

Narratives and people with learning disabilities

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Introduction

Everyone has a story to tell. However, an *entire* life story is rarely told. Instead, it is recounted in a series of oral narratives, or stories, told throughout the life as it is lived (Linde 1993). Only rarely is the full account written down as a life story or autobiography, a preserve that remains largely for the rich and famous. And yet other lives matter too, especially where they shed light on otherwise neglected or hidden areas of social life. This chapter switches the focus away from celebrity stories to celebrating and understanding the life stories of people with learning disabilities.

Not surprisingly, perhaps, there are relatively few published life stories, or autobiographies, written or commissioned by people with learning disabilities. Examples include: *Tongue Tied* (1974) by Joey Deacon; *The World of Nigel Hunt* (1967); *A Price To Be Born* (1996) by David Barron; Mabel Cooper's life story (1997); and *Cold Stone Floors and Carboloc Soap* (2004) by John Able. In addition to the single life stories are the collected narratives and autobiographies in anthologies, such as '*Know Me As I Am*' (Atkinson and Williams 1990) and *Positive Tales* (Living Archive 1996). The anthology '*Know Me As I Am*' contained the life stories, many originally in oral form, of around 200 people with learning disabilities. It demonstrated through its unique size, scope and diversity that people with learning disabilities could, with support, tell their stories in their own words or images.

People with learning disabilities portrayed themselves in the anthology as fully rounded and complex human beings, with distinct personal histories and a wealth of experiences. Together, the anthology contributors brought out the differences and the commonalities between their lives and the lives of other people in society, including the ordinary, the everyday and the mundane as well as stories of loss, separation and segregation.

This chapter explores more fully why life stories matter, especially to people with learning disabilities. It also traces the influences that have come together to make life stories important now, and reviews the ways in which life stories come to be told. Finally, the chapter draws out some of the ethical and practical issues of life story work, and considers what implications they may have for practice.

Exercise 1.1

Think about times when you tell other people about your life. Why is that important to you? Why is it important to the people you are telling?

Why life stories matter

Life stories matter to everyone – they enable us to express our sense of self, conveying to others who we are and how we got that way (Linde 1993; Widdershoven 1993; Meininger 2006). Life stories, and the narratives that make them up, are oral stories, told to another person or audience at various points in time. They may be rehearsed and refined and, over time, may be revised. Life stories, and the opportunity to tell them, are particularly important for people with learning disabilities because often they have been silent, or silenced, while other people – families, practitioners, historians – have spoken on their behalf. Life stories begin to redress that balance as they become a means by which people with learning disabilities have a voice that is theirs.

The life story, when written down, conveys the author's sense of identity and becomes something to show other people, a point made by Mabel Cooper in reflecting on hers: 'You've got something to show for your life. You've got something so that you can say, "That's what happened to me". It will keep history in

my mind for years to come, what's happened to me and a lot of others like me' (Atkinson 1998: 115). Mabel Cooper's life story is no 'ordinary' story; it takes its readers into a separate and segregated world of children's homes and long-stay institutions. The process of telling the story was important to Mabel in making sense of history – not just her own personal history ('what's happened to me') but the history of many thousands of people who, like her, were labelled and excluded from everyday life. The end product, the written story, is 'something to show' for a life lived to a large extent in a separate world.

It is, therefore, possible to suggest that the life stories of people with learning disabilities are important for a number of reasons. They:

- help us trace an otherwise hidden history;
- treat people as 'expert witnesses';
- enable people to represent themselves as fully rounded human beings;
- show the beginnings of a resistance movement;
- encourage historical awareness and reflexivity.

Each of these points will now be considered in turn.

Tracing a hidden history of learning disability

On the whole, people with learning disabilities were silent and invisible in the historical accounts of learning disability policy and practice (Ryan and Thomas 1981). Their very invisibility and silence meant that the degradation and inhumanity of their lives in the long-stay hospitals went unrecorded for many years (Oswin 1978; Ryan and Thomas 1981; Malacrida 2006). These were forgotten people, leading forgotten lives so that telling their stories became a social and historical imperative (Atkinson *et al.* 1997; Potts 1998).

