The public and the relational: The collaborative practices of the Inclusive Archive of Learning Disability History

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Q: Why is it important that people with learning disabilities tell their stories?

A: I think it's to let other people know what's happened to them and make it aware of people so that it doesn't happen. People doesn't go around hurting other people, it's not fair. So I think if they write their story it makes people aware, because years ago it wasn't aware of people with learning disability because they were put away. So now it's time for people with learning disability to write their story and to let other people know. (Cooper 2008 online).

Mabel Cooper, former resident St Lawrence’s Hospital, self-advocate, broadcaster and founder member of the Open University’s Social History of Learning Disability Group.¹

This book’s title – Communities, archives and new collaborative practices – raises the question of who or what is collaborating. The reading of the title most immediately available might be that the collaboration is between communities and those that work in archives. Yet we want to focus on another type of collaboration here, one which is equally crucial in developing new collaborative practices for archives. In a recent action research project to develop an Inclusive Archive of Learning Disability History² it became clear that in seeking to produce an archive we needed to conceive of collaboration not only in terms of people but also in terms of a collaboration between different political theories. In developing the Inclusive Archive we recognised we needed to seek a collaborative relationship between the political ideas derived from public political logics – public service, public sphere, ‘on behalf of the public’ and for posterity – and those that derive from relational and personal-centred politics. While there was constant debate in the team, with some of us favouring one set of political logic and some the other, we realized that for an archive to be an archive, and for it to be an inclusive one, we needed to develop an approach to archival practice which held both the public and the relational political traditions in dialogue. Both political traditions have a history of being very effectively expressed in the learning disability self-advocacy movement as speaking up and being heard and of arguing for services to start with the individual by being more ‘person-centered’ (Brownlee et al. 2017). The task of our archive was to explore fruitful combinations and collaborations between the two political traditions.

Archival politics and the politics of the social history of learning disability

The Inclusive Archive project emerged from an inclusive research group based at the Open University, set up almost 25 years ago, called the Social History of Learning Disability Group (Social History of Learning Disability online). The Social History of Learning Disability Group is made up of researchers with and without learning disabilities and over the years the group has produced many co-authored and co-edited books, alongside running an annual conference. A central issue for the group from the first was the viewpoint of ‘learning disability’ offered in the majority of archives.

¹ A self-advocate is someone who is developing skills in speaking for themselves and making decisions about their own lives. Self-advocacy groups – such as People First – have been crucial in supporting people with learning disabilities to do this.

² The Inclusive Archive of Learning Disability History Project ran from 2014-2017, funded by the ARHC. Its key aim was to increase people with learning disabilities access to and participation in heritage, through the co-production of an online archive of learning disability history, and through the co-development of new systems, processes and guidance in public archives.
Archives, as we know, are never neutral; they exist for specific purposes. What becomes an ‘archive’ is always produced from specific knowledge systems (Swartz and Cook 2002; Gilliland and McKemmish 2014; Cook 2013). The archives of what we now call learning disability, but was then termed ‘mental deficiency’ or being ‘feeble-minded’, often derive from the institutions of late 19th and early 20th century and were bound up with eugenic science (Thomson 1996). The main way in which people with learning disabilities have been represented in archives is as patients: as people to be regulated, picked up from the streets, separated from their families and given medical treatment.

A crucial Social History of Learning Disability Group collaboration – and one that was fundamental to the inception of the Inclusive Archive project – was between Dorothy Atkinson, an academic at the Open University who taught health and social care, and Mabel Cooper who lived in learning disability institutions, including St Lawrence’s long-stay hospital in Caterham, from a young child until she was in her 30s (Atkinson 2001). Mabel was part of the self-advocacy activist movement where people with learning disabilities speak for themselves about their needs and hopes, a crucial aim when so many people had been deprived of any agency over their own lives. Mabel and Dorothy together wrote Mabel’s life story. One aspect of their work together included going to the archives and reading the only formally archived records of Mabel’s life. Mabel reflected on this experience (Cooper 2001) in the following way:

These are some of the things the records said about me when I first went to St Lawrence’s:

- I was an ‘imbecile’. This really hurts.
- I was ‘educationally very backward’.
- I was ‘ignorant of the four rules of numbers’.
- I was ‘dull and slow in response’ and that I did not seem to have any general knowledge at all.
- I was ‘not able to learn to tell the time’.

