

History from the inside: towards an inclusive history of intellectual disability

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This paper reviews the place of the 'voice' in the history of intellectual disability, drawing principally on developments in the UK, but also making reference to comparative developments in other countries. Various approaches have been used by research historians to collect and represent the voices of those involved in this history; including biographical reconstruction, oral history, institutional histories and life histories. In response to the challenge, 'Nothing About Us Without Us' the slogan of the disabled people's movement, the paper argues for the careful use of oral and biographical accounts to augment histories told through official sources and examines some of the methodological challenges associated with such approaches. However, the argument of this paper, ultimately, is in favour of what we are calling 'inclusive history', where academic historians and oral/life historians contribute to the development of a *shared* history of intellectual disability.

Keywords: intellectual disability; biography; oral history; life histories; institutional histories; inclusive history

Introduction

'Nothing About Us Without Us' (Aspis 2000), the powerful slogan of the disabled people's movement, has challenged researchers, including historians, to address the contested issue of authorship of the history of intellectual disability. In this paper we explore how oral history and biographical approaches have enabled the voices of people with intellectual disabilities, and others, to contribute to the construction of history (Atkinson, Jackson, and Walmsley 1997; Brigham et al. 2000; Hreinsdottir et al. 2006). We draw principally on developments in the UK to illustrate the use of a range of sources as advocated by Armstrong (2002) including the perspectives of various participants such as families, practitioners and people who use the services (Welshman and Walmsley 2006, 3), together with primary and secondary documentary accounts. The paper reviews two 'pure' approaches – biographical reconstruction and oral history – and two applied approaches, where oral and documentary sources are combined: institutional histories and life histories. Ultimately we advocate an approach which builds on all of these but goes one step further towards an inclusive history of intellectual disability.

The full potential of these approaches – referred to collectively in this paper as 'lived history' – has yet to be realized. While work has been done to facilitate oral

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accounts, there still remains the challenge of enabling the voices of the recipients of policy and practice from earlier periods to inform historical understanding. In the meantime, articles and papers continue to be published which draw exclusively on documents written by policy-makers and providers which, as Read and Walmsley note, tend to tell the story of 'the march of progress' (2006, 3), rather than a more nuanced account of how policy pronouncements are translated into practice, and experienced by users and their families (Rolph et al. 2005).

The history of intellectual disability emerged in the late twentieth century as a distinctive area of study (Jackson 2000; Noll and Trent 2004). It has proceeded to some extent along parallel lines: as conventional scholarship conducted primarily by academic historians (Bartlett and Wright 1999; Jackson 2004; Hanssen, Sandvin, and Soder 1996); and as oral history (in various forms) undertaken by researchers from other disciplines, mainly psychology, education and applied sociology, often in collaboration with people involved in self-advocacy. In the next section, we look briefly at the emergence of the history of intellectual disability – as an academic discipline and as an area rich in oral accounts.

Background

Although regarded now as a distinct area of historical inquiry (Noll and Trent 2004), prior to the late twentieth century intellectual disability history was subsumed within accounts of psychiatry and psychology (Micale and Porter 1994; Melling and Forsythe 1999), mental health policies and services (K. Jones 1972), educational histories (particularly special education; see, for example, Hurt 1989) and in the study of eugenics and social hygiene (G. Jones 1986). A similar neglect of intellectual disability has been apparent in sociology and social policy, where Goffman's ideas on the 'total institution', for example, excluded any reference to intellectual disability institutions (1968). Similarly, Foucault's exposition of the 'great confinement' (1967) and Scull's depiction of the 'museums of madness' (1979) were based around policy and practice in psychiatry rather than in intellectual disability.

Scholarship in intellectual disability history in North America, Scandinavia and Australia, as well as the UK, has tended to focus on: the history of institutions (see, for example, Wright's 2001 account of The Earlswood Asylum); the lives and works of great men and women (see, for example, Jackson's 1996 study of Mary Dendy); and Merriman's 2007 biography of John Langdon-Down); key social and legislative changes (for example, K. Jones 1975; Malin 1995; Tossebro, Aalto, and Brusen 1996; Borsay 2005); and, latterly, the history of community care (for example, Abbot and Sapsford 1987; Ayer and Alaszewski 1984; Bjarnason 1996; Bartlett and Wright 1999). However, this work is informed only to a limited extent by reference to the many people whose lives were touched by intellectual disability policy and practice, and whose experiences can contribute to a better understanding of history, a topic we return to below.

An early example of what has been called a 'social worker-pragmatist' (Williams and Walmsley 1990, 49) view of history was Kathleen Jones's classic account of the development of UK policy (1972). This saw the 'solution' to the 'problem' of intellectual disability as the presence of well-resourced services and an informed, knowledgeable and trained workforce of professional people, such as social workers. This view of history was 'pragmatic' in the sense that it focused less on debates around the role people can and should play in society, and more on the competing

claims of different approaches to placing people who needed 'care' of some sort. The views of the people most centrally concerned – people with intellectual disabilities and their families – were neither sought nor represented. This is evident in numerous studies of the 1970s, a period of unprecedented change in thinking about what was then called 'mental handicap' or 'mental retardation' (see, for example, the British 1971 White Paper, Better services for the mentally handicapped [Department of Health and Social Security 1971]; Morris 1969; K. Jones 1975).

