This is a repository copy of *Between speaking out in public and being person-centred: collaboratively designing an inclusive archive of learning disability history*.

White Rose Research Online URL for this paper:
http://eprints.whiterose.ac.uk/122237/

Version: Accepted Version

---

**Article:**

Brownlee-Chapman, C, Chapman, R, Eardley, C et al. (13 more authors) (2018) Between speaking out in public and being person-centred: collaboratively designing an inclusive archive of learning disability history. International Journal of Heritage Studies, 24 (8). pp. 889-903. ISSN 1352-7258

https://doi.org/10.1080/13527258.2017.1378901

---

© 2017 Chloe Brownlee-Chapman, Rohhss Chapman, Clarence Eardley, Sara Forster, Victoria Green, Helen Graham, Elizabeth Harkness, Kassie Headon, Pam Humphreys, Nigel Ingham, Sue Ledger, Val May, Andy Minnion, Row Richards, Liz Tilley and Lou Townson. Published with license by Informa UK Limited, trading as Taylor & Francis Group. This is an Accepted Manuscript of an article published by Taylor & Francis in International Journal of Heritage Studies on 15 Nov 2017, available online: http://www.tandfonline.com/10.1080/13527258.2017.1378901. Uploaded in accordance with the publisher's self-archiving policy.

**Reuse**
Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

**Takedown**
If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

eprints@whiterose.ac.uk
https://eprints.whiterose.ac.uk/

# Between speaking out in public and being person-centred: Collaboratively designing an inclusive archive of learning disability history

Chloe Brownlee-Chapman, Rohhss Chapman, Clarence Eardley, Sara Forster, Victoria Green, Helen Graham, Elizabeth Harkness, Kassie Headon, Pam Humphreys, Nigel Ingham, Sue Ledger, Val May, Andy Minnion, Row Richards, Liz Tilley, Lou Townson

## 1. Introduction

**Helen Graham**, Inclusive Archive Research Team, teaches museum and heritage studies at the University of Leeds:

The Inclusive Archive of Learning Disability History is being developed by many people. Some of us have a learning disability and some of us do not. Some of us are researchers, some of us are self-advocates, some of us are designers, some of us are parents and supporters, some of us are practitioners working in the field of health and social care for people with learning disabilities, some of us are working in, or with, archives, museums or heritage organizations. Writers in Critical Heritage Studies have stressed that heritage is a process (Harvey 2001; Smith 2004). Writers in Disability Studies have stressed that (dis)ability is contingent, not a permanent characteristic of specific people but enabled or constrained by social and material conditions (Goodley 2014; Kuppers 2011; Wendell 1996). We want to share in this article our process-orientated way of thinking about both 'heritage' and 'ability' has informed the design of the Inclusive Archive. But there is another process at play too – the process of our collaboration. We have decided not just to tell you about our collaborative process, but, through our conversational writing style, to show you too. This article has been built through bringing together the words of different people, either those who are involved in the Inclusive Archive team or those whose work on the histories of learning disability have made the project possible. To begin we want to introduce you to how this article is going to work – through the voices of different members of the team – and outline our main motivations for starting to work on the Inclusive Archive.

### 1.1 Why design an Inclusive Archive of Learning Disability History?

**Liz Tilley**, Inclusive Archive Research Team, teaches health and social care at The Open University

The Inclusive Archive of Learning Disability History project[1] emerged from the UK Social History of Learning Disability Research Group (SHLD), which has been dedicated to uncovering the 'hidden' histories of people with learning disabilities since it was founded in 1994 (including institutional, community and personal histories). However, these histories are highly dispersed, diverse in form, and often completely inaccessible to people with learning disabilities. There was a recognition that some

---

[1] Funded by the UK Arts and Humanities Research Council, 2014-2017

kind of ‘archive’ was needed to capture and connect these accounts in a form that enabled people with learning disabilities to have better access to their heritage. The project has involved co-designing an accessible digital archive of learning disability history, as well as collaborating with the heritage sector to consider how local archives can adapt their systems and practices to enable more learning disabled people to access and contribute to local collections.

**Dorothy Atkinson**, researcher and teacher and founder member of the Open University’s Social History of Learning Disability Group.

There is and has been silence on the part of people with learning disabilities…..One consequence is that much lived history in the form of personal experiences of people with learning disabilities has gone unrecorded (Atkinson 1997, 1).

**Mabel Cooper**, former resident St Lawrences Hospital, self-advocate, broadcaster and founder member of the Open University’s Social History of Learning Disability Group.[2]

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).

**Elizabeth Harkness**, Carlisle People First Research Team Ltd, a partner in the Inclusive Archive Research Team:

It’s important for other people to find out how disabled people lived. If they went to school. What they did about going to school and getting qualifications?

