

# Research as Social Work: Participatory Research in Learning Disability

Dorothy Atkinson

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*Dorothy Atkinson is professor of learning disability in the School of Health and Social Welfare at The Open University. A trained psychiatric social worker, her earlier social-work career involved working in the mental-health and learning disability fields in Leeds, Croydon and Somerset. Her current research interests include the use of oral and life history work with people with learning difficulties. She has written extensively on the subject, including her book *An Auto/biographical Approach to Learning Disability Research* (1997).*

Correspondence to Professor Dorothy Atkinson, School of Health and Social Welfare, The Open University, Walton Hall, Milton Keynes, MK7 6AA. E-mail: [D.M.A.Atkinson@open.ac.uk](mailto:D.M.A.Atkinson@open.ac.uk)

## Summary

The social-work literature has already made links between social work and research, and has argued in favour of practitioner–research. This paper turns the argument around and looks at how research can come to look and feel like social work. This happens particularly, but not exclusively, in participatory research in the learning-disability field, especially in auto/biographical or life-story research, where long-term research relationships are more in evidence. Drawing on the participatory research methodology literature, and her own oral and life-history research, the author explores the areas in which research comes to emulate social-work practice. There are, of course, practical and ethical issues to be addressed and, as the author concludes, safeguards are needed to clarify roles and foster openness in research relationships.

**Keywords:** Learning disability, participatory research, life stories, oral history

## Introduction

There are links between social work and research. The social-work skills of sensitive interviewing and good listening, combined with counselling-type attributes such as warmth and empathy, also have their place in qualitative research (Plummer, 2001; Hollway and Jefferson, 2000). Furthermore, the reflective practitioner is well placed to become the reflective researcher, using reflexivity to understand and make sense of research findings (Fuller and Petch, 1995). The similarities between social work and research become particularly

significant when applied to narrative research, where the individual's (re)construction of his or her life through narratives also becomes part of the action required to make sense of events and bring about changes (Shaw and Gould, 2001).

The similarities and differences between social work practice and research have been explored by Gilgun (1994), Martin (1995), Fuller and Petch (1995), and Shaw and Gould (2001), amongst others. The case is made that social work is enhanced by developing a stronger research base, and social work practitioners are in a good position to become practitioner–researchers. This paper looks at the other side of the coin, and considers not how social work feeds into and links with research, but instead how research in some instances comes to emulate social work. This is because qualitative research—including oral history and life story or narrative research—requires close contact between the researcher and the researched. It is that closeness of contact (the social and emotional costs of research) which I want to reflect on here. It is my contention that in building up a close research relationship, as advocated in the literature, the researcher inevitably acquires some of the attributes of a social worker, and the research itself comes to resemble key aspects of social work.

The paper draws on two sources: literature and experience. The first source is the methodological literature primarily, but not exclusively, from the learning disability field. The qualitative/participatory research literature advocates building rapport and getting to know people in order to foster closeness of contact. It is considered good research practice to do so, because it gets good results—although some of the literature also draws out the possible adverse consequences of closeness for ‘lonely people’. The second source is my own experience of doing research, especially participatory research with people with learning difficulties. This includes my ‘Past Times’ project, in which I worked with people for over two years, and found it difficult to say ‘goodbye’; and my current auto/biographical research, where the prospects of saying ‘goodbye’ seem even more remote.

## Closeness and its costs

The literature stresses the importance of building rapport. This means getting close to people; getting them to talk; and, quite often, especially in learning disability research, doing things together. Getting people to talk means helping them to relax, using an informal manner and a conversational approach (Edgerton, 1967; Bogdan and Taylor, 1982; Edgerton *et al.*, 1984; Finch, 1984; Booth and Booth, 1994). Getting to know people often means doing things together: ‘All of these persons were visited in their residences, were invited to restaurants, driven on errands, taken grocery shopping and otherwise accompanied as they went about their everyday activities’ (Edgerton *et al.*, 1984, p. 345). Similarly, Booth and Booth reported on their involvement in the lives of the people with learning difficulties whom they were researching where, for example, ‘we accompanied parents on shopping trips, went out to lunch together, attended birthday parties, went with them to court, to a family centre, to a women’s group and so on’ (1994, p. 31).