Thomson's more recent study (1998) of the 'problem' of mental deficiency in the inter-war years in England considers the views of politicians, administrators and families, though not the views of the 'mental defectives'. These are, admittedly, difficult to incorporate when drawing on written sources alone, but the risk of not finding some means of representing their views is that the people subject to the policy and practice under discussion appear as passive subjects in the accounts of others. Subsequent scholarly books in the UK have included those by Wright and Digby (1996); Jackson (2001); and Dale and Melling (2006). In North America, examples include books by Trent (1994); Noll (1995); and Ferguson (1994); and in Scandinavia texts such as Tossebro, Gustavsson, and Dyrendahl (1996) which include accounts of the shift to community services in Nordic countries. Although there is growing recognition in more recent works of the 'patient perspective' (Dale and Melling 2006; Read and Walmsley 2006) nevertheless there is more that can be achieved. We argue that, in spite of the taxing nature of accessing these perspectives, it is both important and possible to do so.

In their recent edited volume, Noll and Trent acknowledge that the development of self-advocacy groups 'has opened new avenues for research on how persons with retardation view themselves and their society' (2004, 16). In the UK, such work has been ongoing since the 1970s, a process which has been supported - and made possible – by the development of self-advocacy. After earlier beginnings in Sweden and the US (Williams and Schoulz 1982), the first known 'speaking up' events in the UK were the participation workshops run by the Campaign for the Mentally Handicapped in the 1970s where people with intellectual disabilities spoke publicly about their past lives and experiences, especially in the long-stay hospitals (Hersov 1996).

The 1980s saw the formation of self-advocacy groups, such as People First organizations and committees in day and residential services, in Western Europe, Australia and North America (Williams and Schoulz 1982; Crawley 1988; Bylov 2006). Self-advocacy groups, in particular, have encouraged people with intellectual disabilities to speak up about their experiences not as 'cases' or 'victims' but as people in their own right. In the anthology Know me as I am (Atkinson and Williams 1990), the contributors came from across the UK, from a variety of backgrounds and expressed their personal and social identities in terms of their gender, class and race as well as (or instead of) their intellectual disability. The collected volumes of testimonies edited by Traustadottir and Johnson (2000) and Johnson and Traustadottir (2005) illustrate the potential of this approach on an international scale.

The growth of self-advocacy has meant that many people with intellectual disabilities have begun to speak for themselves. A manifestation of this is the wish on the part of many people to tell their life story and have it published. Another distinguishing feature of this branch of lived history is its use as a tool for advocacy and campaigning; a means to redress injustices, change practices and further the interests of people with intellectual disabilities, rather than to tell a complex history (Walmsley and Atkinson 2000; Johnson and Traustadottir 2005). Whilst this has meant a central place for the testimonies of people with intellectual disabilities it has at the same time left less space for the perspectives of others – families, professionals and other staff (Walmsley and Johnson 2003). Self-advocacy, then, has made an important contribution to promoting the voices of people with intellectual disabilities but arguably at the expense of other potential contributors, such as staff, families and less articulate people with intellectual disabilities.

This paper aims to review the potential of these different approaches which collectively we have termed lived history. We look first at biographical reconstruction (from documents) and oral history; we then look at how oral and documentary sources can be combined in order to compile institutional and life histories; and, finally, we consider how these approaches contribute to a more inclusive history.

The contribution of lived history

Biographical reconstruction

One of the challenges for 'lived history' is to create a space for 'voices' of experience from a period prior to the mid-twentieth century. Personal written sources are scant. However, work by Jackson (2000) has pointed to strategies for making good this challenge, using what Rolph (2000a) has called reconstructed biography. Although the 'voices' of people from earlier times may prove elusive, there are instances of local studies where sources such as family letters and other personal documents, together with biographical reconstructions from multiple sources, have informed and enriched more traditional documentary accounts (Read and Walmsley 2006). For example, Mark Jackson's account of Sandlebridge colony used documentary sources to reconstruct the lives of some residents and showed how 'Edwardian attempts to control the feeble minded were challenged by inmates and their families' (2000, 168).

An alternative approach was taken by Rolph (2000a) to reconstruct the biography of Alice Chapman, a woman born in 1897. Alice lived in institutions for most of her life until becoming a live-in domestic worker with a family when she was in her fifties. Rolph draws on oral testimony from the family where Alice worked until her death in 1969, a photograph album they compiled to celebrate Alice's life, and some handwritten notes by Alice, stored by the family. Documentary sources are used to contrast Alice's memories with documentary accounts of services. Rolph uses these 'biographical fragments' (Atkinson and Walmsley 1999, 203) to speculate how Alice, unlike many others, was able to cross the boundary from 'mental defective' to inclusion in the life of a family.