You see, for me, it did upset me for them to say I wasn’t teachable. I think if someone goes around and says something like that are you going to learn? You are not! And then they turn round and say ‘Oh, you’re not teachable’. And for them to say, you know, that I need to be looked after, trained for life. I don’t know who made that decision, or who makes those assumptions. Who were they to make these assumptions?

The Inclusive Archive project – like the Social History of Learning Disability Group before it – came about through a strong desire to challenge the archives to ensure that the what is left of people’s histories is not only these objectifying records produced through the state and medical management of people’s lives but their own stories in, as with Mabel’s, their own words. This was never seen by the Social History of Learning Disability Group only as an academic endeavour but – as with many alternative history movements – as one which was actively political (Atkinson, McCarthy, Walmsley et al (2000); Mitchell, Traustadóttir, Chapman, Townsend, Ingham and Ledger (2006)).

**What happens to the politics of archives when the archive becomes person-centred?**

Many of the people who influenced, or were collaborators in designing the Inclusive Archive, are self-advocates. There is a strong tradition of telling stories in self-advocacy; it often called ‘speaking

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3 Over the past twenty-five years as the large long-stay institutions have closed, considerable efforts have been made to record, reveal and share the histories of those who lived, and worked, in these places. The wide-ranging scope of the work in this area spans both the UK (Potts and Fido 1991; Ingham 2003; Keilty and Woodley 2013) and internationally (Manning 2008; Malacrida 2015; Johnson and Traustadottir 2005).
From the work of the Social History of Learning Disability Group and self-advocacy inspired organisations such as our project partners Carlisle People First Research Team Ltd, it is clear that people with learning disabilities wish to add their perspectives to archives as a way of challenging public perceptions and creating a world where people with learning disabilities can live lives they choose. The desire to speak out in public works very much with the grain of traditional archives and museums as public institutions which seek to inform public debate with collections kept for posterity and future generations. Yet there is another well-developed tradition in self-advocacy known as being person-centred. Person-centred approaches – in contrast to older professional interactions with people with learning disabilities – aim to start with that person and the world from their perspective and to avoid imposing external values about what is important or desirable. This tradition indicates an approach to archives that also makes no assumptions about what taking part might include. Both political traditions – both very much consistent with self-advocacy activism – needed to be deployed in our Inclusive Archive design.

When we were briefing for the design of the archive we developed this diagram to illustrate the ‘different ways of thinking about archives’ and to ensure that our design would enable people to choose their own pathway. Where the left-hand side was about engaging archival politics on its own terms, adding new stories into a public sphere, the right hand side was driven by the person-centred and the relational.

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4 From its very first event in the 1990s, people with learning disabilities have shared their stories and perspectives at the Social History of Learning Disability Research Group’s conferences and seminars (http://www.open.ac.uk/health-and-social-care/research/shld/). Archives have often been seen as an important site of activism in other contexts too (Flinn 2010; Flinn, Stevens and Shepherd 2009; Bastian 2002; Buchanan and Bastian 2015; Costa et al. 2012).