See also Kaufman (1984) and Edgerton (1984) for further examples of how researchers become involved in the lives of their respondents.

A relaxed manner, a conversational approach, prolonged contact and doing things together means that not only is rapport built up to facilitate the research, but real feelings are engendered between the researcher and the participant(s). The methodology literature mentions 'empathy', 'intimacy' and 'involvement' as frequently occurring phenomena in close research encounters (see, e.g. Bogdan and Taylor, 1982; Finch, 1984; Kornblum, 1989; Edgerton and Gaston, 1991; Friedman, 1991; Booth and Booth, 1994). Real feelings have real consequences—there are, in fact, dangers in closeness. Qualitative/participatory research is, at least in part, about talking to, spending time with and getting close to 'lonely people' (Edgerton, 1967; Finch, 1984; Booth, 1998). As Smith and Kornblum (1989) found, this meant that researchers often became deeply involved in the lives of the people whom they were studying. This is a point echoed by Wendy Booth: 'Participatory research will always be about more than just including people in the research as, by its very nature, the process of involvement compels the researcher to become part of their lives too' (1998, p. 133). The danger is that being friendly is seen as friendship, and there is a risk of people feeling rejected when the research ends and the researcher moves on (Stalker, 1998; Plummer, 2001).

Closeness in research can be exploitative (Finch, 1984; Stacey, 1991); can lead to dependency (Stacey, 1991; Patai, 1991); and can lead to a sense of loss when the research is over (Hastrup, 1992; Northway, 2000). The kind, friendly researcher can come to be seen as a potential helper—a sort of social worker who can offer support and practical help with everyday problems (Walmsley, 1998; Booth and Booth, 1994). This may be a hard role to resist. Sometimes, the closeness of contact makes it impossible to say goodbye and informal contacts and friendships continue, often for years after the research is finished (Edgerton, 1967; Oakley, 1981; Coleman, 1986).

How far does this discussion apply to contemporary social work? How close is the contact between social worker and client at the turn of the twenty-first century? Although social work has changed, particularly in a local authority context, it has not lost sight of the key relationship at its heart. The drive towards the 'modernisation' of social work may have led to more emphasis in statutory services on a 'technical-bureaucratic' approach, but this co-exists alongside 'professional' and 'committed/radical' approaches, where there is a continuing tradition of close work and empathy with oppressed users of services (Banks, 2001, p. 145). The increasing fragmentation of social work has also led to opportunities, particularly in the voluntary sector, for detached, outreach and other innovative projects where social workers work closely with 'hard to reach' and socially excluded individuals, groups and families. The current emphasis on 'critical practice' and 'critical best practice' sees the skills of engagement, empathy, openness and reflexivity as crucial (Brechin, 2000; Ferguson, 2003). It seems from the literature that best practice in social work still entails the capacity to forge relationships with people using the personal and interpersonal skills of

communication, sensitivity and self-awareness. Similarly, aspects of best participatory research practice find an echo in participatory social work with families facing discrimination and social exclusion (Gray, 2003).

## Reflecting on research practice

In order to explore the research–social work parallels further, I turn now to my learning-disability research. This—I now see—reflects the literature on closeness and its consequences only too well. As stated earlier, this paper draws on two consecutive projects: the Past Times oral history project and the auto/biographical Life Histories project, which followed it. The oral history research (the first project) was meant to be informal and fun; the intention was to provide a relaxed environment in which people with learning difficulties could talk about themselves and their experiences. It became known as the Past Times project after the title of the booklet that emerged from their reminiscences and storytelling (Atkinson, 1993a). The research was my attempt to explore the possible uses of oral history techniques with people with learning difficulties.

The project involved running (weekly, then fortnightly) group meetings with nine older people with learning difficulties, where participants were encouraged to recall and relate events and experiences from their past lives. It was meant to test a method over a matter of a few weeks but, in the event, kept going over the best part of two years. It seemed that the rapport was too good and the relationships too close for it to end when it should. There was no incentive, it seemed, for the research participants to relinquish their group discussions and settle solely for their everyday lives in residential and group homes, day-centres and retirement classes. Eventually, in the fullness of time, I brought the group to an end—in spite of all the protests voiced and the pleas made for its indefinite continuation.