The extent to which personalized accounts can be used when working on the period before living memory is inevitably limited. However, the value of attempting to do so is that the optimism of provider accounts is tempered by accounts of lived experience. In her authoritative account of the Brighton Guardianship Society, Westwood (2007) describes it as an innovative experiment, yet it lacks the benefit of reference to individual experience. There is potential, therefore, for fleshing out the 'official' story. The interwar system of a market in 'defectives' (Walmsley 2000) meant that many people were transported across the country to be placed in Brighton for boarding in people's homes. Papers held by Local Authorities which placed individuals with the Brighton Guardianship Society (BGS) can give insight into the experience of 'users' of the service. The records are particularly rich because

Guardianship cases were inspected and reported to the Mental Health Committees individually. In April 1949 a Report to the Bedfordshire Mental Health sub-Committee included the following report from an Inspector:

On 12th April I visited Tom and Jimmy M – at S- Avenue, Patcham Brighton where they are now residing in the care of their guardian, Mrs. R. They made me feel sad. I found both rather despondent and dejected looking. Neither are in employment, Tom is probably not capable, but Jimmy is of higher grade, he is kept occupied at allotments by Mrs. R. I was not favourably impressed by Mrs. R, she struck me as a hard woman and lacking in sympathetic understanding for these lads... unnecessarily strict.

In this case prompt action was taken; by January 1950 they had been moved to a Mrs. C, extra money had been found to give them treats, and they were allowed access to a 'wireless'. Their story did not end there as reference is made later in the 1950s to the use of money they inherited from their father. Undoubtedly there is much more to be gleaned from local authority records, many of whom used services like the BGS, on the detail of practice on the ground. This in turn can develop our understanding of innovative practice, and the mechanisms required to ensure that quality was maintained, and abuse prevented, particularly for people at a distance from their homes.

While access to direct 'voices' is not possible for periods prior to living memory, there are possibilities for imaginative use of sources of personal experience in order to develop a more inclusive history of intellectual disability.

Oral history

Since 1990, oral history has made an increasingly significant contribution to the history of intellectual disability, especially in enabling the voices of people with intellectual disabilities to be heard as key actors and witnesses in that history (Rolph and Walmsley 2006). Given that the people who had lived through and experienced the policies, practices and regimes of the past had, by and large, remained silent while others recounted their history on their behalf (a point made by Ryan and Thomas 1980), a key driving force for some researchers since the 1990s was to find ways of reaching and recording those voices. Oral history techniques, using individual and group interviews, have been successfully developed, bringing new insights and perspectives on the history of intellectual disability. (See, for example, Atkinson and Williams 1990; Potts and Fido 1991; Walmsley 1995; Atkinson 1997; Atkinson, Jackson, and Walmsley 1997; Brigham et al. 2000; Rolph 2000b; Hreinsdottir et al. 2006; Roets, Adams, and Van Hove 2006).

The development of this history 'from below' was groundbreaking. The influence of eugenics, and the subsequent shift to policies of institutionalization, segregation and sterilization, has been extensively explored in the literature (G. Jones 1986; K. Jones 1972; Trent 2004). However, the experiences of those people who were 'subject to be dealt with' (Potts and Fido 1991) had mostly gone unrecorded. Oral history approaches have succeeded in making known some of those lived experiences and, by bringing past practices to life, have provided new insights into the 'hidden history' of intellectual disability.

Oral history not only allows the individual to speak but to do so within a social and historical context, and alongside the voices of others. However, in the drive to enable people with intellectual disabilities to 'have a voice' in history, the views and perspectives of those 'others' – families, staff and professionals – have had relatively little prominence in oral history accounts. In the UK, in particular, the powerful slogan 'Nothing About Us Without Us' has inhibited the development of a more rounded set of accounts (Walmsley and Johnson 2003). A growing awareness of this gap has resulted in moves to record the voices of other people who were part of the history of intellectual disability. Examples of the 'new wave' of oral history informants include Mental Welfare Officers (Rolph, Walmsley, and Atkinson 2002), families (Rolph et al. 2005) and intellectual disability nurses (Mitchell and Rafferty 2005). A more comprehensive 'stakeholder' approach was used by Welshman and Walmsley (2006) who included the voices of families, staff and service users in their history of community care for people with intellectual disabilities in the UK.

These accounts, informative as they are, represent the tip of the iceberg in terms of accessing insider accounts as a vehicle for a fuller understanding of the history of intellectual disability. In particular, the views and perspectives of three sets of key actors are, by and large, missing from the oral history of intellectual disability: families, front line staff and doctors. Missing family stories include the accounts by those parents who did not give up their children to institutional care; the voices of families who appear to have been abusive or neglectful are also absent (Rolph and Walmsley 2006).

Apart from institutional histories, front line and professional staff are also relatively little featured in the oral history of intellectual disability. This is an interesting omission, given that staff have been much criticised, both by researchers (Morris 1969; Oswin 1971; Rivera 1972) and self-advocates (Atkinson and Williams 1990; Traustadottir 2006). Similarly, there are relatively few oral accounts from doctors, in spite of the fact that they were key actors, responsible for running institutions, certifying 'defectives' and conducting research. Inclusive history requires a wider set of accounts than is currently in existence.

Institutional histories

While oral history has contributed to the history of intellectual disability in its own right, as outlined above, it has also provided an impetus for the development of institutional histories (and life histories – see below). Based partly on oral accounts, though supplemented by documentary sources, these are compilations – a piecing together, from various sources, of the histories of organizations (and, as we outline below, a piecing together of lives).