The telling of history by historians relying on documentary sources has meant losing the 'richness and complexity' of lived historical experience as told through people's life stories (Rolph 1999). Without their own written accounts and, until recently, their own oral accounts, people with learning disabilities were seen as a people with 'no history' (Prins 1991). The development of methods that support people in the telling of their life stories (such as oral history techniques) has meant that 'more history' (new

insights into history) and 'anti-history' (another set of stories or understandings which challenge conventional perceptions) (Frisch 1990) can now be told and recorded.

Treating people as expert witnesses

Life stories can act as 'a counterbalance' to accounts (Williams 1993) which focus on pathological differences or deficits/defects and give a very limited view of people's lives. The life story, or autobiography, allows for a richer and more rounded account that can temper the professional orientation of normalization, for example, or 'the "victim" approach of many of the well-intentioned revelations of the worst aspects of institutional life' (Williams 1993: 57).

In public life more generally, people with learning disabilities are seen as people who have to be cared for – they are the disregarded and excluded, 'the other' (Walmsley 2000: 195). However, in telling their life stories, often in depth (Booth and Booth 1998), they become 'expert witnesses' in the matter of their own lives (Birren and Deutchman 1991; Bjornsdottir and Svendsdottir 2008). They are not simply 'sources of data' for researchers' own narratives, but people with personal stories to tell (Booth and Booth 1996). Without the usual 'stock of stories' from family, friends and community, and the everyday documents, photographs and memorabilia of family life from which to draw in order to make sense of their lives, the need for people with learning disabilities to tell their own story becomes even more compelling and empowering (Gillman *et al.* 1997). What is needed is the time, space and support in which life stories can be told because that enables people to regain their past and 'also helps them towards a future' (Thompson 1988: 265).

Enabling people to represent themselves as fully rounded human beings

Where their own histories remain untold, people may be objectified, seen as members of a homogeneous group, and have identities imposed by others (Sutcliffe and Simons 1993; Gillman *et al.* 1997). By way of contrast, the life story that is initiated and told by the person concerned holds the greatest potential



for self-representation. It allows people with learning disabilities to represent themselves as human beings; to develop their own accounts of family life, school-days, relationships and so on; and to be seen as a person rather than a 'case'. This enhances people's sense of personal identity, which is an empowering process. Those who have been involved attest to the positive affirmation of identity which this has given them: 'We are self-advocates who are running workshops on "telling your life story" for people with learning disabilities. We have both been supported to write our own life stories and want to help others to do theirs' (Able and Cooper 2000: 7).

Beginning a resistance movement

There are two ways in which life stories can be part of a resistance movement. First, when telling their own stories, people can actually demonstrate their resilience in the face of adversity (Goodley 2000). Rather than portraying themselves solely as victims they see themselves as people who showed resistance against the forces of oppression (see Chapter 21). From their own accounts, they resisted, they fought back and they mocked the people, and the systems, which sought to control them (Potts and Fido 1991; Sibley 1995; Goodley 1996; Stuart 1998, 2002; Rolph 1999). Fighting back (see Chapter 7) is one way to become a 'border crosser' from a segregated life to an inclusive one in the mainstream of society (Ramcharan *et al.* 1997; Rolph 1999).

Second, people's life stories become part of a resistance movement when their individual and collective accounts connect to tell a different, and more complex, story of their lives (Gillman *et al.* 1997). Put together, life stories become historical documents, between them mapping the events of the twentieth century. In their accounts, authors emerge not only as victims of an oppressive system but as people who survived it, and were actors in their own lives (Stefansdottir 2006). They showed resistance in the face of adversity; agency in the shaping of their lives; and a capacity to reflect on how, and why, they survived (see Chapter 21 for further discussion of resilience).

