Oral History, Ethics, Intellectual Disability and Empowerment: An Inside Perspective

Jan Gothard

Ethical considerations are an important component of my present research project, which is an attempt to understand what it is like living with Down syndrome (hereafter DS) at the turn of the twenty-first century. By ‘living’ with DS, I mean, on the one hand, living with other people who have DS, but I am also seeking first hand accounts of what it is like to have DS. Interviewing individuals with a learning difficulty or an intellectual disability such as DS has attracted some attention from oral history practitioners, which has informed my own practice. My work differs from other writers, however, in that I have lived with DS for a number of years. In that sense, I am both researcher and informant in this project, which raises further ethical issues about the role of the implicated researcher.

Until recently there was a dearth of material on the history of intellectual disability in Western Australia but, over the past decade, more has appeared as disability has become a more generally recognised dimension of social difference.¹ The book I am working on is part of that relatively new wave. It will be based largely on oral interviews but is grounded in research and ranges over a number of themes: birth experience and the acceptance of disability, family and community support; health issues; education; recreation; sexuality; post school options; employment; accommodation; and legal issues such as migration. I am working on this project with the Down Syndrome Association of Western Australia (Inc.) (hereafter DSAWA) but, while the organisation is not funding or commissioning this history, I do want to represent how the DSAWA sees its role, namely, supporting families in making their own choices, rather than advocating one view over another. On that basis, an important theme of the book will be family decision making: continuing or terminating pregnancies;

adopting or fostering children; accepting or relinquishing children at birth. As such, some of my interviews have been painful, both for the informant and for me as an interviewer.²

I have over one hundred recorded and transcribed interview hours, conducted in Perth, Albany, Denmark, Broome, Derby, Kununurra and Wyndham,³ with my culturally diverse informants including Aboriginal and migrant families. While most of the parent/carer informants have been mothers, there are also a number of detailed interviews with fathers. Having conducted interviews over several years, I am now revisiting some of the earliest informants in what has become a longitudinal study. Parent and sibling informants outnumber people with DS interviewed, but interviewing both these groups involves ethical considerations.⁴

I need to start by locating myself as an historian and showing how that in itself is not a neutral position. Of course this is always the case for a researcher, writer and editor, but I have felt particularly challenged by this interviewing and writing process. My interest in disability is precisely as old as my daughter, born in 1992. As she has grown up I have become increasingly aware of how an everyday life lived with disability is a political and social battle ground, one of which my daughter still remains largely unaware (and I will return to that point below), but one in which her parents engage on a daily basis.

For as long as I have been actively aware of disability as an aspect of society, I have experienced it, both second and first hand, as both oppressive and disabling and, as an interviewer of both parents and individuals with DS, I have always kept that framework in mind. I have much in common with many of the parents interviewed, in terms of experiences associated with recognition of a child’s disability and working through the consequences in terms of health, education, and social interaction; yet many parents do not share my view of disability as a condition made worse by, but which could be made better by, social attitudes. This is a difficult line to tread for a politically-committed researcher. As an historian and interviewer, however, I have attempted to remain neutral and to render my views invisible in an interviewing situation. My intention was after all to see how a range of people experience living with a disability, not to proselytise or see how many people share my point of view.

In selecting informants, I consciously sought to encompass views I don’t necessarily share. My reasonably intimate knowledge of some of the DSAWA community has enabled me to record a broad sample of views – perhaps not representative numerically, as such a small sample never will be, but at least giving the opportunity for people who value different things to express their

² Susannah Thompson’s paper in this volume, “‘I didn’t talk to anybody’: Reflections on Researching the History of Perinatal Loss in Australia’, deals more directly with the issue of interviewing on painful or distressing personal topics.
³ I would like to acknowledge the receipt of a Community History grant from LotteryWest which enabled me to interview people outside the metropolitan area.
opinions. It has also enabled me, in other cases, to select people for interview who are particularly outspoken. One thing many parents of a person with a disability share is forcefully held views on the topic!