It was only later, when reflecting on the work of the group, that I began to realize its significance in the lives of its members:

The project, initially seen (by me) as lasting a few weeks, in fact lasted almost two years. The acute worry I confided in my diary at the outset ('How can I retain their interest?') soon became, and remained, a more chronic anxiety ('How will it ever end?'). The group, it seemed, had a life and momentum of its own, in spite of my efforts to impose boundaries on its work and limit its lifespan.

I brought the group to an end. It was a 'happy ending' for me (and probably for staff members who were involved in organising transport) but not necessarily for anyone else. . . . In a very real sense, then, this could be seen as an *unhappy* ending, with the termination of the group's life and the subsequent loss of friendships (Atkinson, 1993b, p. 69).

My current Life Histories project involves auto/biographical or life story research with a self-selected group of people with learning difficulties. They are researching their own lives, but are also reflecting on, and sharing, the finding

out of each other's lives; and looking at where their experiences fit into a wider historical picture. In that sense, they are co-researchers, as well as research participants, with all the practical and emotional aspects of working together, and being close, that participatory research entails.

This is where research echoes aspects of social work, including contemporary accounts of 'critical practice' where social workers work alongside people who are at risk of being marginalized and/or socially excluded (Ferguson, 2003; Gray, 2003). The research participants are also people who have been labelled and discriminated against. In a sense, they are people whose life stories are 'missing' because of their institutional histories, and because their personal case notes (often the only documentary record of their lives) are fragmented, lost or even destroyed. Where such personal records do exist, they are likely to be difficult to find or inaccessible without special and multiple permissions (in writing)—as we found to our cost in the course of this research. And yet, case notes are needed as an account of the past; as a record of family and friends; and as that 'stock of stories' which everyone needs to help them to make sense of their lives (Gillman *et al.*, 1997).

This project has involved all the usual ways of building rapport, as outlined above; spending time together and doing things jointly, such as going on trips, talking over lunch or over a drink, and, all the while, developing a relaxed and informal set of (taped) conversations. In addition, we have done some very practical searches for information, going to hospital records, public archives, county record offices and to Barnardo's in our quest to find out more. We have looked at case notes, diaries, books, photographs, films and newspaper cuttings to help us to reconstruct personal and shared pasts. It is a slow, painstaking and sometimes painful business.

The following account is taken from my research diary. It records a fact-finding visit that I made with Mabel Cooper, one of my co-researchers, to the archives held by the Lifecare Trust. This is where her old long-stay hospital case notes were held and where, after a period of negotiation, we were granted permission to see them. The visit proved to be quite a revelation for us both:

Mabel's case notes were put on the table in front of us. Not the huge file, or set of files, I had anticipated, just one ordinary-looking A4 folder. Not much to show for a life. As Mabel is not able to read it fell to me to find a way through the file and read out items of interest. We soon got the hang of it, and found a lot of routine doctors' notes, medical test results and nurses' everyday diary-type comments, which we skipped through. Basically Mabel was interested in her family and her origins: her parents, her brothers/sisters (of whom she knew nothing), the homes where she had spent her childhood, and the circumstances of her admission to St Lawrence's Hospital [in Caterham, Surrey]. There were the original formal forms and certificates from Islington children's department in the file, together with all the Mental Deficiency Act forms recording Mabel's admission in the 1950s.

This was a process of discovery for Mabel about who she was and where she came from. Personally I found the unrehearsed readings quite heart-rending. Three features stood out for me:

- The *details* (some of which I passed over) which included descriptive accounts of Mabel's manner and appearance; speculative comments about her capability; and generally negative pointers as to her future chances.
- The *circumstances*: Mabel's mother was said to be 'feeble minded' and was admitted to Darent Park Hospital [in Kent]; Mabel was then a four week old baby in her mother's arms when the latter was found begging on the streets of London; they were separated forever, a file note saying simply 'mother's whereabouts unknown'.
- The *language* of the 1950s leapt off the page and it really hurt to hear the words 'mental deficiency', 'mental defective' and 'imbecile' as applied to her. Mabel found the terminology hard to accept: Why? What does it mean?