Encouraging historical awareness and reflexivity

Life stories can bring with them a greater personal awareness of history and an understanding of how past policies and practices have shaped people's lives. This is because the telling of the life story allows the narrator to stand back and develop reflexivity, to begin to explicate his or her own history as part of the wider history of people with learning disabilities.

These are points echoed by Mabel Cooper in reflecting on the importance of her (written and published) life story:

You've got something so that you can say, 'This is what happened to me.' Some of it hurts, some of it's sad, some of it I'd like to remember. My story means a lot to me because I can say, 'This is what happened to me', if anyone asks. So it's great, and I will keep it for the rest of my life. I will keep the book.

(Atkinson *et al.* 1997: 11)

Working on her life story enabled Mabel to start to make sense of her life, and to put past events into perspective (life review). In addition, she is able to tell other people what it was like to live a separate and segregated life – to be a historical witness. The written word is important in this context: it is enduring, and it is 'something to show' for the life that has been led.

Exercise 1.2

Think of one or two people with learning disabilities with whom you work or have worked. What do you know of their history? From what sources does that history come? Is there anything else you might want to know that would help you in your support role?

Why life stories have come into prominence now

There are three key factors, in particular, that help explain how and why life stories have come into prominence as a late twentieth- and early twenty-first-century phenomenon: normalization, participatory research and self-advocacy. The people who were

involved in the life story research that underpins this chapter have all, at some point in their lives, been labelled and segregated, often in long-stay hospitals. Normalization brought in its wake a pool of people with learning disabilities who were leaving the long-stay hospitals and who were more accessible as potential participants in research. Normalization also helped create the conditions in which 'speaking up' became possible (Walmsley 2001). 'Valued' research roles, such as respondent, interviewee, oral historian and so on, have been attributed to normalization's insistence on valued social roles. Similarly, the researcher in some post-normalization research is seen as an advocate, as well as a researcher, a development also attributed to the legacy of normalization (Walmsley 2001; Walmsley and Johnson 2003).

Subsequently, the development of participatory research in learning disability has also helped bring life stories to prominence. Life story work is by its very nature participatory, as it involves a person, or a group of people, in a very active process of storytelling. Participatory research lends itself well to engaging people in the various stages of the research process, and it changes the social relations of research, making it a partnership rather than a hierarchical relationship where people 'take charge' of their history (Westerman 1998: 230). Participatory research, in these terms, can be seen as part of the struggle of people with learning disabilities to name oppression and counter it; to develop a historical awareness of their situation and the situation of others (Freire 1986). The capacity of participatory research to encourage and support the empowerment of people with learning disabilities makes it an attractive option both for researchers and participants, and helps explain how it has become an important development for learning disability research (Chappell 2000). See also Chapter 35 in this volume.

Finally, it could be argued that self-advocacy was also a factor in the growth of interest in life stories, demonstrating to researchers both that people with learning disabilities *wanted* to 'speak up' and that they *could do so*. At the same time, it seems likely that self-advocacy influenced the people who were involved in it, showing them the value of research and giving them the confidence to take part.

It is through self-advocacy that people with learning disabilities have started to articulate their

experience of being labelled, or categorized, as different. This trend has been accompanied by a steady stream of autobiographies (already referred to) which have challenged their negative portrayal by others, including the eugenicists, who saw them as the perpetrators of social ills (Abbot and Sapsford 1987; Williams 1989), and the normalization writers, who portrayed them as the victims of an oppressive system (Wolfensberger 1975).

How life stories come to be told

In essence, life stories are told through a 'mixed method' approach, drawing on the techniques of oral history, life history and narrative inquiry. They may be told on a one-to-one basis, with the interviewer/researcher being the audience – or told in a group setting where the researcher and the peer group form a combined audience. The development of oral history from the 1960s provided a means by which the accounts of ordinary people could be recorded and preserved as historical documents in their own right (Thompson 1988; Bornat 1989). Oral history involves people remembering and recalling past personal and social events. It enables people to 'put a stamp on the past' (Bornat 1994) and provides the means by which people in oppressed groups (e.g. women, black people and disabled people) can record, document and reclaim their individual and shared histories. The reclaiming of history in this way can be seen as a way of resisting the accounts and interpretations of others, and celebrating a distinctive identity (Walmsley 1998).