Institutional histories, using oral and documentary sources, have gathered impetus as long-stay hospitals have closed. Oral history has proved useful to researchers as a means of ensuring a more comprehensive historical record than would otherwise be possible. Informants have included nurses, doctors and other staff as well as former residents (Stevens 1997). Examples across the world include Dillon and Holburn (2003) in the US, Malacrida (2006) in Canada, Hreinsdottir et al. (2006) in Iceland and Manning (2008) in Australia. All have highlighted the capacity of oral testimonies to add details that cannot be found in more abstract accounts. New insights emerge via oral history, allowing people with intellectual disabilities to portray themselves not just as victims of an oppressive system but as its survivors and critics; people with the capacity to resist and fight back (Atkinson 1997).

Manning's oral history account of Kew Cottages (2008), an institution in Australia, brought together testimonies from residents, families, staff, volunteers, administrators, policy-makers, emergency service personnel, advocates and visitors. This wide range helped avoid an over-glowing and sanitised history of the institution while also avoiding the danger of portraying it in an entirely negative light (Walmsley 2005).

Malacrida combined oral testimonies of residents and ex-workers with archival records, in order to construct a history of the Michener Center in Canada; this acted as a 'counter-narrative to the official institutional memory' (2006, 400). The 'insider perspective' of oral history, following Frisch (1997), can be seen as contributing to 'more history' by filling in the details of the past and to 'anti-history' by providing counter narratives to dominant accounts. The danger for oral history is that, without reference to a wide range of documentary and oral sources, new myths can develop and the counter-narratives themselves can become the new orthodoxies: for example, a lack of recognition that for some people institutional care had positive dimensions (Rolph and Walmsley 2006).

Life histories

Life histories are also compilations – the bringing together of oral and documentary sources to piece together the lives of individuals with intellectual disabilities. Life history research 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). This approach flourished in the 1920s and 1930s, then declined but reemerged in the 1980s to enjoy considerable attention (Stanley 1992; Rolph 2000b; Gillman, Swain, and Heyman 1997). In an influential text, Plummer (1983) argued for the re-inclusion in sociological research of life history methods, whilst Maines (1993, 17) noted that 'narrative's moment' had arrived in social sciences' methods of inquiry. This reflected a more general move towards what Booth and Booth (1996) called the 'age of biography', including storytelling and narrative methods of research.

Life history methodology has now been adopted by some researchers in the intellectual disability field. However, as it is a recent development the literature is relatively sparse. The slow take-up of life histories in the intellectual disability field may reflect the perception that this approach required people who could articulate and reflect on their experiences (Plummer 1983; Thompson 1988). Researchers have subsequently shown how barriers to inclusion and participation can be overcome, and have demonstrated the contribution that life histories can make to the history of intellectual disability (see, for example, Stuart 2002; Rolph 2000b; Atkinson 2000).

Life history research in intellectual disability is by its very nature a collaborative and participatory process, involving researcher and life historian in co-researching the latter's personal history. This process helps change the social relations of the research and provides opportunities for participants to become reflective about their lives. One of the other advantages of a life history approach is that people with intellectual disabilities have an opportunity to place their experiences in the wider social historical context; to understand, for example, why they were 'put away'.

Some people who told their life stories from memory have been subsequently supported to use historical documents to give them this understanding. Mabel Cooper and Gloria Ferris, for example, told their life stories initially from memory, describing their personal experiences of segregation and exclusion from the 1940s to the 1970s. As they came across gaps in their accounts, they turned to documentary sources. Combining memory with documentary evidence helped them situate their lives (Cooper 1997; Ferris 2000) in the wider history of intellectual disability.

Accessing voices: methodological challenges

Of all groups of marginalized people, people with intellectual disabilities may present some of the greatest challenges for historians to represent. Not only are there likely to be difficulties in communication, there are also ethical issues, and barriers to access. One of the reasons that self-advocates have been most prominent in 'telling their stories' is that they have emerged from the shadows to a place in the public realm, accessible to historians and researchers in their own right, rather than through more powerful others, whether family members or service providers.

Malacrida documents her challenges in accessing people to interview about the Michener Centre in Canada, with resistance from 'powerful social actors' (2006, 397) who used quasi-legal means to bar her. In the UK, Walmsley graphically describes the challenge of explaining her research into caring to those she sought to interview. This involved working her way through multiple stakeholder layers to reach respondents with intellectual disabilities living in 'the community' (Walmsley 1993), noting as she did so that people with their own homes were in a position to negotiate directly with her, whilst those who lived with parents or in services were 'protected' from her questioning by others.

Once access is achieved, further issues arise. Memory is a delicate mechanism, perhaps even more so for people with intellectual disabilities. Walmsley (1998) and Rolph (1998) both comment on the importance of prior work to establish the sequential and service frameworks if the researcher is to understand the meaning of people's responses. 'Lynne' for example, spoke of going to school, but documentary sources, and information from others who knew her, showed that in fact she had attended an occupation centre. 'School' was a normalizing discursive device, possibly one others had used with Lynne in conversation (Walmsley 1998).

There are many people with intellectual disabilities who quite literally lack a voice that others can understand. In such instances, the type of reconstruction advocated by Rolph (2000a) for more distant biographies can also be used – using photographs, testimony from close informants and observation. Owen and Ledger (2006) provide two examples: the story of Yvette, whose life story was compiled through interviews with two people who had known her as residential social workers, and had followed her life subsequently as friends; and Samantha, whose biography was reconstructed through participant observation combined with interviews with her aunt and members of staff, together with nursing assessments (following the methodology advocated by Di Terlizzi 1994).