Clearly, interviewing from within a community has a number of implications. From the outset of the project, I have always identified myself as a parent of a child with DS. Ann Curthoys has addressed the issue of shared experience in writing the history of an episode in which she participated, the Freedom Ride in New South Wales in the 1960s.\(^5\) As she later wrote, after interviewing one fellow participant,

I realised that I could not be the interviewer of the rest. Beth was, naturally, too aware that I had been there too, finding it difficult to tell me about things she thought I would already know, and feeling wrong-footed if I asked about the details of events that I remembered or knew about and she didn’t.\(^6\)

Curthoys was able to find and pay an interviewer. I did not have that opportunity and would not have taken it had it been available. In my interviews, I believe the informants’ awareness that I had also ‘been there’, in fact still ‘was there’, was an opportunity for sharing deeply-buried, sometimes painful memories with someone who would not judge. My questions included: Did you ever consider relinquishing your baby? How did you feel towards your child when you first knew it had a disability? Did you ever contemplate the possibility of it not surviving? All of these questions are hard to ask but it is my belief that they can be considered more honestly if asked by someone who has possibly shared the thoughts or memories which one might subsequently deny or try to suppress, about a child who is now much loved and much wanted.

Similarly, the question of a child’s progress. Naturally one always wants to put a positive spin on one’s child’s achievements, especially if one has fought, for example, for access to educational opportunities. But sometimes a child doesn’t live up to deeply held hopes and, as a parent ages, new fears replace the old – that the child will grow old lonely, perhaps, or with too little independence. The frustrations of dealing with a 16-year-old boy not yet fully bowel competent, for example, or a young woman who can’t cope with menstruation: these are topics one can’t always discuss over a coffee with one’s peers, but they can be shared with someone who just might be facing the same problems.

The questions of pre-natal testing and of subsequent pregnancies were also fraught. Did an informant have pre-natal testing before the birth of the child with DS? If they had known they were expecting a child with a disability, would they have had a termination? And how would they and their partner have reacted had they found themselves expecting a subsequent child with DS? Most informants gave me a range of disarmingly honest responses to those questions. In some cases they admitted that they had never discussed the possible consequences of finding they were expecting a second child with

---


\(^6\) ibid., p. xix.
DS with their partners because they were fearful of what such a discussion might reveal about their, or their partner’s, feelings towards their first child. One informant, for example, said her husband had never raised the prospect of a termination should their next child have DS but if he had, she doubted they would still be married. Others were forthright about the decision they would have made: they could cope with one child with a disability but their family resources were not able to cope with a second.

The painful nature of these questions, the intimacy of the subjects addressed, and the fact that they relate to one’s most private feelings about family, children and life itself, meant that all interview material from this project will be used anonymously. The DS community in Western Australia is a reasonably small one, which raises issues about the extent to which interviews can be totally anonymous. All those interviewed accepted this. Yet the question of anonymity has other ethical implications, for those with disabilities in particular. At a symposium I attended in December 2007, where a number of formerly institutionalised people with intellectual disabilities spoke out about their hidden lives behind the walls of places such as Kew Cottages in Melbourne, discussants were vehement about the need both to have their voices heard and to be named. This aspect of using informants with DS anonymously had not occurred to me, despite my own reasonable awareness of the politics of empowerment. If conducting this project again, I would ask my informants with DS to permit me to use their names, which would be a decision they would typically make in the context of discussion with their families. The process I previously understood as ‘protecting’ informant anonymity now in some ways seems to smack of denying individuals important visibility within the community.

More challenging perhaps has been the question of how to use my own voice. I am an interviewer and researcher, but I too have a story to tell. As I come to edit the interviews, this becomes more pressing. The question of selecting interview extracts, locating them within the text, and above all, giving them weight, is a difficult one. Commenting elsewhere on the task of ‘writing a history in which one was involved’, Curthoys noted

> [i]t is very tempting to use the authority of the historian to add weight to the reminiscences of a participant, and conversely the authority of having been there to add piquancy and authenticity to the academic account. Yet all this can seem self-indulgent, and to be taking risks with my sense of intellectual integrity.  

In *Freedom Ride*, Curthoys adopts the method of shifting the narrative voice between first person (usually plural) and third person – sometimes ‘we’ did this, sometimes the Freedom Riders did. It is a device which serves both to personalise and retain ownership of the account while also externalising it.