Alongside the growth in popularity of oral history has been the re-emergence of life history research, which seeks to draw out and compile individual auto/biographies. The life history/narrative tradition in sociology can be traced back to the work of the Chicago School in the US in the 1920s, in particular to the work of Thomas and Znaniecki (1918–20). The approach flourished in the 1920s and 1930s, then declined, but re-emerged in the 1980s and flourished again in the 1990s (Stanley 1992; Gillman *et al.* 1997; Rolph 1999). Plummer (1983) argued for the reinclusion of life history methods in sociological research, and Maines (1993: 17) noted that the 'narrative's moment' had arrived in social science methods of inquiry. This reflects a more general move towards what Booth and Booth (1996) have called the 'age of



biography', including storytelling and narrative methods of research.

Life story research sheds light on history by making possible the telling of insider accounts by people on the 'fringes' or margins of society, accounts which are grounded in real-life human experience (Booth and Booth 1994). In learning disability research, however, researchers needed to overcome barriers such as 'inarticulateness, unresponsiveness, a concrete frame of reference and problems with time' (Booth and Booth 1996: 55). Although life stories tell the stories of individuals, they are part of a wider social, historical and political context; they form a bridge between the individual and society, showing up the structural features of people's social worlds (Booth and Booth 1998). Thus, life story methods allow for 'listening beyond' the words of the informant to the world around and beyond the person (Bertaux-Wiame 1981): to other people in similar situations, and to the networks of the wider society to which they belong. The common threads which emerge from life story research reveal how individual lives are shaped and constrained by the social world – and historical era – in which they are situated (Goodley 1996; Booth and Booth 1998).

Life story research (including both oral and life history methods) is now being used in the learning disability field. Literature is still relatively sparse, however, the slow take-up perhaps reflecting the fact that this approach was seen to require people who could articulate and reflect on their experiences (Plummer 1983; Thompson 1988). Only recently has it become apparent that barriers to life story research could be overcome (Booth and Booth 1994, 1996, 1998; Goodley 1996; Rolph 1999; Stuart 2002).

The role of the researcher is important in enabling people to tell history 'in their own words'. This, however, may be problematic as some people with learning disabilities may not easily find the words with which to recount their stories. What is emerging in the literature is the need sometimes to co-construct accounts with people where the words are hard to find, and where researchers have to listen to silences and proceed using 'creative guesswork' (Booth and Booth 1996) or the strategy of 'successive approximation' (Biklen and Moseley 1988). Instead, the challenge is to overcome the barriers to involvement through sensitivity and innovation on the part of the

researcher (Ward 1997; Owen and Ledger 2006). 'Guided tours' of familiar places and 'guided conversations' using props such as photographs and drawings may be needed to dismantle the barriers (Stalker 1998; Ledger 2008).

Inclusive methods involve the researcher working closely with the oral or life historian to enable them to tell their story (see Chapter 35 for a discussion of inclusive research methods). A 'feeling human observer' (Booth and Booth 1994: 36) is needed not only to facilitate the proceedings, but also to observe the consistency and coherence of the stories as they emerge. The researcher needs to be reflexive and self-aware: to facilitate stories, not to take them over; to work with people, not to exploit them; and to 'listen beyond' words, not speak for people (Goodley 1996). Echoing this, Ristock and Pennell (1996) recommend constant self-monitoring by researchers as a safeguard against making and acting on unwarranted assumptions about research participants.

Exercise 1.3

Think about a person with learning disabilities who you work with. How would you enable that person to 'tell their story'? What approaches would you use? What places would you visit? Where else might you look for information?

Research roles can include acting as advocate, scribe or supporter as well as researcher. Similarly, where people with learning disabilities are unable to articulate or elaborate on their experiences, the researcher may become their interpreter or biographer (Goodley 1996). Close and prolonged involvement between researcher and participants can continue long after the research has ended (Booth 1998).

