

Institution: The Open University

Unit of Assessment: C22 Social Work and Social Policy

Title of case study: Learning disability: making a difference to policy, practice and experience

1. Summary of the impact

The research undertaken by the Social History of Learning Disability (SHLD) group at the Open University (OU) has not only shaped the policy and practice of service providers but has transformed the learning skills of the disabled people taking part, some of whom have gone on to develop international profiles as advocates and campaigners. Its work, looking at the history, policy and practice of learning disability, has been pioneering in its use of an inclusive approach, as well as innovative life story work for the benefit of person-centred care. As a result it has this year been shortlisted in the Department of Health’s 2013 Good Practice Project, which was initiated in the wake of the Winterbourne View patient abuse scandal.

2. Underpinning research

Since its foundation in 1994, the SHLD group has been at the forefront of uncovering the history of learning disability (Brigham et al, 2000). Its work began in the context of mass de-institutionalisation, recording people’s experiences as they were moved into the community, revealing a previously undocumented oral history of institutional and community care. The work was pioneering in its use of inclusive methodologies to capture data and narratives from people with complex needs, many of whom had been on the margins of society for most, if not all, of their lives (Atkinson and Walmsley, 2010). This participatory approach developed the capacity of learning disabled service users to co-produce research into the history, policy and practice of learning disability (Walmsley and Johnson 2003).

There are a number of key projects, related to this work, which underpin the impact outlined in Section 4. Atkinson (OU Lecturer/SL/Professor from 1984–2010, now Emeritus Professor) conducted two projects in the 1990s (‘Past times’ and ‘Life histories’), working with people with learning disabilities in reconstructing their lives through memories and documents. As well as producing new findings (including how and why individuals were institutionalised) these projects enabled participants to reclaim their individual and shared pasts. Alongside this work, Walmsley (OU Lecturer/SL 1993–2004) was undertaking oral history research on gender, caring and learning disability, and the history of community care, also using inclusive approaches. Through the process of co-producing stories, Atkinson and Walmsley, along with learning disabled researchers (see Mabel Cooper, Section 4), developed methods to reveal and record memories of institutional and community life (Atkinson et al, 1997).

These developments laid the foundations for subsequent OU projects that adopted participatory approaches: for example, the oral histories of local Mencap groups, by Walmsley and Rolph (2000–04); the history of day centres in Croydon, by Atkinson (2006–07); and research into supported living and quality of life for people with learning disabilities, by Atkinson and Tilley (2009–11). They also fed into the SHLD’s annual inclusive conferences (Marshall and Tilley, 2013). More recently Sue Ledger, supervised by Atkinson, Walmsley and Tilley, completed her PhD research ‘Staying local: support for people with learning difficulties from Inner London 1971-2007’. This adopted an inclusive life story approach to explore why some people manage to remain local when so many of their peers are sent to out-of-area placements (Ledger and Shufflebotham,

2006). The research revealed the importance of responsive short breaks, staff who worked across service boundaries and who advocated for local support, and of long-standing relationships between individuals, families and service users. It also revealed that key areas of personal histories, such as family and friendship networks and details of where people had lived previously, were not recorded in people's case notes and were thus excluded from Person Centred Planning. The work was also innovative in its use of mobile interviews, digital photography and the development of life journey maps. Its impact upon Yarrow Housing is detailed in Section 4.

The impact and scale of the SHLD's contribution to the history of learning disability, and to inclusive research, has been recognised in a grant from the Arts and Humanities Research Council for the co-production of an accessible, distributed and living archive of learning disability. Developing a co-produced, digital, and living archive of learning disability history: An exploration of ethics, ownership and new connectivities. Dr Elizabeth Tilley: Open University, AH/K007459/1.

3. References to the research

Atkinson, D., Jackson, M. and Walmsley, J. (1997) *Forgotten Lives. Exploring the History of Learning Disability*, Kidderminster, BILD Publications.

Atkinson D. and Walmsley J. (2010) 'History from the inside: towards an inclusive history of learning disability', *Scandinavian Journal of Disability Research*, 12, 4, pp. 273–286.

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.

Ledger, S. and Shufflebotham, L. (2006) 'Assessing the quality of service provision for people with challenging needs placed out of borough', *Tizard Review*, 11, 4, pp. 19–27.

Tilley, L. and Marshall, K. (2013) 'Life stories, intellectual disability, cultural heritage and ethics: dilemmas in researching and (re)presenting accounts from the Scottish Highlands', *Ethics & Social Welfare*, 7, 4, (in press).

Walmsley, J. and Johnson, K. (2003) *Inclusive Research with People with Learning Disabilities: Past, Present and Futures*, London, Jessica Kingsley Publishers.