**Robert Ewbanks**, self-advocate and life history researcher:

Staff might not know about their background and what people did before. What people did is important. Your […] story makes you who you are today really (cited in Ledger and Shufflebotham, 2008, 703)

**Vicky Green,** Inclusive Archive Research Team Research Associate**:**

What’s important to me is hearing about the medical records of people in long stay institutions is about how the language used to talk about people with learning disabilities has changed. The words used in the film *No Longer Shut Up*[3] inspired by Mabel Cooper’s life are really insulting and disrespectful now. Looking at people’s stories of what life used to be like in St Lawrence’s and other institutions makes me think about the difference between myself, who has got a mild learning disability and people who I know who have got more severe learning disabilities. In the past we might have been sent to long stay institutions like St Lawrence’s. Thinking about some of what happened to people like Mabel and her

---

[2] 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.

[3] No Longer Shut Up is a film about Mabel Cooper’s life, and the relevance of her story today. It was produced by Advocreate in 2015, in collaboration with The Open University. The film can be viewed on youtube: https://www.youtube.com/watch?v=BZAgOs4Ngn4

friend Gloria makes me feel quite sad. I started to put myself in their shoes and think about how it would be for me in that situation, not nice.'

**Row Richards**, Inclusive Archive Research Team, working with Vicky as a Personal Assistant:

Talking with Vicky and reading and looking at the same information as above, my thoughts are that it is also important to see how people's stories of their experiences have helped to influence policy and legislation.

**Rohhss Chapman**, Carlisle People First Research Team Ltd, a partner in the Inclusive Archive Research Team:

Andy [a member of the Carlisle People First Research Team Research Team] saw that younger people didn't know about institutions, they didn't know the things people had gone through. If they don't know then it makes your past insignificant in some way. It's almost as if it hadn't happened, so it's important for that older generation. So it doesn't happen again.

**Clarence Eardley**, Carlisle People First Research Team Ltd, a partner in the Inclusive Archive Research Team:

[When people look at our Carlisle People First Research Team Archive they'll say]: 'Who done that? What was that? That's good, that's marvellous?' They will look at that saying to themselves, those that are looking at it, they will be smiling, grinning. We did so much.

## 2. Who we are and how we work

**Liz Tilley**, Inclusive Archive Research Team, teaches health and social care at The Open University

Our research team is an inclusive one. It includes researchers with and without learning disabilities and two partner organisations, Carlisle People First Research Team Ltd and the Woodbine Group. Throughout the project, we have also worked with a wider network of stakeholders including people with learning disabilities and their families, learning disability service provider organisations, archivists, technologists, academics and schools.

Drawing on long standing approaches developed in inclusive research design with people with learning disabilities (Walmsley and Johnson 2003; Seale et al. 2015), our research design was deliberately open from the outset in order to facilitate the most inclusive and innovative methods possible. We describe this as a multi-methods qualitative 'Bricoleur' approach (Denzin and Lincoln 1994, 2-3). This methodological approach – far more than 'a simple eclectic approach' (Rogers 2012, 1) – relies on flexibility, responsivity and creativity in order to invent or piece together new methodological tools to enable the inclusion of the hardest to reach participants (Ledger 2012). In practical terms, this has led us to facilitate a number of workshops and conduct interviews with key stakeholders in order to generate data in the form of narratives, visual images, audio, film and ethnographic observations which have subsequently been collaboratively analysed.[4]

'Conversations' have been a key feature of our research and became a way for us to connect a variety of individuals and groups (spread across wide geographical areas), to share ways of working and develop ideas. While recognising that any conversation is always embedded with social rules and power (Rapley 2009; Wilkinson and Kitzinger 2008), an explicit focus on 'conversations' has enabled us to build trust and rapport amongst different members of our team, break down barriers, and helped us to share information and expertise and to find solutions *together* to the problems we've identified (Zeldin 1998). An example of the 'conversations' approach has been the production of our literature review on inclusive/participatory research methodologies.[5] We felt that established ways of conducting literature reviews – focused on lots of reading – would work to exclude members of the team without formal academic training. Instead Vicky and Sue conducted conversations with people with experience of doing inclusive research and used powerpoint slides sent between team members to debate key issues (see figure 1). The result is a resource we have called 'Top Tips for Inclusive Research'. The aim here was to de-mystify the research process, challenge the perception that this is the kind of work that only 'academics' do, and find practical ways to involve people. This process has also enabled dialogue to develop between a new generation of learning disabled researchers and people with learning disabilities who are experienced researchers who have already published more widely.

Figure 1: A slide about data analysis from our 'Top Tips for Inclusive Research'

## 3. Between being person-centred and speaking out in public

**Nigel Ingham**, Inclusive Archive Research Team Research Associate:

Archives play a crucial role in enabling the histories of people with learning disabilities. Parliamentary debates contained in Hansard offer insights into the eugenic context for the profoundly influential 1913 Mental Deficiency Act that led to Mabel Cooper being sent to St Lawrence's Hospital. Case files held by the London Metropolitan Archives and explored by historian Mathew Thomson have enabled us to gain an understanding of the politics of 'mental deficiency' in the wake of the 1913 legislation (Thomson 1996). Research into court records, newspapers and various archival sources from the 18th and 19th centuries is informing and challenging our ideas about past lives of people with learning disabilities in surprising ways (Jarrett 2010).  However, while preserving records such as those highlighted here has a value, public archives are dominated by the viewpoint of those in power, the decision makers (Zinn