Although this one folder was not much to show for a life, it meant everything to Mabel Cooper in her quest to find out about her past. This is Mabel's own (oral) reflective account of the same visit:

In the hospital they said that I hadn't got anybody. That's how it was till we went up to Lifecare, and we found some of the bits I wanted to know. Some of it's not in there. It tells you about Mum but it doesn't tell you about Dad. It tells you the name. I didn't know about Mum till then. I was shocked only by the names I was called and for the places they've put me in.

We sat in a little room for ages, it was 12 o'clock when we stopped. We found out a lot, that was great. But what I'd really like to find out is why I was separated. Why did Mum get put in hospital when she had a child to look after? Why did they separate us? OK, so Mum was begging, well people still do that nowadays but their children don't get put in care.

I'd love to know why—why we were separated? Mum hadn't done a crime or anything. If I'd known where Mum had gone I would have gone looking for her, but it took me over 50 years to find this much out. And we asked just in time, just before they threw the records out. . . .

Although she did not know it at the time, Mabel Cooper was admitted to St Lawrence's Hospital under the terms of the 1913 and 1927 Mental Deficiency Acts. It was only through our search for her recorded history that she found this out. It was the terminology of this legislation which was particularly shocking to Mabel. However, she was also shocked to find that she had spent her entire childhood in a succession of children's homes, only one of which she could recall. Her use of the word 'only' in this context is a figure of speech and is used by her to convey emphasis. The whole story was shocking but made worse by the language in which it was couched.

## Discussion

Participatory research engenders closeness, but co-researching life stories takes the whole process a step further. This is where research seems to take on

aspects of social work. This is because in working within existing social networks to enable individuals, separately and together, to tell and research their stories, the researcher inevitably becomes involved in working within close individual and group relationships, where there are likely to be tensions and rivalries between the people involved. Considerable research time is spent, therefore, in being supportive, diplomatic and even-handed.

There are other links with social work too, as the research involves tracking down family and friends. It entails gaining access to the documented past, in all its formality and starkness, and working with people to make sense of records couched in the language of the past. In my experience, it means facing the raw truth about separation and rejection with the person who wants to find out what really happened to him or her in childhood. This means, wherever possible, scanning ahead in the file, even whilst reading it, in order—where possible—to soften the blow when it comes. It is no easy task to read aloud the pejorative comments from a bygone era. All this and more bring everyone involved in the research into close working relationships from which it is difficult to walk away. It has led me to reflect that it probably means also never quite being able to say goodbye.

Or does it? What safeguards exist to enable the researcher and the research participants to observe boundaries that protect them both? Self-awareness on the part of the researcher is important, in order to become attuned to his or her own feelings and the feelings of others, and to be mindful of ethical pitfalls, where possible, monitoring and mitigating any dangers that lie ahead (Goodley, 1996; Stacey, 1991). It is also considered useful, if not vital, for the researcher to have someone to talk to; this could range from some sort of nominated mentor or supervisor, to a reference group (Booth and Booth, 1994) or a 'network of trusted supporters' (Friedman, 1991). Some sort of 'field log' to record and 'manage' the researcher's observations and feelings is also important, according to Friedman (1991).

Clarity of roles matters too—a point made by Walmsley and Johnson (2003). They argue that participatory research, especially life story research, often obscures the roles of the key players. They suggest that openness about roles, especially the role of the (often) woman researcher, would enable the distinctive voices of all to be heard more clearly. The current blurring of roles, they argue, serves no one well and the reflective voice of the researcher is too often the 'hidden' story in the research. Reflexivity and openness then are safeguards that are needed alongside self-awareness, mentoring/supervision and the keeping of a field log or diary throughout the research.

The research–social work analogy is a useful device for reflecting on how to manage research relationships better, but it may also serve to mask some crucial differences. Thus, however difficult it may be, in the end, the researcher may walk away, whereas the social worker cannot. The researcher's role is not to solve problems but to record them. The social worker's role is to make a difference; to work towards identified outcomes. Social work has to take on 'all comers' and to temper empathy with the need, at times, for protection and enforcement.