Compiling individual life stories

A classic approach to co-constructing a life story is to work directly with the person who wants to tell it. This applied to my work with Mabel Cooper, some of whose words have already been quoted in this chapter. Our work together started when Mabel asked me to help her write her life story. We met at her home where she talked to me about her childhood

in children's homes, her subsequent move to St Lawrence's Hospital and her later life in the community, including her work in the self-advocacy movement. We tape-recorded our conversations and I later transcribed them word for word. From those question-and-answer transcripts, I prepared a more flowing and chronological account which I then read back to Mabel for confirmation or amendment. The readings triggered more memories which were themselves woven into the emerging story. The result was initially a private publication for Mabel and her friends, but subsequently the life story was published in a book (Cooper 1997) and placed on the internet.

As suggested above, the autobiographical process enabled Mabel to make sense of her life and to see it in a wider social context. In telling her life story, she was not only reclaiming her past, she was at the same time reflecting on the social history of learning disability in the second half of the twentieth century. The extract below combines personal history with period detail. Here, Mabel recalls how and why she came to leave the children's home in Bedford to move to St Lawrence's Hospital:

I moved to St Lawrence's when I was seven, because they only took children what went to school in this home. And I never went to school, so I had to move. In them days they give you a test. You went to London or somewhere because they'd give you a test before they make you go anywhere. It used to be a big place, all full of offices and what-have-you. Because they said you should be able to read when you're seven or eight. I couldn't read, I hadn't been to school. That was 1952, I was seven years old . . . When I first went in there, even just getting out of the car you could hear the racket. You think you're going to a madhouse. When you first went there you could hear people screaming and shouting outside. It was very noisy but I think you do get used to them after a little while because it's like everywhere that's big. If there's a lot of people you get a lot of noise, and they had like big dormitories, didn't they?

(Cooper 1997: 22)

There seems little doubt that Mabel gained historical awareness and understanding through the

process of compiling her life story – and also that the finished product brought with it a great sense of achievement. The experience of being an autobiographer has proved a rewarding one. Mabel is well aware of her role as a historical witness, a role which entails letting people know what life was like for her and others in the past. In one of our many subsequent conversations about the meaning and significance of her life story, Mabel pinpointed both the sense of personal achievement it brought for her and its importance as a historical record of the past:

It's an achievement with me being in St Lawrence's for so many years, and not knowing anything else but St Lawrence's. I thought it would be nice to let people know what it was like, and to let people know how difficult it was for someone with a learning disability, and who was stuck away because of that. I thought that people outside should know these things because they're not aware of it at the moment and I think it would be nice.

(Atkinson *et al.* 1997: 9)

The compilation of Mabel's life story, initially from memory, pinpointed many gaps. She was left with unanswered questions such as: Who was she? Who were her parents? What had become of them? Mabel's need to know led her into a search for documentary evidence from her own case records and from the archived papers of the institutions where she had spent her childhood and much of her adult life. Such a quest seemed daunting at times, and some of the language of the past proved hurtful, but the need to know became a strong driving force. Consequently, we visited together the records of the Lifecare Trust, the London Metropolitan Archives and the Bedfordshire Record Office, in search of case notes, diaries, photographs, newspaper cuttings and any other documentary evidence of the time. The successful location and access to personal records for Mabel (and subsequently the four other people who later became involved in what is now known as the Life History Project) meant that many long-forgotten – or never known – areas of life were revealed. Since those early visits with Mabel, the life story process with other people with learning disabilities invariably includes whatever written accounts of the time can be



unearthed, the aim being to confirm key dates, times, places and people. It is important to note, though, that these records are not simply 'there', waiting to be perused, they have to be searched for and then accessed, mediated and understood.