---

[4] We have given a full account of how we worked together on our project wiki website: www.inclusivearchiveproject.org

[5] For the Inclusive literature review see: www.inclusivearchiveproject.org

1971; Swartz and Cook 2002; Evans, McKemmish, Daniels and Mccarthy 2015). Official records, for example in public archives, can skew our picture of the history of long-stay institutions. The first-hand accounts of the people described *by* the administrators and doctors have not tended to make their way into the mainstream archives. In common with a longstanding trajectory in archive and heritage studies (Swartz and Cook 2002; Gilliland and McKemmish 2014; Cook 2013) addressing this has been the focus of the Social History of Learning Disability Group and others over the last quarter of a century.[6]

**Helen**:

Many of the people who influenced or were collaborators in designing the Inclusive Archive are, as you have seen, self-advocates. There is a strong tradition of telling stories in self-advocacy; it often called 'speaking up' or 'speaking out'. 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 the kinds of archives mentioned by Nigel as a way of challenging public perceptions and creating a world where people with learning disabilities can live lives they choose.[7] The desire to *speak out in public* works very much with the grain of traditional archives and museums as pubic institutions which seek to inform public debate with collections kept for posterity and future generations. Yet there is another crucial 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.[8] This tradition means a need for an approach to archives that also makes no assumptions about what participation might include.

---

[6] 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 and internationally. Examples of the latter include Australia (Manning 2008), Canada (Malacrida 2015; Out From Under online) and New Zealand, Australia, USA and Scandinavia (Johnson, Traustadottir 2005). In the UK there have also been numerous oral history projects researching the lives of those who lived and worked in various institutions (Potts and Fido 1991; Ingham 2003; Keilty and Woodley 2013). In addition current and recent research projects – many with Heritage Lottery Fund support – embrace the stories of those associated with former institutions across the UK. Current examples include projects looking at Brandesburton Hospital in Yorkshire, the institutions of Calderstones and Brockhall in Lancashire, as well as the Welsh large long-stay institutions.

[7] 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/conferences). Presenters have included individuals with learning disabilities from across the UK, as well as those from Ireland and Scandinavia. This local and international flavour is also represented in publications (Atkinson et al 2000; Mitchell et al 2006). 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).

[8] Valuing People guidelines describe person-centre 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). There is an ongoing tension in

As part of our research we sought to build participatory and post-custodian approaches to archives, where ownership is seen as distributed and shared (Cook 2013; Ham 1981; Gilliland and McKemmish 2014). Joanne Evans, Sue McKemmish, Elizabeth Daniels and Gavan McCarthy advocate for the idea of 'archival autonomy': 'Archival autonomy is here defined as the ability for individuals and communities to participate in societal memory, with their own voice, becoming participatory agents in recordkeeping and archiving for identity, memory and accountability purposes' (2015, 337-8). For our purposes, we recognised that this would require a way of approaching archives which can take into account traditional ideas of archives as enabling public debate, now and for posterity, as well as more person-centred approaches.

Philosophically-speaking, I was constantly reminded of a famous essay by Michel Foucault called 'What is Enlightenment?'. The Enlightenment was a movement often dated as beginning in 17th Century and is associated with development of science, reason, a sense both of history and of future progress and the idea of the public sphere and citizenship which emerged through the political revolutions in Europe and America. Archives and museums emerged from the Enlightenment in that they seek to hold materials that help produce knowledge, they are for a public and aim to keep things for future generations, for posterity. In his essay, Foucault argues we cannot be 'for or against' the Enlightenment (1991, 45). Instead he says we should see the legacy of the Enlightenment not as faithfulness to doctrinal elements (such as archives as keepers of knowledge for the public and future generations) but rather as being in an ethos, a limit-attitude, 'in which the critique of what we are is at one and the same time the historical analysis of the limits that are imposed on us and an experiment with the possibility of going beyond them' (1991, 42, 45, 50). In the case of our archive, we *both* needed to keep some of these doctrinal elements of archives – to enable speaking out in public – *and* at the same time, in order to *be person-centred*, experiment with 'the possibility of going beyond them'.

**Nigel**: These issues led us to illustrate these different dynamics (Figure 2). Can we value and support the right to be heard in public – and all the arguments I outlined – with other more person-centred political logics? We came to think that an archive that claimed to be inclusive needed to navigate between the different political logics developed by the self-advocacy movement. It is not one or the other. We want to value - and actively design for - both sets of ideas as well as any points in between.

---

learning disability politics, policy and practice as revealed in this *Valuing People* definition) between person-centred and seeking inclusion (Graham 2010).