---

7 Life histories and intellectual disability symposium, La Trobe University, December 2007.
underlining academic authenticity. Another model is that adopted by the Western Australian Women's Cancer Group in their publication *Songs of Strength: Sixteen Women Talk about Cancer*.9 Their approach is closer to mine in that the text is primarily based on interviews with sixteen members of the group, each of whom participated in designing an oral history project, establishing themes, directing the interviewer and the questions asked, and overseeing the use of their words in the final publication. Though the interviews are not used in their entirety, being broken up and interwoven with supplementary research, the work is an example of an oral history-based book in which ownership is strongly vested in the informants.

I have had responsibility for the DS project in the sense of undertaking the interviewing, editing and writing. However, in order to give my voice what I hope is no more than equal weighting with other parent informants, I primed a friend on the questions I had asked other parents and asked her to interview me. That interview too will be used anonymously, and satisfies my desire to have 'my' voice heard directly. Yet I cannot deny that as editor I will have the capacity to weight material to serve my own ends. As Curthoys has noted of her experience: 'Even if I satisfy myself that I have avoided these traps, will others believe that I have?'10

Issues relating to being both participant in and director of a research project are numerous. Equally taxing has been the process of working directly with people with intellectual disabilities and in the field of disability more generally. Some of my dilemmas also have resonance for any outsider interviewing members of a particular group. One ethical challenge particularly relevant to disability is the notion of an emancipatory research paradigm. In their 1996 paper with the rather pointed title of '[p]arasites, pawns and partners', authors Stone and Priestley outline issues faced by a non-disabled researcher, such as myself, working in the disability field.11 They constitute disability as a social relationship, created and fostered by a social environment and social attitudes,12 and argue that research into disability should have less to do with charting how disabled people 'cope with' or adapt to their situations than with the political process of removing disabling barriers. Within this framework, Stone and Priestley argue that the researcher should be committed to providing politically positive ends for people with disabilities, demanding that:

[c]ommitment on the part of the researcher, both to a social analysis of disablement and to the development of the disabled people's movement, must ... form the basis of emancipatory disability research...13

---

10 Curthoys, 'History and reminiscence', p. 118.
12 ibid., p. 701.
13 ibid., p. 702.
Oral History, Ethics, Intellectual Disability and Empowerment

and that

[t]he political standpoint of the researcher is tied to political action in challenging oppression and facilitating the self-empowerment of disabled people. The researcher engages in processes of emancipation, rather than merely monitoring them from sympathetic sidelines.14

According to these criteria, empowering research also requires a recognition of the oppressed position of people with disabilities and a rejection of previous research models which have rendered disabled people as ‘passive research subjects’. It therefore demands that people with disabilities, or their organisations, be ‘at the apex of the research hierarchy’.15

Stone and Priestley point to the sometimes contradictory impulses between ‘personalizing the political’ and ‘politicizing the personal’, and they identify the need to ‘giv[e] voice to the personal as political whilst endeavou ring to collectivize the political commonality of individual experiences’16 and the need to adopt a plurality of methods of data collection and analysis in meeting these needs. Finally they articulate how they met – or failed to meet – these criteria in their own research, and note that any attempt to engage or practice emancipatory research is necessarily daunting!

I offer this example of a methodological approach for non-disabled researchers, such as myself, working with people with disabilities, not because I endorse it in toto, but because, like Stone and Priestley, I have always adopted a reflexive approach to my work in this area. In contemplating some of the tenets of emancipatory research, I also question how far my work can or ought to fit this model. In particular, I question how this research paradigm relates to oral history; and how it relates to people with intellectual disabilities.

I was an historian and an oral history practitioner before I became involved in disability, and as an historian I have always been motivated by an understanding of oral history as a research methodology which ‘gave voice to the inarticulate’, a view which underpins so much of oral history practice that it seems almost redundant to make that statement. Yet as Karen Hirsch contends,

so far most of the literature based on interviews with disabled individuals has not demonstrated the empowering shift of focus that Paul Thompson describes in The Voice of the Past... Published with the explicit purpose of allowing people with disabilities to speak for themselves, these interviews do not serve the same function for the disabled community as oral histories collected about other groups.17

Hirsch attributes this to a number of factors but the most important feature seems to be the individualizing focus of this work. [T]he presence of a disability in an individual’s life story is not sufficient to create a sense of a group with

14 ibid., p. 703.
15 ibid., p. 704.
16 ibid., p. 706.
shared experiences’,\textsuperscript{18} and she accounts for this by arguing that there had been some tendency for people with disabilities to eschew group identities. This, she argues, is associated with a belief that embracing a collective identity can lead to increased discrimination, which builds on the fact that segregation and incarceration have been the historical legacies of such aggregation.\textsuperscript{19} Unity in this case may not be a strength; it could lead to identification, rather than the safety of invisibility, and could promote discrimination.