5 Valuing People guidelines describe person-centred practice in the following terms: ‘When we use the term “person centred” we mean activities which are based upon what is important to a person from their own perspective and which contribute to their full inclusion in society’ (DoH 2009 p. 2 emphasis original).
The idea of the significance of ‘relationships’ has become a crucial way of conceiving contemporary life, whether in art practice as ‘relational aesthetics’, in psychology and medical contexts as ‘relational ethics’ or, as we will develop here, as ‘relational politics’. Taking a cue from a feminist emphasis that the personal and everyday life is political and politics does not operate in a separate domain, a number of theorists have drawn out the implications of relational political theorising. As Kenneth J. Gergen has put it, ‘Politics in the relational mode may be subtle, fluid and unceasing – not the work of specific groups on specific sites identified as “political”, but the work of us all, in all relationships’ (2001, p. 180). This chimes in tone with a series of significant work in a learning disability context looking at the everyday production of disability and ability in social care practices (Antaki and Kent 2012; Rapley 2009; Williams 2011). This work – often drawing on very close readings of conversation – shows how people’s lives can be closed down or radically enabled through seemingly very small everyday actions. If the negative denial of people’s ability and choices are produced and reproduced through many small everyday interactions, a relational form of learning disability politics is one where the means are the ends and making space for dialogue with people on their own terms for its own sake is a way of creating positive change.
As suggested in the illustration, in designing the digital archive, we sought to make the archive flexible and varied in the kinds of contributions produced:

**Share with everyone / Share with people you know**
The first shift here was to enable people to have choice over who they shared their contribution with. They might share it publicly, only with people they knew or not share at all. To design this aspect of the digital archive we drew on established social media conventions that enable selective sharing of media; with identified ‘friends’ or ‘groups’ or across public networks. Many we worked with were familiar with such conventions through Facebook and such choices are made more explicit and simple to understand in the accessible learning disability social media sites that we drew from as we developed the inclusive archive, Multi Me (www.multime.com) and the RIX Wiki (www.rixresearchandmedia.org/rix/home-media).

**What is important to others / What is important to you**
One concern many people articulated was that their life could not possibly be interesting to others. We needed a way to breakdown that barrier and so we wanted to emphasise that people could share whatever they wanted and they were able to say what was ‘important’ (or ‘significant’ in heritage terms).

**Share forever / Share for a while**
The idea of posterity was an issue for many people. For some it was important that experiences, especially of institutionalisation and long stay hospitals, must not be forgotten. But for others ‘forever’ seems like a long time. And having to consent for something to be shared publicly forever became a big barrier in enabling consent. We wanted to ensure that people could share for a while and, if then they chose, to change their minds.

**Easy to find / Easy to put in**
We wanted to ensure that documentation and meta-data were accessible as well. One of the researchers of the project, Nigel Ingham, in collaboration with Carlisle People First Research Team Ltd, developed an accessible survey to produce catalogue entries.

**Use disability labels / Choose your own labels**
For some people the label of ‘having a learning disability’ is an important political statement, while for others it is not an important description – or even a label they might reject. We wanted people to be able to label – tag – their contributions in ways that made sense to and for them.

**Lives on in buildings / Lives on in people**
From the outset, we were interested– as many have been in archive and heritage contexts – in conceptualising the archive as living. This draws on the biological definition of living: that it grows, changes, adapts and gets energy from feeding. We wanted the energy of the people that care about the archive to be important in sustaining its future, not only institutional structures.

**Speaking up in public: issues of capacity to consent**
As explored above, the left hand side of the diagram above reflects more traditional ideas of what the archive might do and how it might be sustained. Many of our collaborators were very clear that the public side of archives must not be forgotten and remain crucial to the Inclusive Archive. We were reminded by self-advocates, social care providers, and supporters and family members that in social care service contexts the presumption is always against the open and public approach. Risk
aversion in staff and lack of clarity over the law and good practice tends to stop people with learning disabilities being supported speaking out, using social media, being filmed or appearing on TV. This is especially the case for people who might not be able to consent themselves to any of those things. As a result, it was essential that we addressed questions of consent and of the law on capacity to consent.