Ethical safeguards are important. The potential for historians to take people's lives through using apparently 'empowering' methods, but using them as debating fodder, has been highlighted by, among others, Plummer (2001). It is fear of being accused of such practice that, we would argue, has inhibited the full exploitation of lived history for historical purposes. This inhibition may have been bolstered by the views of some activists that history-writing properly belongs to those who have experienced oppression – 'Nothing About Us Without Us' (Aspis 2000). Almost a

decade since Aspis wrote this challenge, it is timely to review it, and, while mindful of the ethical pitfalls, ensure that accounts narrated by people with intellectual disabilities, staff and families find a place alongside those written by researchers.

Contrasting discourses: towards an inclusive history

Biographical and oral accounts contribute 'more history' through the personal and period details that only insider stories can give, but are also 'anti history' in telling a richer, more complicated and nuanced story of the past than can be found solely in documentary sources (Frisch 1997). This combination of oral and documentary sources is a step towards a more inclusive approach to intellectual disability history.

The authors have elsewhere (Walmsley and Atkinson 2000) combined oral and documentary sources to piece together a local history of intellectual disability in Bedfordshire. Using oral accounts, combined with documentary sources, we portrayed a situated picture of intellectual disability covering the post Second World War period and subsequent decades. The accounts, by a Mental Welfare Officer and a person with intellectual disabilities, both contrasted with and corroborated each other. Each was corroborated by other sources. When we revisited the accounts in preparing this paper, we juxtaposed a third contemporary oral history interview – this one involving a parent. When re-interrogating the three accounts, we found contrasting discourses. The MWO's view was that 'mental deficiency' was a fact of life, incontestable because it was in the legislation. Services were needed because 'families couldn't cope'. This gave no insight into the agonising that the parent described when institutional care proved to be the only option for her son; nor the sort of domestic dramas described by the person with intellectual disabilities from her memories of family life prior to her incarceration in the same institution.

The MWO's dispassionate view contrasted with the mother's fear when she 'put away' her own son, that she was condemning him to a kind of social death. This was complemented by the ex-resident's story of being 'put away' in hospital, a story which captured the key policy changes of the twentieth century. Margaret Day was certified and taken from her family home as an adolescent into the local institution, just as it was expanding in size in the 1930s; she was incarcerated there during the middle years of the century, enduring the work-and-punishment ethos in vogue then; and was resettled in the community as deinstitutionalization got under way. And yet, in her story, she was a survivor and a resistor:

I ran away from F2 [ward in Bromham Hospital]. We hid in a haystack and got frost bitten feet. I ran away with another girl and caught yellow jaundice... I planned it with another girl, we planned it together. She was fed up. She was doing the dayroom, cleaning and polishing. Then I was put on it, as well as scrubbing. We planned to get into Bedford, walk across the fields [Bromham was about 3 miles from Bedford Town Centre]. (Atkinson 1993, 91)

Combining oral and documentary sources in this way is one step towards an inclusive history of intellectual disability. Further steps involve the inclusion of a wide range of views from people with and without intellectual disabilities, who are also part of this history; including the 'voices' of people who cannot be heard directly but whose lives and experiences can still contribute to our wider understanding. An important stage in developing inclusive history is the creation of spaces in which people may speak,

and be heard, on equal terms – this is where history becomes shared between those who research it and those who have lived it.

Spaces for inclusive history

What would such a space look like? An example is furnished by the annual conferences hosted by the Social History of Learning Disability research group at the UK Open University since 1997. The conferences provide a national and increasingly international forum where researchers and those with experience of living with intellectual disability meet to share accounts. The conferences are chaired by people with an interest in history, both with and without intellectual disabilities; similarly, the presenters and the audience are historians (or people interested in history) with and without intellectual disabilities. Themes have included institutional life; language, labels and identities; relationships and sexuality; testimonies of resistance; changing nature of childhood; and public and private lives. Calls for papers attract a range of presenters, including people with a personal interest in and experience of intellectual disability history (people with intellectual disabilities and families), but also historians and practitioners (including psychiatrists, psychologists, social workers and nurses). Personal and anecdotal accounts are juxtaposed with research based papers on similar themes.

The conferences provide a forum where people can not only tell their stories, and be listened to, but can engage with the stories of others and the ideas developed by researchers. This is a potent mix, as ideas, policies and practice that researchers present provide the wider context in which people's lived experience can be placed and better understood. Researchers' accounts drawn from documentary historical sources can be challenged by members of the audience whose experiences suggest other ways of viewing historical evidence. The conference forum is a place where historical findings are shared, compared and challenged, and where new historical understandings emerge. This is an important part of the journey towards a truly inclusive history of intellectual disability. (Conference abstracts and recordings can be accessed on the website http://www.open.ac.uk/hsc/ldsite/).

Conclusion

We have argued in this paper that oral history and biographical approaches – lived history – have much to contribute to a deeper understanding of the history of intellectual disability. However, it is important to move on from a simple 'Nothing About Us Without Us' position, at the same time as challenging the assumption that only researchers have a contribution to make. One way of doing this, as we have shown here, is to draw on a range of sources, including oral and documentary accounts from different perspectives, in order to develop a more complex history of intellectual disability. To borrow ideas developed by Frisch (1997, 36), we contend that the lived history approach can be both 'more history', adding to the stock of knowledge about historical events, and 'anti-history', challenging conventional perceptions.

