked often fell beyond the control of the researcher. For us, this entailed an increased degree of uncertainty, insecurity and role ambiguity and it would clearly not suit all researchers. However, the research role occupied by participants became an empowered one. This resulted in the development of a method that we believe led to more authentic data. Participants, acting as co-researchers, were able to identify a method that more effectively communicated their experiences of living in the community to the researcher. Through relying on the expertise of our research participants, we were able to develop a qualitative method that we believe more effectively offered them a voice.

The method developed in this project was, in many respects, locally based and the research processes described here may be idiosyncratic to the particular relationships that developed between fieldworker and participants. However, we feel the person-centred protocol and the co-research stage of our methodological design can and should be usefully transferred to future research involving disempowered research respondents. The specific context-sensitive methodological innovation in this particular study with people with learning disabilities was participant-led neighbourhood tours. However, we believe that further research within this general co-research ethos would lead to more reflexive, creative and sensitive research with disempowered members of our communities.

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