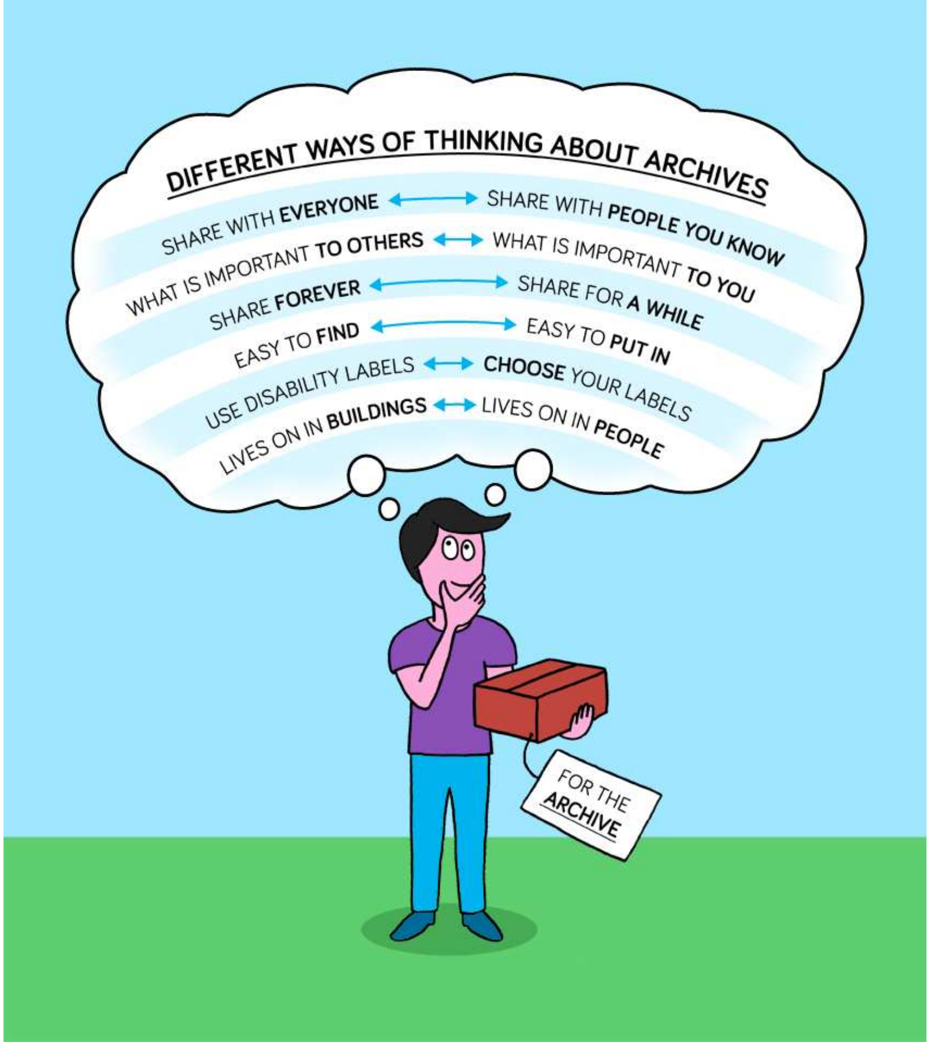

Figure 2: Different ways of thinking about archives. We wanted to ensure our design took these different ideas into account.

## 4. Consenting: breaking down decision-making

**Helen:**

When we were thinking about these different logics it became clearer – especially when we went and shared the ideas with more people at our collaborative workshop events – that the crucial idea of 'consent' sits in the middle of these different ways of thinking about archives. Being able to consent is what enables you to move from your story being personal, only shared with people you know and potentially 'hidden from history', in terms Nigel used above, towards being heard by the public. If we want to enable people to make the choices that are right for them between the dynamics we've described above then we need to look hard in both directions. We need to break down what 'archives' are and challenge some of the assumptions.

But we also needed to make sure our design was really building the capacity for people to understand and consent to their stories becoming shared online and becoming part of the public record if this is what they want.

The question of consent was something I went and talked about with Carlisle People First Research Team Ltd who are developing an archive of their Research Team. In the discussion there was a sense that the team wanted the archive to be used – so to be very much in the speaking out in public mode – but also that there might be a need to have some control over that use:

> **Rohhss:**
>
> Thinking about our Carlisle People First Research Team archive. I don't want it to be stuck somewhere. It's what Lou [Townson, another member of the Carlisle People First Research Team] says about archives, 'What's the point in doing research for it to be stuck on a dusty old shelf, you have to do things with it'. You have to use archives. Go to conferences. Publish it. Get it out there.
>
> **Elizabeth Harkness:** I would be happy about giving our history to an archive as long as we got to keep it and own it. It is about us. We want to have control over it and how it is used.
>
> **Helen:** What kinds of things would you like control over?
>
> **Elizabeth:** The things we want to put in the archives how they used them and not how we want them to be used.
>
> **Rohhss:** You would be worried that they might use them in the way we don't want them too?
>
> **Elizabeth:** Yes.
>
> **Rohhss:** I am more worried that they might not be used. But I can see what you mean. We talked about this at the archive the other day. They prefer people to donate so that they have control. They weren't saying it has to be like that. They were talking about how it is possible to make agreements about which bits are used and how.