We have sought to show the unique contribution that oral and biographical accounts can make to the history of intellectual disability – and how oral testimonies enrich and are themselves enriched by accounts drawn from documentary sources. This inclusive approach has the capacity to uncover a range of perspectives, bring

past practices to life and remind us of the human dimension of history. What emerges is not a grand narrative of intellectual disability history but an inclusive history which makes space for a diverse compilation of individual and shared stories, combining historians' accounts with insider perspectives.

Notes

- 1. Bedfordshire Record Office, Mental Health sub-Committee papers, He Sub P 6/2, April
- 2. Bedfordshire Record Office, Mental Health sub-Committee papers, He Sub P 6/2, January 1950.

References

- Abbot, P., and R. Sapsford. 1987. Community care for mentally handicapped children. London: Croom Helm.
- Armstrong, F. 2002. The historical development of special education: Humanitarian rationality or 'wild profusion of entangled events'? History of Education 31, no. 5: 437-56.
- Aspis, S. 2000. Researching our history: Who is in charge? In Crossing boundaries: Change and continuity in the history of learning disability, ed. L. Brigham, D. Atkinson, M. Jackson, S. Rolph and J. Walmsley, 1–5. Kidderminster, UK: Bild Publications.
- Atkinson, D. 1993. Past times. Milton Keynes, UK: Private publication.
- Atkinson, D. 1997. An autobiographical approach to learning disability research. Aldershot, UK: Avebury.
- Atkinson, D. 2000. Bringing lives into focus: The disabled person's perspective. In Transition and change in the lives of people with intellectual disabilities, ed. D. May, 157-75. London: Jessica Kingsley.
- Atkinson, D., M. Jackson, and J. Walmsley, eds. 1997. Forgotten lives: Exploring the history of learning disability. Kidderminster, UK: Bild Publications.
- Atkinson, D., and J. Walmsley. 1999. Using autobiographical approaches with people with learning difficulties. Disability and Society 14, no. 2: 203-16.
- Atkinson, D., and F. Williams. 1990. 'Know Me As I Am'. An anthology of prose poetry and art by people with learning difficulties. London: Hodder and Stoughton.
- Ayer, S., and A. Alaszewski. 1984. Community care for the mentally handicapped: Services for mothers and their mentally handicapped children. London: Croom Helm.
- Bartlett, P., and D. Wright. 1999. The history of care in the community 1750-2000. London: Athlone.
- Bjarnason, D.S. 1996. Iceland: From institutions to normalisation? In *Intellectual disabilities in* the Nordic welfare states, ed. J. Tossebro, A. Gustavsson and G. Dyrendahl, 90–105. Norway: Hoyskole Forlaget.
- Booth, T., and W. Booth. 1996. Sounds of silence: Narrative research with inarticulate subjects. Disability and Society 11, no. 1: 55-69.
- Borsay, A. 2005. Disability and social policy in Britain since 1750: A history of exclusion. Basingstoke, UK: Palgrave Macmillan.
- Brigham, L., D. Atkinson, M. Jackson, S. Rolph, and J. Walmsley, eds. 2000. Crossing boundaries: Change and continuity in the history of learning disability. Kidderminster, UK: Bild Publications.
- Bylov, F. 2006. Patterns of culture and power after the 'Great Release': The history of movements of subculture and empowerment amongst Danish people with learning difficulties. British Journal of Learning Disabilities 34, no. 3: 139-45.
- Cooper, M. 1997. My life story. In Forgotten lives: Exploring the history of learning disability, ed. D. Atkinson, M. Jackson and J. Walmsley, 21–34. Kidderminster, UK: Bild Publications.
- Crawley, B. 1988. The growing voice: A survey of self-advocacy groups in adult training centres and hospitals in Great Britain. London: Campaign for People with Mental Handicaps.
- Dale, P., and J. Melling, eds. 2006. Mental illness and intellectual disability since 1850: Finding a place for mental disorder in the United Kingdom. London: Routledge.
- Department of Health and Social Security, 1971. Better services for the mentally handicapped. Cmnd. 4683. London: HMSO.