Mabel's involvement in the 'telling' of the history of learning disability owes much to the development of the self-advocacy movement, which has enabled her and other people to 'speak up' about themselves and their lives. She and others in the life story research were, or are, self-advocates; their capacity to 'speak up' in self-advocacy groups has enabled them to speak up in the telling of their life stories. Just as self-advocacy is about self-representation, so too is the recounting of the life story. It enables people to make sense of their own lives but also to understand their lives in relation to those of other people. This has proved to be, for Mabel and others, an empowering process.

Using group work for storytelling

An alternative to individual work is to invite people to join a group. This was an approach I used in what came to be known as the Past Times Project – an approach which aimed to capture, if possible, the richness of individual accounts but to do so within what I hoped would prove to be the more insightful and reflective mode of a group setting. The Past Times Project involved a group of people with learning disabilities recalling and reflecting on their past lives. The group consisted of nine people; seven men and two women. The age range was 57 to 77, with most participants being in their late sixties or early seventies. Potential group members were approached, and invited to join, via the staff of the special residential and day settings of which they were currently users. The group met over a two-year period, each meeting lasting an hour and, with permission, being tape-recorded and later transcribed. This is where oral history techniques proved invaluable as I was able to use reminiscence and recall to enable group members to talk about their past lives.

At the time, this was set up as a history project which would cover not only the history of difference (exclusion, separation and incarceration) but also the history of sameness. The research participants were, accordingly, invited to remember and share the

ordinary and everyday experiences of their lives; to recall happy memories as well as sad ones and to see their lives as part of the unfolding and wider history of the twentieth century. Against this backdrop, of course, emerged the histories of difference, where people's lives diverged from the ordinary and the everyday.

The Past Times Project used a group setting in order to provide a supportive and friendly atmosphere where (sometimes) painful memories could be shared, and to provide a forum where one person's memories of past events would spark off memories in others. The group format in the end worked well in that the group eventually became that supportive-but-stimulating environment that I had anticipated. But it took time, practice and patience to reach that point. Early group meetings were characterized at times by silence and, at other times, by anarchic cross-talking and multiple side conversations. Some members loved to hold the floor and recount extended anecdotes whereas others seemed content to sit quietly, venturing little. Various memory triggers were used, ranging from the simple, 'Do you remember . . .?' to the use of professionally produced reminiscence slides and tapes, and our own authentic cigarette cards, photographs and other memorabilia of the time.

Running the group was never easy. There were problems of communication throughout our meetings, as it was often difficult for me to understand the words and content of many of the contributions, even when the tapes were replayed later at home. One or two staff members from the day and residential services, who knew group members well, helped where they could with translation and interpretation. Thus we struggled together to hear and be heard for the whole of the first year. At that point we took a break from meetings so that I could compile the numerous fragments and vignettes from the (by now) large pile of transcripts into a booklet which I entitled *Past Times*.

This booklet was, as it turned out, the first of a series of versions of 'our book' (as members preferred to call it). A series of readings from *Past Times* over a period of many weeks triggered off more and deeper memories. A second draft was compiled which incorporated these new accounts. Again, I proceeded on a series of readings from the expanded version and, again, more memories emerged. Thus a third and final

version of *Past Times* was produced, reflecting the group's wish that we should produce a 'bigger and better' book rather than just a booklet (Atkinson 1993). Looking back, it seems as if the process of readings-and-amendments could have continued indefinitely with the book continuing to grow and grow. Certainly, at the time, group members were united in their wish to continue with the project rather than being persuaded to stop after two years.

As it was, the written account, *Past Times*, proved to be of immense importance to its contributors. As people with learning disabilities they had had restricted access to the written word. Yet they clearly recognized its value as a means of influencing opinion and shaping attitudes. They wanted their work to be in print because – like Mabel Cooper in another context – they wanted other people to know about them and their lives. They also saw the written word as authoritative. Their experiences were, it seemed, validated through being written down.

The book proved of interest to people beyond contributors, and their immediate circle of families and friends. Some accounts of childhood and schooldays were quite ordinary for their time and place; an example being Brian Sutcliffe's memory of his northern working-class childhood in the early/mid years of the twentieth century: 'We had a back-to-back house with a cellar and gas lights. We had a coal fire and a coal hole.'