**Sue Ledger**, Living Archive Research Team Research Associate:

The act of giving informed consent has been an arena where the rights of people with learning disabilities have been repeatedly disregarded (Calveley, 2012; Tilley et al 2012; Ledger et al, 2016). Self-advocacy groups (People First, 2016) and researchers (Bell, 2012 Heslop et al. 2013) highlight how services have repeatedly failed to provide accessible information and to ensure that people have all the necessary time and support needed to make genuinely informed decisions in their own right. This happens even though the law in England and Wales specifically requires that everything possible is done to maximize the capacity of the individual to understand relevant information and to support their involvement decision-making (House of Lords Select Committee 2014).

In our pilot study (Atkinson et al, 2010) and from the outset of our work on the inclusive archive consent and capacity were repeatedly identified as significant barriers to participation by a range of our inclusive archive stakeholders including advocates, families, health and social care staff, managers, technologists, academic researchers and archivists and heritage practitioners. As my colleague Vicky says, in order to say 'yes' – to give your informed consent – you have to know what you are saying 'yes' to. As a team we puzzled about how we could best enable people with learning disabilities to get involved in deconstructing consent in relation to archives.

**Vicky:** You have to know what difficult words like 'consent' and 'archive' mean otherwise they don't mean anything. Back to square one. It might be easier to say do you want to go ahead yes and share this or no?' I mean I didn't really know those words – 'consent' and 'archive'– before you explained them.

**Sue:**

Many people with learning disabilities have become separated from aspects of their own cultural history (Green et al. 2015). Many have never heard of an archive, have never visited a physical archive (Ledger 2016) or seen one online. As team members we all came with our own experiences and ideas of what an archive is so we had to make sure we were all clear that we were talking about roughly the same thing!

**Vicky:**

We can't ask people to put their stuff in an archive if they don't know what an archive is.

**Sue:**

To help with this Vicky, her PA, Row, and I took photographs and researched images that we felt might help explain what an archive could be. We also read definitions together and asked a speech and language therapist colleague to demonstrate and record the signs for an archive in BSL.

Vicky then produced an accessible glossary of terms to explain an archive and what we mean by consent and the difference between physical and digital archives.

**Vicky:**

I called it my consent glossary. We were asked to run two consent sandpits and we thought it would be really good if we had a separate brand new glossary with easy read pictures and words[9]. The consent words are on one side and the easy read pictures and words on the other. There is a lot of complicated words, ideas and phrases that you need to understand and think about consent. I have a bigger glossary that I call my 'buddy' for the whole inclusive archive project and this contains some consent words too.

**Sue:**

This served as a useful frame of reference within the team and for sandpit participants.

In our inclusive sandpits we asked participants to 'bring a thing' they might want to deposit in the archive and to use this thing to think through some of the issues that might come up in giving their consent. What would be the pros and the cons of sharing? What might go right? What might go wrong? We improvised role plays to act out the process of decision-making.

**Vicky:**

We thought together about how we would make a decision to put something of our own in an archive. We found that we would weigh up the pros and cons. This led us to talking about the good and bad things about putting things in an archive. People said it was the same process for people with learning disabilities who have high support needs but sometimes people might need help from people who know them very well and really care about them in order to decide.

**Sue:**

But I often make big decisions with people I know really well. I might ask them what they think. Talk to them about what to do.

**Vicky:**

Me too. I often ask my mum or dad or my mates what they think.

**Sue:**

We also explored the difference between making small decisions (like what to wear) and big decisions (like having an operation). We considered whether, in relation to the archives, we could break down big decisions like putting everything in an online archive forever into smaller

---

[9] Easy Read is simplified words supported by images (Department of Health 2009).

steps or a series of smaller decisions, such as starting my putting something into an online or physical archive and seeing what it looked like and how it felt - that might be easier to make.

**Vicky:**

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.

**Sue:**

This is a very important point because sometimes when people deposit in an archive they don't get a chance to try it out. They don't have a chance to break the process down, to see what their story, photos or object might look like before agreeing, to think about who they might share their things with, or for how long. We needed to take the lid off 'archive'! In this way the Inclusive Archive Team, through sandpits events, discussions with research partners Carlisle People First Research Team Ltd and The Woodbine Group as well as Jan Pimblett and her colleagues at the London Metropolitan Archives, began to deconstruct the idea of an archive and explore the possibility of designing in new flexibilities.

In doing this we began to see that we also needed to take the lid off informed consent. Working inclusively to unpick and clarify what people are consenting to by depositing also afforded new opportunities for people with learning disabilities to take the lead in identifying potential barriers and in making suggestions as to how they could be overcome. For example, if a person was worried about agreeing to share their story with everyone, could they be offered a chance to share with some groups and not others? If people wanted to share their story but were scared of being bullied – could we build in safeguards that would address this? For people who have never seen a digital archive can tasters be provided to enable people to try out what depositing may involve? If I want to deposit after I die, can I? Can I re-write my story if things change? For people who can't use words to communicate, who might work with them to try out an archive and help them decide?

As Helen introduced above, these questions have led our project team to explore how we can work with the wider heritage sector and legal experts to loosen the traditional rules and systems around archive depositing and ownership. We need to break down the depositing process into chunks that people can understand and relate to their own specific circumstances. It involves looking at creating options to give people more choice and control about how they share their material; with whom; and for how long.