- Di Terlizzi, M. 1994. Life history: The impact of changing service provision on an individual with learning disabilities. Disability and Society 9, no. 4: 501–17.
- Dillon, M., and S. Holburn. 2003. Preserving oral histories: Example of the institutional experience. Mental Retardation 41, no. 2: 130-2.
- Ferguson, P.M. 1994. Abandoned to their fate: Social policy and practice toward severely retarded people in America, 1820–1920. Philadelphia: Temple University Press.
- Ferris, G. 2000. Muriel and me. In Good times, bad times: Women with learning difficulties telling their stories, ed. D. Atkinson, M. McCarthy, J. Walmsley, M. Cooper, S. Rolph, S. Aspis, P. Barette, M. Coventry and G. Ferris. Kidderminster, UK: Bild Publications.
- Foucault, M. 1967. Madness and civilisation: A history of insanity in the age of reason. London: Tavistock.
- Frisch, M. 1997. Oral history and hard times: A review essay. In The oral history reader, ed. R. Perks and A. Thomson. London: Routledge.
- Gillman, M., J. Swain, and B. Heyman. 1997. Life history or 'case' history?: The objectification of people with learning difficulties through the tyranny of professional discourses. Disability and Society 12, no. 5: 675-93.
- Goffman, E. 1968. Asylums. Harmondsworth, UK: Penguin.
- Hanssen, J-I., J.T. Sandvin, and M. Soder. 1996. The Nordic welfare states in transition. In Intellectual disabilities in the Nordic welfare states, ed. J. Tossebro, A.Gustavsson and G. Dyrendahl. Kristiansand, Norway: Hoyskole Forlaget.
- Hersov, J. 1996. The rise of self-advocacy in Great Britain. In New voices: Self-advocacy by people with disabilities, ed. G. Dybwad and H. Bersani Jr, 130-9. Cambridge, MA: Brookline Books.
- Hreinsdottir, E.E., G. Stefansdottir, A. Lewthwaite, S. Ledger, and L. Shufflebotham. 2006. Is my story so different from yours? Comparing life stories, experiences of institutionalisation and self advocacy in England and Iceland. British Journal of Learning Disabilities 34, no. 3:
- Hurt, J. 1989. Outside the mainstream. London: Batsford.
- Jackson, M. 1996. Institutional provision for the feeble-minded in Edwardian England. In From idiocy to mental deficiency, ed. D. Wright and A. Digby, 161–83. London: Routledge.
- Jackson, M. 2000. The borderland of imbecility: Medicine, society and the fabrication of the feeble mind in late Victorian and Edwardian England. Manchester: Manchester University
- Jackson, M. 2004. 'A menace to the good of society'. Class, fertility and the feeble-minded in Edwardian England. In Sex and seclusion, class and custody: Perspectives on gender and class in the history of British and Irish psychiatry, 271–94. Amsterdam: Rodopi.
- Johnson, K., and R. Traustadottir, eds. 2005. Deinstitutionalisation and people with intellectual disabilities: In and out of institutions. London: Jessica Kingsley.
- Jones, G. 1986. Social hygiene in 20th century Britain. London: Croom Helm.
- Jones, K. 1972. A history of the mental health services. London: Routledge and Kegan Paul.
- Jones, K. 1975. Opening the door. London: Routledge and Kegan Paul.
- Maines, D.R. 1993. Narrative's moment and sociology's phenomena: Toward a narrative sociology. The Sociological Quarterly 34, no. 1: 18–38.
- Malacrida, C. 2006. Contested memories: Efforts of the powerful to silence former inmates' histories of life in an institution for 'mental defectives'. Disability and Society 21, no. 5:
- Malin, N., ed. 1995. Services for people with learning disabilities. London: Routledge.
- Manning, C. 2008. Bye bye Charlie: Stories from the vanishing world of Kew Cottages. Sydney: UNSW Press.
- Melling, J., and B. Forsythe, eds. 1999. Insanity, institutions and society: New approaches to the social history of insanity. London: Routledge.
- Merriman, A. 2007. Tales of Normansfield: The Langdon Down legacy. Teddington, UK: Down's Syndrome Association.
- Micale, M., and R. Porter, eds. 1994. Discovering the history of psychiatry. Oxford: Oxford University Press.
- Mitchell, D., and A.-M. Rafferty. 2005. 'I don't think they ever really wanted to know anything about us': Oral history interviews with learning disability nurses. Oral History 33, no. 1: 77-87.