Yet Hirsch further points out that, while recognizing individual differences and circumstances, disability activists have begun consciously to assert their commonalities, as a way of acting against and rejecting discriminatory treatment. Looking to the politics of other minority groups, Hirsch reasserts the need for people with disabilities to turn their status as minority group to social and political advantage. Like Paul Longmore does,\textsuperscript{20} in his passionate advocacy of the need to embrace disability as a category of historical political and social analysis, Hirsch calls for people with disabilities to participate in reclaiming their own histories and sees oral history projects as important opportunities for scholars of disability to take the lead in ‘focusing the questions, interpreting the findings, and developing the language and images that can begin to give the disability community its history’.\textsuperscript{21} My own work was premised on a belief in the importance of having people with disabilities speak for themselves, and a desire to use their voices as a way of highlighting the socially-constructed dimensions of disability. Nonetheless I did not find it easy linking theory with practice, as I go on to explore.

\begin{footnotesize}
\begin{itemize}
\item I wanted to focus very much on the personal experiences of having DS – what difficulties people had encountered, for instance that they could attribute to their disability – and I approached these issues in the broader context of finding out how young adults with DS lived their lives. What I found was how very like, in many ways, the lives of my informants were to those of their peers who did not have a disability. Ranging in age from 16 to 30 when I interviewed them, the majority lived at home with their parents. One young woman shared her unit with a friend who also had DS – she had taken out a mortgage and was buying her own home; and another man in his late twenties rented a unit in Fremantle, where he lived by himself. None was in any form of group housing or residential facility; and none had been institutionalised at birth, the experience which is more typical of a slightly older generation with DS. Social interaction, recreation, education and training, relationships, work and family were the main focus of their lives and, while some clear differences existed, largely associated with independence, my interviews reinforced Jan
\end{itemize}
\end{footnotesize}

\begin{footnotesize}18 ibid.  
19 ibid.  
21 Hirsch, ‘Culture and disability’, p. 221.\end{footnotesize}
Walmsley’s observation that: ‘being a person with a learning disability is most akin to being a human being’. At least that is how my informants related their lives. Yet my own knowledge of disability and observation of the lives led by people with DS led me to think they experienced more ‘difference’ than they claimed.

In my interviews, I approached the question of discriminatory treatment both obliquely and more directly, but seldom elicited the kinds of responses I sought. Some respondents were surprised at these questions, and politely expressed the view that people should and did treat them ‘nicely’ and ‘normal’. However the stories they told about their lives led me to believe otherwise. Some informants recounted incidents of teasing, others talked about leaving sporting or recreational groups because they felt uncomfortable, or of experiencing loneliness at school. My most articulate respondent, David, spoke at length about disability as a general topic and expressed his anger at his observed treatment of another person with a disability; but he conceptualised his own disability in terms of a particular health issue which he also experienced, and saw as a much more significant issue. So, as the following interview extract illustrates, his understanding of (or his readiness to acknowledge) discrimination on the basis of disability was externalised.

JSG You were talking about Down Syndrome and about how people can discriminate; and illness, cancer, diabetes …

David Yes. It’s a sad thing that people do judge and it’s not right for them to judge, because they have a life too and – I mean, you may see someone on the street talking to themselves a lot, and in a surrounding where there’s other people walking by. They don’t know whether that person is wanting help or not, but they … sometimes they are left on their own, because no one wants to do something about it.

Quite a while ago, I was getting on a bus next to Target and I was going to my mentorship at that time in DADAA and there was a guy in a wheelchair that was wanting to catch a bus. This is all true. But the bus driver wouldn’t let him on, and that was very sad. I mean, I thought … and that’s upsetting! So the person in the wheelchair swore at the bus driver for not letting him on the bus, because the bus driver didn’t want to let him on because he was in a wheelchair and didn’t want to have the responsibility of putting him on, and because of time and stuff like that – and I found that was very upsetting. If there were more buses that are wheelchair accessible in Fremantle, that would be good.