## The Mental Capacity Act: 'Best Interests' and 'Public Interest'?

**Sue**:

A key theme arising from our sandpit data was that the voices, experiences and stories of people with learning disabilities who have high support needs or profound and multiple disabilities (PMLD) – people who under Mental Capacity Legislation (MCA,2005) may be assessed as lacking capacity to consent – must not be excluded from either local archives, or from a digital archive of learning disability history. Sandpit participants argued that fears about people's vulnerability and concerns about legal compliance often meant the stories and images of people with more profound disabilities were inadvertently excluded from the public domain. Consultation with the archive sector confirmed that none of the archivists had experience of receiving deposits from an individual with complex disabilities where mental capacity legislation might apply. Interviews with providers of health and social care highlighted a clear request for easy to follow, step by step advice on how to safely and legally support people with the most complex disabilities to consider sharing their life stories and experiences more publicly. Our commitment to including people with the most complex disabilities is raising new questions about the application of Mental Capacity legislation in the context of an archive.

**Helen:**

A close reading the Mental Capacity Act 2005 (England and Wales) is very interesting for navigation between *speaking out in public* and *being person-centred*. Like a lot of recent theorisations of ability and disability, underlying the Mental Capacity Act (MCA) is a contingent mode of personhood. What this means is that someone's capacity is specific to a particular decision and ability to take one decision – or not – cannot be generalised to another. To identify if someone can consent to a decision they need to be able to understand the information relevant to the decision, retain the information and, as Sue and Vicky have explained above, weigh it up and communicate what they would like to happen (2005, 3). If they cannot do this for that specific decision then a decision is made by others in their 'best interests' (2005, 4). However – and this is crucial for the design of the Inclusive Archive – while there is a very strong sense of personal interest the Mental Capacity Act through the 'Best Interest' clause there is no explicit concept of the kind of 'public interest' which has animated so much of the movement for learning disability history.[10] Most examples of the use of the Mental Capacity Act and 'best interest decisions' related to decisions about an individual's health, well being, finances or social care choices such as where to live or who to live with. We were worried when we started the project that 'best interests' did not necessarily contain an idea of benefit to a wider community or to political change more generally. In other words, we were worried that 'best interest' was in danger of being read narrowly as only in that person direct interested.

**Liz:**

---

[10] 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).

To address our concern head on, we sought legal advice and the guidance of a steering group of people experienced in this area so that we could draw on recent case law and best practice. We were reassured the case law has developed to include ‘altruistic sentiments and concern for others’[11]. This might include concern for other people in the future (Lee, 2017). We were also advised that the Court of Protection has upheld the significance of the ‘emotional dimension’ of the best interests:

> There is of course more to human life than [physical care needs], there is fundamentally the emotional dimension, the importance of relationships, the importance of a sense of belonging in the place in which you are living, and the sense of belonging to a specific group in respect of which you are a particularly important person.[12]

Moreover our legal advice noted that under human rights and equality legalisation, preventing someone from depositing in an archive (i.e. one that holds the status of a public authority) for reasons of disability could itself be considered to be unlawful (Lee, 2017). The advice we received was clear that ‘best Interests’ in practice often means the people closest to that person working collaboratively to reach a consensus about what is best. However, our advisors emphasised how crucial it is to develop ways of establishing a person’s own wishes and feelings as part of the best interests decision-making process.

**Sue:**

To really explore a good ‘best interest’ process that is driven by establishing a person’s own wishes and feelings we agreed that the best way to take things forward was to work closely with one person with high support needs and the people who know them best to develop what we are calling an ‘archive depositing pathway’. In this part of the research the archive team used film and photographs to document each stage of the depositing pathway.[13] 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

---

[11] *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 (paragraph 24)

[12] *FP v GM and A Health Board* [2011] EWHC 2778 (COP) (paragraph 21).

[13] We received ethical approval from the Health and Social Care Research Ethics Committee to begin this pathway work, which is documented on our project website (www.inclusivearchiveproject.org). Under the Mental Capacity Act, England and Wales (2005) it is necessary for research with people who may not be able to consent to be passed through a special ethics committee called the Health and Social Care Research Committee.

understanding of an archive – for example making films, signing, identifying and learning from past 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.

To explore Cherry's own wishes and feelings we undertook a number of visits to the archives where Isilda 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.

**Helen:**

Crucially our legal advisor pointed us towards the 'reasonable adjustments' aspects of the Equality Act 2010 which emphasises to make reasonable adjustments where 'a provision, criterion or practice […] puts a disabled person at a substantial disadvantage in relation to the relevant matter in comparison with persons who are not disabled' (Section 20). Sue and Liz's work on the consent pathway indicated the need for robust MCA compliant process that would enable people unable to consent to still potentially take part. This required – on the *speaking out in public* side of our archive – that the consent process to deposit needed to be adjusted so it could develop a picture of the person's wishes and feelings as Sue and Isilda did with Cherry and her mum. Yet – and to the take us back to the *person-centred* dimension of our design – this work also showed that there was a good argument for more fundamentally adjusting *what archives are* to enable more people to be able to take part.