- Morris, P. 1969. Put away. London: Routledge and Kegan Paul.
- Noll, N. 1995. Feeble minded in our midst: Institutions for the mentally retarded in the South 1900–1940. Chapel Hill: University of North Carolina Press.
- Noll, S., and J.W. Trent, Jr., eds. 2004. Mental retardation in America. New York: New York University Press.
- Oswin, M. 1971. The empty hours. Harmondsworth, UK: Penguin.
- Owen, K., and S. Ledger. 2006. People with learning disabilities: Perspectives and Experiences. In Community care in perspective: Care, control and citizenship, ed. J. Welshman and J. Walmsley, 159–72. Houndsmill, UK: Palgrave Macmillan.
- Plummer, K. 1983. Documents of life. London: Allen and Unwin.
- Plummer, K. 2001. Documents of life 2. London: Sage.
- Potts, M., and R. Fido. 1991. 'A fit person to be removed': Personal accounts of life in a mental deficiency institution. Plymouth, UK: Northcote House.
- Read, J., and J. Walmsley. 2006. Historical perspectives on special education 1890–1970. Disability and Society 21, no. 5: 455-69.
- Rivera, G. 1972. Willowbrook: A report on how it is and why it doesn't have to be that way. New York: Random House.
- Roets, G., M. Adams, and G. Van Hove. 2006. Challenging the monologue about silent sterilisation: Implications for self advocacy. British Journal of Learning Disabilities 34, no. 3:
- Rolph, S. 1998. Ethical dilemmas: Oral history work with people with learning difficulties. *Oral* History 26, no. 2: 65-72.
- Rolph, S. 2000a. Surprise journeys and border crossings. In Crossing boundaries: Change and continuity in the history of learning disability, ed. L. Brigham, D. Atkinson, M. Jackson, S. Rolph and J. Walmsley, 69–86. Kidderminster, UK: Bild Publications.
- Rolph, S. 2000b. The history of community care for people with learning difficulties in Norfolk 1930-1980: The role of two hostels. Unpublished PhD thesis, Open University, Milton Kevnes.
- Rolph, S., and J. Walmsley. 2006. Oral history and new orthodoxies: Narrative accounts in the history of intellectual disability. Oral History 34, no. 1: 81–91.
- Rolph, S., D. Atkinson, M. Nind, and J. Welshman, eds. 2005. Witnesses to change: Families, learning difficulties and history. Kidderminster, UK: Bild Publications.
- Rolph, S., J. Walmsley, and D. Atkinson. 2002. 'A man's job?' Gender issues and the role of mental welfare officers, 1948-1970. Oral History 30, no. 1: 28-41.
- Ryan J., with F. Thomas. 1980. The politics of mental handicap. Harmondsworth, UK: Penguin. Scull, A. 1979. Museums of madness: The social organisation of insanity in nineteenth century England. London: Allen Lane.
- Stanley, L. 1992. The auto/biographical I. Manchester: Manchester University Press.
- Stevens, A. 1997. Recording the history of an institution: The Royal Eastern Counties Institution at Colchester. In Forgotten lives: Exploring the history of learning disability, ed. D. Atkinson, M. Jackson and J. Walmsley, 47-64. Kidderminster, UK: Bild Publications.
- Stuart, M. 2002. Not quite sisters and daughters: Women with learning difficulties living in convent homes. Kidderminster, UK: Bild Publications.
- Thomas, W.I., and F. Znaniecki. 1918-20. The Polish peasant in Europe and America. 5 volumes. Chicago: University of Chicago Press.
- Thomson, M. 1998. The problem of mental deficiency: Eugenics, democracy and social policy in Britain c. 1870–1959. Oxford: Clarendon Press.
- Thompson, P. 1988. The voice of the past: Oral history. 2nd ed. Oxford: Oxford University Press.
- Tossebro, J., with M. Aalto and P. Brusen. 1996. Changing ideologies and patterns of service. In Intellectual disabilities in the Nordic welfare states, ed. J. Tossebro, A. Gustavsson and G. Dyrendahl, 45-64. Kristiansand, Norway: Hoyskole Forlaget.
- Tossebro, J., A. Gustavsson, and G. Dyrendahl, eds. 1996. Intellectual disabilities in the Nordic welfare states. Norway: Hoyskole Forlaget.
- Traustadottir, R. 2006. Learning about self advocacy from life history: A case study from the United States. British Journal of Learning Disabilities 34, no. 3: 175–80.
- Traustadottir, R., and K. Johnson, eds. 2000. Women with intellectual disabilities: Finding a place in the world. London: Jessica Kingsley.

- Trent, J.W., Jr. 1994. Inventing the feeble mind: A history of mental retardation in the United States. Berkeley: University of California Press.
- Walmsley, J. 1993. Explaining. In *Reflecting on research practice*, ed. P. Shakespeare, D. Atkinson and S. French, 36–46. Buckingham, UK: Open University Press.
- Walmsley, J. 1995. *Gender, caring and learning disability*. Unpublished PhD thesis, Open University, Milton Keynes.
- Walmsley, J. 1998. Caring in families. In *Understanding health and social care: A reader*, ed. M. Allott and M. Robb, 40–7. London: Sage.
- Walmsley, J. 2000. Straddling boundaries: The changing roles of voluntary organisations, 1913–1959. In *Crossing boundaries: Change and continuity in the history of learning disability*, ed. L. Brigham D. Atkinson, M. Jackson, S. Rolph and J. Walmsley, 103–22. Kidderminster, UK: Bild Publications.
- Walmsley, J. 2005. Institutionalization: A historical perspective. In *Deinstitutionalization and people with intellectual disabilities*, ed. K. Johnson and R. Traustadottir, 50–65. London: Jessica Kingsley.
- Walmsley, J., and D. Atkinson. 2000. Oral history and the history of intellectual disability. In *Oral history, health and welfare*, ed. J. Bornat, R. Perks, P. Thompson and J. Walmsley, 180–202. London: Routledge.
- Walmsley, J., and K. Johnson. 2003. *Inclusive research with people with learning Disabilities:* Past, Present and Futures. London: Jessica Kingsley.
- Welshman, J., and J. Walmsley, eds. 2006. *Community care in perspective: Care, control and citizenship.* Houndsmill, UK: Palgrave Macmillan.
- Westwood, L. 2007. Care in the community of the mentally disordered: The case of the Guardianship Society. *Social History of Medicine* 20, no. 1: 57–72.
- Williams, F., and J. Walmsley. 1990. Workbook 3: Transitions and change. Learning disability: Changing perspectives. Milton Keynes, UK: The Open University.
- Williams, P., and B. Schoultz. 1982. We can speak for ourselves: Self-advocacy by mentally handicapped people. London: Souvenir.
- Wright, D. 2001. Mental deficiency in Victorian England: The Earlswood Asylum, 1847–1901. Oxford: Oxford University Press.
- Wright, D., and A. Digby, eds. 1996. From idiocy to mental deficiency. London: Routledge.