In later years, Brian's life, and the lives of other contributors, turned out to be far from ordinary because, sooner or later, they became users of separate or segregated services. For some people, like Margaret Day, this happened in childhood, as the following extract illustrates: 'When I was a little girl I was put away. I was 14 and a half. I went to Cell Barnes to live because they said I was backward. My dad refused to sign the papers for me to go, but the police came and said he would go to prison if he didn't. I cried when I had to go with the Welfare Officer.'

In addition, *Past Times* also includes shared memories of hospital life. These afford us glimpses into a hidden world hitherto described primarily in formal documents. In the following extract, George Coley recalls a well-remembered character from years ago: 'I don't know if Bert still remembers Lewis? He was a Charge Nurse. He used to have three stripes on each arm and three pips on the top of his jacket. And

first thing in the morning you knew he was about. If you said anything, and he went like that [raises his arm], you knew what he meant. Bed!'

Overall, the stories told in the group had many classical 'narrative features' (Finnegan 1992: 172). They were clearly bounded and framed narratives, containing characters in addition to the narrator. They portrayed an event or episode, or a series of events and episodes, featuring a sequence of moves or actions, and were often spoken in different voices to indicate a dialogue. Sometimes the story also conveyed some sort of moral or message. In addition, the performance element of storytelling, and the audience effect, meant that the stories became more complex over time with increased exposure and practice.

Reviewing ethical and practical issues

There are, undoubtedly, important moral and ethical issues that arise in working with people with learning disabilities on their life stories. For example, the close involvement with 'vulnerable' or 'lonely' people over a period of time feeds into the debates in feminist and disability literature on the dangers of exploitation in participatory research (Gluck and Patai 1991; Finnegan 1992; Ristock and Pennell 1996; Oliver 1997; Stalker 1998; Rolph 1999). There are complex issues around ending research, and its aftermath – the sense of loss and betrayal which may be felt by ex-participants (Ward 1997; Booth 1998; Northway 2000) and in some participatory research the option of contact continuing beyond the life of the project is built into the process. Not all participants opt for this but it is considered by some researchers to be an important safeguard, especially for people with relatively few social networks (e.g. see Booth 1998; Northway 2000).

The 'telling' of life histories involves close personal contact over time between the 'feeling human observer' and the research participants (Booth and Booth 1994). This means that self-awareness, and the capacity to be self-critical and reflective, are vital attributes in oral and life history research. The importance of researcher awareness and reflexivity is echoed in the wider literature (Goodley 1996; Ristock and Pennell 1996). The process of recording and co-constructing life histories involves telling, recording, searching (through records), revising (through



'readings') and compiling the words and fragments into a coherent whole. The researcher's role also entails 'listening beyond' the words of each life story to pick up echoes of other people's stories; to tease out the common threads which have shaped their lives; and to see the links into the networks and structures of the wider society (Bertaux-Wiame 1981; Booth and Booth 1994; Goodley 1996).

Finally, what are the implications of life story work for practice? One thing to note in this context is that nurses, care workers, social workers, occupational therapists and other people at the front line of practice are uniquely placed to promote and support life story work, not only through their existing relationships with people with learning disabilities, but also through their access to documentary and family sources. Good practice in field work emulates good practice in research. Enabling people with learning disabilities to develop a life book or multi-media profile, for example, involves the same processes of spending time and working closely with potential authors; searches for, and interrogation of, docu-

mentary sources; and the tracking down and interviewing, where appropriate, of family, friends and other significant people (Fitzgerald 1998). This is a labour-intensive process which, at its best, will feed into and influence person-centred planning (Chapter 25). It is important to note in this context, however, that life stories are not the same as case notes or case histories, as they are told (or compiled) from the point of view of the people most centrally concerned. Case notes/histories, on the other hand, are formal and more 'distant' accounts of the person, told by others.