## Designing between the personal and the public – making the archive

**Andy Minnion** Inclusive Archive Research Team (technical lead) and Director, RIX Research & Media, University of East London:

The team at Rix Research & Media were tasked with working with a range of different stakeholders to co-design and create a digital archive of learning disability history. To respond to the issues outlined throughout this article, we made a number of design decisions through some experimental workshops – which we called sandpits – with a wider range of people. 'Sandpits' have been a popular idea of late that suggest new informal ways in which to explore ideas with various people being able to contribute, to get people thinking differently, be more spontaneous and lose some of the constraints that affect more formal forums. For example, as

Sue has mentioned, to every sandpit we asked people to 'bring a thing'.[14] This helped enable accessibility and inclusion as objects of reference are a key component of the communication pallette that is applied to engage non-verbal people with learning disabilities. We also wanted to bring diverse people together and encourage/facilitate them to discuss things with each other more effectively e.g. technical people, people with learning disabilities and archivists.

**Kassie Headon**, Inclusive Archive Research Team Technical Liaison Associate:

Out of the sandpits we identified a number of different ideas that made up the brief for our technical team and is present in the beta version of our archive.

> *Choose what you share:* We designed the archive to take photographs, video and text.
>
> *Choose who to share it with:* We have designed the archive so you can choose with whom you want to share your contribution. It could be with people who know, specific interest groups (like teachers or self-advocates). Or, if you want, you can share your contribution publicly.
>
> *Choose when to share it and for how long:* In designing the archive we did not want to assume people would want to share their contribution forever. Our design means that you can limit how long it is shared. Or, if you want, you can absolutely share it on an ongoing basis.
>
> *Change your mind!:* Consent in archives and museum can sometimes be 'all or nothing'. This can be a bit like a line on the sand – once you cross it that's it (Graham, Mason and Nayling 2012). However, as part of building capacity to consent, we want people to be able to be able to try things out but change their mind easily if it did not then feel right.
>
> *Use offensive words from the past but also words we feel more comfortable with now:* We have talked a lot about this and have recognised that while some word used to described people with learning disabilities are offensive we have to allow them to exist in our archive or researchers will not be able to find out how people were treated then.
>
> *Use 'learning disability' or not:* The archive makes room for you to use whatever words you want to describe yourselves and your contributions.

---

[14] A full account of our sandpit workshops is available on our project website under 'How we worked': www.inclusivearchiveproject.org.

*Tag with words or images:* We will encourage tagging and have designed the archive so you might want to tag with pictures or words.

*Sustainable through institutions + sustainable through networks:* We recognise that sustaining this archive online will not be easy. So we want to make sure that anyone who wants to deposit in a traditional local archive has the information they need to make an approach. We are also aiming to build a network of archivists, museum and heritage professionals interested in supporting this. At the same time, we also want to think about sustainability differently. We know that for the Living Archive to be living it needs to be sustained not only through formal structures but through ongoing use and social networks and community that develops around the archive.

*Safely and legally - Mental Capacity Act compliant:* We have designed the archive to build the conditions where as many people as possible will be able to consent themselves. We have also created flexibility so the decision can be of different scopes and scales which might enable more people to be able to consent themselves. Through the work led by Sue and Liz, we have also designed a Mental Capacity Act compliant 'Best Interest' documentation process and are hopeful this will mean services will feel confident supporting people to use the archive.

## Conclusion and next steps

**Liz:**

In the Inclusive Archive project we have attempted to take some big, conceptual questions about the nature of time, identity, archives and consent and make them as concrete as possible for people, through our inclusive research design.

**Helen:**

In doing this, and throughout the project, we've been guided by two different crucial political contributions made by the learning disabled self-advocacy movement. The first – *speaking out in public* – really underpinned the motivations for beginning the Inclusive Archive project in the first place. Yet the second key idea – *being person-centred* – led us to also ensure that people can make lots of choices over how their contributions are used.

Although our project and our archive design is very rooted in learning disability self-advocacy and responses to the Mental Capacity Act in England and Wales, the ideas have wider relevance for archives, museums, heritage and community engagement and participation internationally. As someone steeped in heritage studies I was very keen from the first – drawing on the discipline's strong critical tradition – to challenge the premise of the archival desire. Yet I was constantly reminded by Carlisle People First Research Team Ltd and Access All Areas, how powerfully important it was to ensure people with learning disabilities can take advantage of the public space offered by archives and previously only available to those in power. Archives remain an important way to enable people to *speak up in public*. Yet – and this was clear through our work with the Woodbine Group where person-centred logics were crucially important – that we should not make assumptions that everyone will want the same thing. Instead we also need to draw on critical traditions of heritage studies to challenge archival logics in order to be *person-centred.* Our Inclusive Archive design seeks to hold together, and navigate between, the traditional political contributions of archive – to influence public debate now and for the future – and a person-centred archive where there are no assumptions. In Foucault's terms we needed some 'doctrinal' commitments (to the archive, to the public sphere, to political agency through voice) and a 'limit-attitude' to critically question archival logics (1991, 42, 45). That is to imagine the archive 'otherwise than it is, and to transform it not by destroying it but by grasping it in what it is' (1991, 41).