David is an unusually articulate and loquacious informant. Thus his response to my subsequent direct question about having experienced any negative treatment relating to his disability struck me as uncharacteristically short, and his hesitation mid-sentence, ‘I’m fine with my…’ also seemed revealing.

23 Not his real name.
Yes. Have you yourself experienced any bad things because of disability?

No.

No personal incidents that you can think of? You mentioned a few earlier once when you were a lot younger.

Well, I’m not really sure really. I’m fine with my … I am proud of who I am and I can be polite and kind to people and people can be polite and kind to anyone, you know. It’s just having self will and great strength to be where you want to be in life.

Similarly none of my other informants directly acknowledged DS as having any impact on their lives. Yet in some cases, parents had asserted that their children knew very well the meaning and the negative connotations of having DS: rejecting the prospect of a boy friend or girl friend with DS; or self-consciousness about the appearance of their eyes. Other parents and researchers have made the same observation. Sigrid Kaly, in her book about her 25-year-old son with Down syndrome, wrote:

[t]here is a rather big chip on Anthony’s shoulder – more like a log. He does not like to associate with people who have a disability. He definitely sends out the message: “I’m not one of you. There’s nothing wrong with me.”

So I could not conclude, as Aull Davies and Jenkins have done, that the individuals interviewed did not recognise their disability or the constraints it had placed on their lives. Rather I looked to the interview situation itself for answers. Mark Rapley’s work on interviewing people with learning difficulties proved useful. A psychologist, Rapley has written extensively about the language and conversation of people with intellectual disabilities, and his research confirms the apparent reluctance of people so labelled to self-identify, though his analysis of interviews reveals, as did mine, that there is definitely an awareness of disability and of its consequences. Yet Rapley also asks, in the words of Shakespeare and Watson: ‘what is wrong with … identifying simply as a human being, or a citizen, rather than as a member of a minority community?’

I agree; but it does challenge the notion of empowering research if participants on the whole do not want to be so empowered or prefer not to acknowledge what others would see as their oppression. What then is the role of the politically-committed researcher? Where individuals with disabilities are distanced from the political hardcore of the disability movement (and this in my experience is typically the case of people with intellectual disabilities), I do not believe

25 Charlotte Aull Davies and Richard Jenkins, ‘She has different fits to me’: how people with learning difficulties see themselves, Disability and Society, vol. 12, no. 1, 1997, pp. 95-109.
it is the interviewer’s role to attempt to politicise. That may well take place elsewhere, as part of a process of developing self-advocacy skills for example, or indeed in writing a book. Within the parameters of an interview or research project, however, entered into by an informant on the understanding that it will involve a sharing of their life experiences, I believe it would constitute both a breach of ethics and an abuse of power.

Rapley also interrogates the social context of the interview situation and the power relationship between the interviewer and the informant, which is yet another focus of empowering research. He points out that for many people with intellectual disabilities, the interview situation is a reasonably familiar one, usually associated with an authority figure such as a bureaucrat, teacher or counsellor, whose task is effectively to test the informant.28 In such a situation, Rapley contends it is possible to get an apparent pattern of acquiescence or compliance, initiated by the respondents’ desire to give the answer they assume the interviewer wishes to hear; which has led some researchers to conclude that it may be difficult to get at anything like ‘the truth’ from the interview process with individuals with intellectual disabilities or learning difficulties. Rapley’s close analysis of discourse however led him to suggest that patterns of resistance are evident. What I draw from this is confirmation that it is possible to gain an understanding of what life is like and how disability is experienced, even if an interview question doesn’t elicit a direct or reflective answer on that topic. And again, this has resonance with my own interviewing experience.

The question remains, then, how can you use interviews to produce an account of what it’s like to live with DS? Oral historians typically conduct a recorded interview which becomes the master document; and from this, depending on the needs or aims of the project, they might produce a verbatim transcript; beyond that an edited document which might or might not include the interviewer’s questions. If you have a respondent who is as articulate as David, then the fact that he happens to have DS is of no significance when it comes to using his words: he has plenty of them, he is beautifully lucid, and he willingly shared a great deal about his life. Most of my other informants, however, are far less articulate, and some have very little speech. In these cases, the interview process is much less a conversation than coaxing out of information, usually based on seeking answers to closed ‘yes/no’ questions, which in more usual interviewing circumstances would be seen as a definite ‘no no’.