The crucial piece of legislation for our project was the Mental Capacity Act (MCA) England and Wales 2005. It governs decision-making for people who may lack capacity ‘because of an impairment of, or a disturbance in the functioning of, the mind or brain’ (MCA 2005, section 2 (1)). Through the diagnostic threshold component of the MCA, people labelled with learning disabilities fall under its jurisdiction and can therefore be subjected to a ‘functional capacity test’ to ascertain whether or not the individual has capacity to make a specific decision at a specific time. Important principles underpinning the legislation include a presumption of capacity in the first instance; that a person is not to be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success; the right to make an unwise decision; and that because you cannot consent to one thing doesn’t mean you can’t consent to another. Someone might be able to consent to what to have for dinner or moving house but not to spending money on a holiday. Under the Act, capacity relates to being able to understand, retain and weigh up information that pertains to the decision, and to be able to communicate that decision. When designing our digital archive, we wanted to ensure we built in processes that supported people to do – and demonstrate – these things. When we asked our wider research community what would help support inclusion participants highlighted the need for greater understanding of how to support communication and a legally compliant decision-making pathway that is easy to follow and yet keeps the person right at the centre.

To build people’s capacity to make an informed decision to consent to sharing in archives, we drew on the definition of decision-making that was articulated by our Research Associate, Vicky Green. Vicky describes herself as a researcher who has mild learning disabilities. Drawing upon her lived experience, including attending school alongside individuals with more complex learning disabilities, she reflected:

To make a good decision you must:
1. Know about it.
2. If you do not know about it, you have to try it.
3. Then you decide. (2017, p. x)

Under the Mental Capacity Act, if a person is judged not to have the capacity to consent to a decision, then a substitute decision is made by those that know the person in what must be their ‘best interests’. This presented another potential barrier for our archive, as families and service providers who support people with very complex disabilities (including those who communicate in non-formal ways such as facial expressions and gesturing) were anxious about whether they could make a best interest decision about depositing in archives. This boiled down to one key question:

6 Consultation with our wider archive research community included people with learning disabilities, advocates, families, archivists, heritage sector workers, health and social care staff, academics, technicians, photographers and performers.

7 In 2009 the UK ratified the United Nations Convention for the Rights of Disabled People (UNCRPD). At the time of writing in 2017 the UK is undergoing formal UN review of its progress towards full compliance. The use of substitute decision-making in accordance with current MCA legislation, is the subject of further legal examination following concerns raised by the UN review that this approach contravenes article 12 (Equal recognition before the law). The committee has recommended replacement by supported decision making (see Ruck Keene 2017, Martin 2017).
what counted as ‘best interests’ in this matter? A wider idea of public benefit is included in the MCA in relationship to research but could this count for archives? Could best interests be read broadly to include the wider public sphere arguments Mabel made? In discussions with a QC, we were reassured to understand that the case law has developed to include ‘altruistic sentiments and concern for others’, including a concern for other people in the future (Lee, 2017). In addition, case law is increasingly emphasising the importance of maximising capacity (CH v A Metropolitan Council [2017] EWCOP 12) involving the person in every stage of decision-making process, with a particular focus on ascertaining the individual’s ‘will and preferences’ (Lee 2017). With this in mind, the project undertook a piece of work – led by one of us, Sue Ledger – to explore with people the practicalities of legally supporting someone with complex needs to deposit to an archive. As Sue has put it elsewhere:

This involved working with an individual (Cherry) and her closest supporters, alongside an outreach and learning officer at The Keep Archive, Brighton, Isilda Almeida-Harvey, to explore:

1. What material Cherry may wish to deposit
2. How Cherry could be best supported to make an informed decision about whether or not to deposit her items in an archive by exploring ways to maximize her understanding of what an archive is – for example by using photos, making films, identifying and learning from an individual’s past and present experiences of sharing with the public, visiting.
3. If Cherry was unable to make the decision for herself, to work through a robust best interest decision making process.
4. Transparent documentation of Cherry’s step by step decision-making process – whether or not to deposit in her local archive - through the use of photography, film and examples of documentation completed by Cherry and her circle of support. (2017, p. x)