4. Details of the impact

The inclusive research approach in learning disability, pioneered and developed at the OU, is part of the wider advocacy and resistance movement in learning disability. By working with people with learning disabilities as 'expert witnesses' and co-producers of knowledge, we have enabled the development of new skills that are transferable beyond the research context for building independence and self-esteem. In this way, our research has not only empowered people with learning disabilities to own and control their stories, but it has enabled them to make changes in their lives. For example, Central England People First, a self-advocacy group, describe how a member was given the confidence to engage with the NHS National Institute for Health and Care Excellence's Public Involvement Programme. In addition they commented: 'Being part of SHLD helped us meet and develop partnerships with other groups, and understand how to write funding bids, like the bid to the Heritage Lottery Fund (Your Heritage Programme, £50,000, Central England People First Ltd) which we won with help from SHLD to write our own history.'

Other people with learning disabilities, who are also members of the SHLD group, have been inspired to undertake projects to uncover previously unknown histories, such as that conducted by People First Carlisle Research Group (part of Cumbria People First), who were awarded a Heritage Lottery Fund grant (£50,000) to undertake a 'Keeping Wartime Memories Alive' heritage project, with the aim of gathering testimonies about the experiences of learning disabled people during the Second World War.

People with learning disabilities participating in OU projects have gone on to develop national and international profiles as advocates and campaigners. For example, Mabel Cooper, one of the

participants in Atkinson's 'Life histories' project, became a regular conference contributor and achieved an Honorary Degree from The Open University in 2010 for her contribution to giving people with learning disabilities a voice. Mabel sadly died earlier this year, but her advocate Jane Abraham has written to us stating that:

'Because of her involvement in the OU research, Mabel Cooper grew in self-confidence and in the ability to pass the skills she had gained onto others. Over this period she regularly talked to trainee Social Workers about her life story ... Mabel also led the training for a group of self-advocates to help them tell their life stories and went with them into two primary schools to talk to children. Her story, and the way she told it, inspired others to tell their stories and to write a play. Mabel also joined the Board of Trustees for Walsingham, a housing and support provider working across the UK'.

The SHLD's research has had other notable impacts on practice. For example, Ledger's research empowered people with learning disabilities to shape how their care is delivered. Tenants of learning disability housing provider Yarrow took pictures of their local area and places key to their personal history. Using multi-media, photographs were superimposed onto local maps to create life journey maps. These helped the tenants to share with staff life story information that was previously missing. Having demonstrated the importance of life story maps to person-centred care, the findings of the work were incorporated into Yarrow's Business Plan and practice. Lindy Shufflebotham, Deputy Chief Executive at Yarrow, wrote to us saying: 'Sue's research supported Yarrow's ongoing commitment to the provision of very flexible responses and respite/short break support, developing models with the capacity to respond very quickly in crisis-periods, when Sue's research highlighted people are especially vulnerable to a move out of area. Influenced by the research, the importance of life story work and documenting key relationships is covered as part of our staff induction programme.'

The SHLD's research has also influenced policy. In November 2012, following the serious case review into the abuse of patients with learning disabilities at the Winterbourne View hospital, we submitted three examples of good practice to the Department of Health's consultation '*What does good look like?*' These were:

- The SHLD's annual Inclusive Conferences, where people with learning disabilities come together with academics, practitioners and policy-makers to network, disseminate research findings and share personal experiences;
- Life journey maps, based on Ledger's research;
- Mabel Cooper's schools project, in which she visited primary schools to tell her life story in order to inform attitudes about learning disability among young people.

These have since been selected for inclusion in the Department of Health's 'Good Practice Project', providing a powerful endorsement of the OU's work and its ability to influence policy and practice. The DH's *Good Practice Report* will be circulated to commissioners and providers nationally as part of the Joint Improvement Programme.

5. Sources to corroborate the impact

Central England People First History Project:

<http://www.peoplefirst.org.uk/default.aspx?page=26488>

Cumbria People First 'Keeping Wartime Memories Alive' project:

<http://www.peoplefirstcumbria.org.uk/groups/heritage-project/>

Days gone by: the history of day centres in Croydon:

<http://www2.open.ac.uk/hsc/research/research-projects/history-day-centres/index.php>

DoH Good Practice consultation: 'What does good look like':

<http://www.dh.gov.uk/health/2012/11/letter-learning-disabilities/>

Submitted case studies: www.dh.gov.uk/health/2012/06/interimwinterbourne/

Reclaiming the Past and a Hidden Heritage: histories of Mencap and community care in East

Anglia: <http://www7.open.ac.uk/shsw/reclaimingthepast/index2.htm>

<http://www7.open.ac.uk/shsw/reclaimingthepast/hiddenheritage/index2.htm>

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The Social History of Learning Disability Research Group: [http://www.open.ac.uk/hsc/ldsite](http://www.open.ac.uk/hsc/ldssite)

Yarrow Housing: <http://www.yarrowhousing.org.uk>

Sources to verify the Impact:

Advocate and Service User Involvement Worker, Voiceability Lambeth

Support Worker and Project Manager, Central England People First

Deputy Chief Executive, Yarrow Housing

Training and Development Advocate, Cumbria People First

Learning Disability Policy Lead, the Department of Health