The researcher, in the end, works with people who want to take part, who are willing to participate in research. Participatory research, by its very nature, cannot take on all comers, and it is likely that some people, including, for example, disabled activists and mental health survivors, will rule themselves out of the process. The skills and attributes of the participatory researcher are those required to work with people motivated to take part. The social worker's role is more complex and onerous than this, requiring the capacity to work with people who are reluctant, unwilling and rejecting, as well as those who welcome the contact.

## Conclusion

This paper has considered the social and emotional costs of research to the people involved. Researchers in qualitative research projects deliberately set out to foster closeness with their respondents. This is thought to be good practice because it gets good research results. However, it also leads the people involved to think of the research relationship differently—as a potential friendship or helping relationship. This is the case especially in life story research, where the work involves relatively intense and long-term relationships. This paper focuses on participatory research in learning disability. However, when an earlier version of it was presented at a seminar, it resonated with the experiences of colleagues. They were involved in qualitative research, but not of a participatory nature and not directly involving people with learning difficulties:

Not having done any really long-term research yet myself, I've not been able to build up such relationships. Even so, it has sometimes been hard just to walk away from somebody who has opened up for my research. I think it is also quite hard in some circumstances for researchers to be friendly and accessible to people without misleading either themselves or the other person about the nature of the relationship. I've certainly come across this in housing research where expectations have been raised. Assuming we always try to be ethical in dealing with issues that come up, I wonder if we also need a bit of that 'ice in the heart' which enables novelists to use other people's lives (Researcher in the field of older people and environment).

I have just had an interview cancelled for this morning. The poor woman left it until today in case she felt better when she got up this morning. (She did not say 'woke up' because she rarely gets a night's sleep.) She sounds terrible with a cold and a cough, and is very low. She said she was so looking forward to our meeting and was very tearful. She sounds on the verge of a breakdown. She made me promise that I would phone her in a couple of weeks to make a new appointment. She has a daughter with learning difficulties and also a very supportive husband, but she has all kinds of other problems as well. Sometimes I wonder if this research is turning us into social workers and psychological support workers just by listening to people (Researcher exploring the nature of care at home).

The issues of closeness, and the expectations that go with it, are writ even larger in learning disability research, as my own work has demonstrated. However, it is, from all accounts, a recognized phenomenon in qualitative research more generally. Although participatory research is not the same as social work, nevertheless, the reliance of the former on close working relationships may mean that it can look to social work practice for ways of managing those relationships more effectively. This is not to suggest that researchers train as social workers but that they continue to develop current safeguards—such as self-awareness, research logs and supervision—to something more akin to critical practice in social work. This would serve to clarify the respective roles of the researcher and the researched, for the greater well-being of all concerned. It would also encourage reflexivity on the part of the researcher, and help to foster openness in research relationships.

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## References

- Atkinson, D. (1993a) *Past Times*, Milton Keynes, private publication.
- Atkinson, D. (1993b) 'Relating', in Shakespeare, P., Atkinson, D. and French, S. (eds), *Reflecting on Research Practice*, Buckingham, Open University Press.
- Atkinson, D. (1997) *An Auto/biographical Approach to Learning Disability Research*, Aldershot, Ashgate.
- Banks, S. (2001) *Ethics and Values in Social Work*, 2nd edition, Basingstoke, Palgrave.
- Bogdan, R. and Taylor, S. J. (1982) *Inside Out: The Social Meaning of Retardation*, Toronto, University of Toronto Press.
- Booth, W. (1998) 'Doing research with lonely people', *British Journal of Learning Disabilities*, **26**(4), pp. 132–4.
- Booth, T. and Booth, W. (1994) *Parenting under Pressure: Mothers and Fathers with Learning Difficulties*, Buckingham, Open University Press.
- Brechin, A. (2000) 'Introducing critical practice', in Brechin, A., Brown, H. and Eby, M. (eds), *Critical Practice in Health and Social Care*, London, Sage Publications.
- Coleman, P. G. (1986) *Ageing and Reminiscence Processes: Social and Clinical Implications*, Chichester, John Wiley.
- Edgerton, R. B. (1967) *The Cloak of Competence*, Berkeley, University of California Press.
- Edgerton, R. B. (1984) *Lives in Process: Mildly Retarded Adults in a Large City*, Monographs of the American Association of Mental Deficiency, No. 6, Washington, AAMD.
- Edgerton, R. B. and Gaston, M. A. (1991) *'I've Seen It All!' Lives of Older Persons with Mental Retardation in the Community*, Baltimore, Paul H. Brookes.
- Edgerton, R. B., Bollinger, M. and Herr, B. (1984) 'The cloak of competence after two decades', *American Journal of Mental Deficiency*, **88**, pp. 345–51.
- Ferguson, H. (2003) 'Outline of a critical best practice perspective on social work and social care', *British Journal of Social Work*, **33**(8), pp. 1005–24.
- Finch, J. (1984) '“It's great to have someone to talk to”: The ethics and politics of interviewing women', in Bell, C. and Roberts, H. (eds), *Social Researching: Politics, Problems, Practice*, London, Routledge and Kegan Paul.