Hirsch has warned researchers against the tendency to speak on behalf of people with disabilities, cautioning, ‘[i]t is hard to overstate how resistant and pervasive is the cultural assumption that people with disabilities cannot speak for themselves’.29 Yet herein lies another challenge to the notion of empowering research and oral history when working with informants with intellectual disability. Projects designed to give voice to the inarticulate are all very well but, when dealing with people with intellectual disabilities, in some cases their voices are so mute as to be almost inaudible. The question then becomes one

of how to use the material gathered. People’s experiences cannot be recorded in their own words if their words are very few.

Tim Booth and Wendy Booth have also wrestled with the problem of inarticulate subjects and conclude, of people with learning difficulties, ‘[t]he only way of collecting their stories may be to loan them the words’. 30 They illustrate this process by reconstructing a narrative account of the life of one of their informants whose responses, like many of the people I have interviewed, were little more than ‘yes’ or ‘no’. Instead of taking the informant’s words as one would usually do after an interview, and using them to create a narrative, the researcher takes the meaning, gleaned from each ‘yes’, ‘no’ or silence, and creates a narrative. Thus, along the lines suggested by Booth and Booth, I might write up a narrative about Rachel:

Rachel lives at home with her parents. Sometimes she stays over with her sister Clare and husband, and Rachel adores playing with her nephew Ben. She enjoys going out to work at Spotlight three times a week but prefers the days when she is picked up by a bus and goes to a recreational centre for a line dancing class. Winter is her favourite time of the year because she can go to watch the Dockers play at Subiaco. Recently she celebrated her 25th birthday and one day would like to live in her own flat with her friend Sarah.

Such an approach, as Booth and Booth point out, undoubtedly misrepresents the capacity of the speaker to speak for themselves and also loses the authenticity of the informant’s own voice. These are not Rachel’s words – I gave them to her, and she accepted or rejected them. But this process does enable the telling of a person’s story.

In the same vein, I might describe an interview situation to give an idea about how an informant responded to a question: ‘after a long pause Mark indicated his inability to respond to the question’; or ‘Jodie was very excited when we talked about going to the dance and clearly seemed to have enjoyed the event’. The narrative created can then be supplemented by material from other sources including, but not confined to, oral accounts from friends, parents and siblings. Thus the researcher can build up a picture of the person’s life, with the interview not the end in itself but part of a larger body of documentary material. Interviewing then becomes a process of creating a partial record of the experience of those less comfortable with written or oral expression which is generally privileged as historical evidence. For as Kelly writes of researchers, ‘it is we who have the time, resources and skills to conduct methodical work, to make sense of experience and locate individuals in historical and social contexts’. 31 Framed this way, I see the role of the interviewer/editor and historian not as dis-empowering, because it detracts from the authority of the informant, but as ‘enabling’. The alternative may well be silence.

Amongst people with DS there are certainly many who would be able to tell their own stories. David is one, advocates like Karen Gaffney and Chris Burke are others; and there are publications, such as Kingsley and Levitz’s *Count Us In*,\(^{32}\) authored by people with DS. These certainly contradict the image I have been presenting of individuals with DS not recognising their oppression or not wanting to become self-advocates, but they remain a tiny minority at present. One of the dilemmas I have faced in undertaking this research project has been balancing the desire as an interviewer to find articulate respondents such as David with the recognition that other people’s stories, less clearly verbalised and much harder to render meaningful, are just as valid and are perhaps more typical. An interview programme which focuses only on the most successful or the most articulate individual is neglecting many of the realities of living with DS; and thus I have framed my interviewing and editing of interview material in non-conventional ways.

Though this project is located in Western Australia and deals specifically with the Down syndrome community here, it has much broader geographical and social application. Presented in terms of its personal challenge, the ethical issues outlined here have implications both for those working as oral historians, whether or not the researcher is part of the community under study, and across the disability arena. The complex question of oral history as an empowering research method has particular resonance within the disability field yet, as I have suggested, it is not a model to be applied without cautious reflection in the area of intellectual disability.