Crucially through working to build the possibilities for an individual to consent, our team had to thoroughly breakdown what an archive is and what it means. We had to explore creative and experiential ways for people to understand archiving and the ideas of ‘the public’ and of ‘the future’. As Sue has described in terms of the collaboration with the archivist at the The Keep and Cherry:

To explore Cherry’s own wishes and feelings we undertook a number of visits to the archives where Isilda (the archivist) introduced Cherry to the stories and to archival boxes. We also actively considered whether Cherry enjoyed sharing things about her life with other people – including people she didn’t know personally. A key indication used to determine the best interests decision was that Cherry had publically exhibited her art work in the past and had clearly really enjoyed this process. (Brownlee et al. 2017, p. 9)

As is indicated in Sue’s description, through this strand of the project we have come to see that the public forms of ‘speaking up’ and the relational ‘person-centred’ forms are, in fact, highly productively connected. The route to Cherry being supported to explore public depositing in an archive and, in this case, for a ‘best interests’ decision to be made, was enabled and structured

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8 The idea of a legitimate Best Interest decision which is based on an idea of benefit to others exists in the MCA explicitly only in terms of research: 5) The research must—(a) have the potential to benefit P without imposing on P a burden that is disproportionate to the potential benefit to P, or (b) be intended to provide knowledge of the causes or treatment of, or of the care of persons affected by, the same or a similar condition. (MCA Section 5).

9 Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67 (paragraph 24)
through detailed relational work. Both between Sue, The Keep, Cherry and her Mum and wider support circle and between the idea of the public archive and keeping in view constantly the very person-centred sense of what was important to Cherry.

When we first conceived the ‘different ways of thinking about archives’ illustration above we called it ‘the binaries’ as a shorthand. We conceived them as a heuristic to enable design, to guide us that there would be differentiated ways of being part of our archive. Yet, we always knew that ‘binaries’ was not quite right as we saw the different choices set out in our diagram as being in dynamic relationship. The work of the project – and especially in the context of people with complex needs and the Mental Capacity Act 2005 – showed that the route to the political logics of the public has also to begin in a person-centred way. But equally that being person-centred also meant that we needed to anticipate in our design that not all engagements with the archive would necessary lead to public sharing.

Public and Relational: a new collaborative practice?
In designing the inclusive archive we needed a rich variety of archival practices to enable a variety of ways of being, of taking part and of reflecting different theories of how positive change in people with learning disabilities’ lives comes to happen. We wanted to ensure the archive enables anyone who wants to speak up and claim the space of the public sphere and also for more person-centred, networked and relational ways of being part of an archive. As part of enabling speaking up, as we have just shown, we also needed to draw on emerging Mental Capacity Act 2005 case law to understand ‘best interests’ not only as very bounded and private but as including more expansive ideas of altruism and claiming a space in the world for the benefit not only of yourself but also for others and future generations too.

Archives, legislation, oral histories and everyday conversations are not passive representors of the stories and dynamics already there, they are productive; they are ways in which we produce the present and the future. Archiving requires varieties of ways of knowing and of accounting for the complexity of power, varieties of ways of being and to be designed to make way for a variety of possibilities for political change. The politics of the public sphere, of public service and of posterity remain crucial in speaking up and contesting policy and prejudice, but they also need to be open to different person-centred modes, of small and everyday change. What we found was that both these political logics needed to be planned in. We also found – through our work linked to the Mental Capacity Act – that the route to public depositing is also a highly relational one, whose legitimacy comes ultimately from being person-centred. It is likely that twenty-first century archival politics and its new collaborative practice will also benefit – inspired by the learning disability self-advocacy movement as well as women’s liberation and civil rights movements more generally – from a very active collaboration between these two different political genealogies: the public and the relational.

Bibliography:


RIX Wiki, www.rixresearchandmedia.org/rix/wikis


Social History of Learning Disability online http://www.open.ac.uk/health-and-social-care/research/shld