Exercise 1.4

You can try out the difference between a life story and case notes by (a) writing a paragraph about yourself as if it is written by a professional who knows you (but not well) and (b) by writing a paragraph directly about yourself. Compare the two – they should look very different.

Conclusion

Life stories are not just a series of events in more or less chronological order but are narratives, shaped and structured by the author in the telling of the story. People tell their stories in order to make sense of their lives, to establish their identity, and to make connections with others (Gillman *et al.* 1997). This is where research emulates good practice in fieldwork. The telling of the story as part of historical research can be empowering – but so too can the constructing of a life story book by people with learning disabilities with a care worker, social worker or other practitioner. A life story book gives people an opportunity to 're-author' their life history, and to bring out those bits which have been repressed and silenced (Sutcliffe and Simons 1993; White 1993). The life story book becomes an alternative or counter document which can recount the person's resilience and struggle against discrimination and exclusion (Goodley 1996; Gillman *et al.* 1997). The success of narrative research in influencing practice still remains to be seen but it has the potential to strengthen self-advocacy through the emerging sense of a shared history among people with learning disabilities and to improve practice in both research and field work settings.

Life story research can harness the reflexivity of people with learning disabilities, and heighten their historical awareness. As research awareness grows, more people are likely to become involved in the telling of their personal histories and thus in the telling of history itself. Those accounts, separately and together, will help tell the history of learning disability in the twentieth and twenty-first centuries. The challenge that still remains is how that history is presented, and to whom – and how it properly becomes a history that is known and owned by people with learning disabilities themselves.

Exercise 1.5

If you want to follow up the possible ways of enabling people with learning disabilities to tell their stories, there are a number of things you can do next:

1 Discover more about oral history

Oral History – a journal

Consider joining the Oral History Society (which runs oral history conferences and training workshops)

Tips on doing oral history: <http://www.ohs.org.uk/advice/>

Visit the national sound archives at the British Library, London

2 Find out about doing oral history interviews

Ritchie, D.A. (2003) *Doing Oral History: A Practical Guide*, 2nd edn. Oxford: Oxford University Press.

Thompson, P. (2000) *The Voice of the Past: Oral History*, 3rd edn. Oxford: Oxford University Press.

Yow, V. (2005) *Recording Oral History*, 2nd edn. Walnut Creek, CA: AltaMira Press.

3 Look at examples of life story work with people with learning disabilities

Ashby, I. and Lewis, K. (1996) *Real Lives: Memories of Older People with Learning Difficulties*. London: Elfrida Rathbone.

Atkinson, D. (1997) *An Auto/biographical Approach to Learning Disability Research*. Aldershot: Avebury.

Atkinson, D., McCarthy, M., Walmsley, J. et al. (2000) (eds) *Good Times, Bad Times: Women with Learning Difficulties Telling their Stories*. Kidderminster: BILD Publications.

Brigham, L., Atkinson, D., Jackson, M., Rolph, S. and Walmsley, J. (2000) *Crossing Boundaries. Change and Continuity in the History of Learning Disability*. Kidderminster: BILD Publications.

Manning, C. (2008) *Bye-Bye Charlie: Stories from the Vanishing World of Kew Cottages*. Sydney: University of New South Wales Press.

Traustadottir, R. and Johnson, K. (2000) *Women with Intellectual Disabilities: Finding a Place in the World*. London: Jessica Kingsley Publishers.

4 Consider using other resources to get you started

Gibson, F. (2006) *Reminiscence and Recall: A Practical Guide to Reminiscence Work*, 3rd revised edn. London: Age Concern Books.

Hewitt, H. (2006) *Life Story Books for People with Learning Disabilities*. Kidderminster: BILD Publications.

Looking Forward, Looking Back: Reminiscence with People with Learning Difficulties (1998). A training resource developed by Mary Stuart. Available from Pavilion Publications, Brighton.

The Open University's Social History of Learning Disability website contains examples of life stories: <http://www.open.ac.uk/hsc/lds/site/>

A group of story tellers with learning disabilities living in Somerset have a website about their work: <http://www.openstorytellers.org.uk>

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