- Friedman, T. (1991) 'Feeling', in Ely, M. with Anzal, M. *et al.*, *Doing Qualitative Research: Circles within Circles*, London, Falmer Press.
- Fuller, R. and Petch, A. (1995) *Practitioner Research: The Reflexive Social Worker*, Buckingham, Open University Press.
- Gilgun, J. (1994) 'Hand in glove: The grounded theory approach and social work practice research', in Sherman, E. and Reid, W. J. (eds), *Qualitative Research in Social Work*, New York, Columbia University Press.
- Gillman, M., Swain, J. and Heyman, B. (1997) 'Life history or "case" history: The objectification of people with learning difficulties through the tyranny of professional discourses', *Disability and Society*, **12**(5), pp. 675–93.
- Goodley, D. (1996) 'Tales of hidden lives: A critical examination of life history research with people who have learning difficulties', *Disability and Society*, **11**(3), pp. 333–48.
- Gray, B. (2003) 'Social exclusion, poverty, health and social care in Tower Hamlets: The perspectives of families on the impact of the family support services', *British Journal of Social Work*, **33**(3), pp. 361–80.
- Hastrup, K. (1992) 'Writing and ethnography: State of the art', in Okely, J. and Callaway, H. (eds), *Anthropology and Autobiography*, ASA Monograph 29, London, Routledge.
- Hollway, W. and Jefferson, T. (2000) *Doing Qualitative Research Differently*, London, Sage Publications.
- Kaufman, S. (1984) 'Friendship, coping systems and community adjustment of mildly retarded adults', in R. B. Edgerton (ed.), *Lives in Process: Mildly Retarded Adults in a Large City*, Washington, American Association of Mental Deficiency.
- Kornblum, W. (1989) 'Introduction', in Smith, C. D. and Kornblum, W. (eds), *In the Field: Readings on the Field Research Experience*, New York, Praeger.
- Martin, R. R. (1995) *Oral History in Social Work*, London, Sage Publications.
- Northway, R. (2000) 'Ending participatory research?', *Journal of Learning Disabilities*, **4**(1), pp. 27–36.
- Oakley, A. (1981) 'Interviewing women: A contradiction in terms', in H. Roberts (ed.), *Doing Feminist Research*, London, Routledge and Kegan Paul.
- Patai, D. (1991) 'US academics and Third World women: Is ethical research possible?', in Gluck, S. B. and Patai, D. (eds), *Women's Words: The Feminist Practice of Oral History*, London, Routledge.
- Plummer, K. (2001) *Documents of Life*, London, Sage Publications.
- Shaw, I. and Gould, N. (2001) *Qualitative Research in Social Work*, London, Sage Publications.
- Smith, C. D. and Kornblum, W. (1989) *In the Field: Readings on the Field Research Experience*, New York, Praeger.
- Stacey, J. (1991) 'Can there be a feminist ethnography?', in Gluck, S. B. and Patai, D. (eds), *Women's Words: The Feminist Practice of Oral History*, London, Routledge.
- Stalker, K. (1998) 'Some ethical and methodological issues in research with people with learning difficulties', *Disability and Society*, **13**(1), pp. 5–19.
- Walmsley, J. (1998) 'Life history interviews with people with learning disabilities', in Perks, R. and Thomson, A. (eds), *The Oral History Reader*, London, Routledge.
- Walmsley, J. and Johnson, K. (2003) *Inclusive Research with People with Learning Disabilities*, London, Jessica Kingsley Publishers.