**Liz:**

A crucial aspect of the work we've done is to legally underpin people with learning disabilities' involvement in archives and heritage. While we always valued the way in which the Mental Capacity Act 'best interests' process is fundamentally person-centred, we were delighted to be reassured that 'best interest' can be read through case law to include notions of contributing the public debate, to a wider community and therefore to archives.

**Helen:**

We will now leave Carlisle People First Research Team Ltd with the final words. Through their exchange, they pull out the crucial insight of our project that we need to be both and between. We need to use what archives are and challenge what they might be.

**Elizabeth:**

It is about us. It is all about archives engaging more with people with learning disabilities. […] We want to have control over it and how it is used.

**Pam:**

And [it is] about archives working more with other people.

**Clarence:**

[And it is about] keeping the history alive and being used.

**References:**

Advocreate. 2015. *No Longer Shut Up: Finding Mabel Cooper's Voice,* accessed 15 August 2017. https://www.youtube.com/watch?v=BZAgOs4Ngn4

Atkinson, Dorothy. 1997. *An Auto/Biographical Approach to Learning Disability Research*, Ashgate: Avebury.

Atkinson, Dorothy, Caroline Holland, Lee Humber, Nigel Ingham, Sue Ledger and Elizabeth Tilley. 2010. *Developing a 'Living Archive' of Learning Disability Life Stories: Project Report*, Milton Keynes: Open University

Atkinson, Dorothy, McCarthy, Mary, Walmsley, Jan, Cooper, Mabel, Rolph, Sheena, Aspis, Simone, Barette, Pam, Coventry, Mary and Ferris, Gloria, eds, 2000. *Good times, bad times: Women with learning difficulties telling their stories.* Kidderminster: BILD.

Bastian, Jeanette A. 2002. 'Taking Custody, Giving Access: A Postcustodial Role for a New Century', *Archivaria: The Journal of the Association of Canadian Archivists,* Spring. Available at: http://archivaria.ca/index.php/archivaria/article/view/12838

Bell, Ruth. 2012. 'Does he have sugar in his tea? Communication between people with learning disabilities, their carers and hospital staff. *Tizard Learning Disability Review* 17 (2): 57–63.

Buchanan, Alexandrina and Michelle Bastian. 2015. 'Activating the archive: rethinking the role of traditional archives for local activist projects', *Archival Science*, 15: 429–451

Calveley, Julie. 2012. 'Including Adults with intellectual disabilities who lack capacity to consent in research', *Nursing Ethics*, 19 (4): 558-567.

Cook, Terry. 2013. 'Evidence, memory, identity, and community: four shifting archival paradigms', *Archival Science*, 13: 95–120.

Cooper, Mabel. 2008. 'An Interview with Mabel Cooper'. At the Forgotten Citizens Conference, Learning Disability Week 2008, accessed 15 August 2017. https://vimeo.com/1406390.

Costa, Lucy, Jijian Voronka, Danielle Landry, Jenna Reid, Becky McFarlane, David Reville and Kathryn Church. 2012. 'Recovering our Stories: A Small Act of Resistance', *Studies in Social Justice* 6 (1): 85-101.

Department of Health. 2009. Basic guidelines for people who commission Easy Read information. London: Department of Health.

Norman K. Denzin and Yvonna S. Lincoln. 1994. *Handbook of Qualitative Research*. Sage Publications.

Evans, Joanne, Sue McKemmish, Elizabeth Daniels, and Gavan McCarthy. 2015. 'Self-determination and archival autonomy: advocating activism', Archival Science, 15: 337–368.

Flinn, Andrew. 2010. 'Independent Community Archives and Community-Generated Content: 'Writing, Saving and Sharing our Histories', *Convergence: The International Journal of Research into New Media Technologies*, Vol 16(1), pp. 39–51.

Flinn, Andrew, Mary Stevens and Elizabeth Shepherd. 2009. 'Whose memories, whose archives? Independent community archives, autonomy and the mainstream', *Archival Science* (2009) 9: 71–86.

Foucault, Michel. 1991. 'What is Enlightenment?' in *The Foucault Reader: An Introduction to Foucault's Thought* edited by Paul Rabinow. London: Penguin.

Graham, Helen. 2010. 'How the tea is made; or, The scaling of "everyday life" in changing services for "people with learning disabilities', *British Journal of Learning Disabilities,* 82 (2): 133-143.

Graham, Helen, Rhiannon Mason and Nigel Nayling. 2013. 'The Personal is still Political: Museums, Participation and Copyright', *Museum & Society,* 11 (2): 105-121

Gilliland, Anne J. and Sue McKemmish. 2014. 'The role of participatory archives in furthering human rights, recovery and reconciliation', *Atlanti: Review for Modern Archival Theory and Practice,* 24 (1): 79-88.

Green, Vicky, Sue Ledger, Jan Walsmley and Rowena Richards. 2015. 'How come we didn't know about all this stuff', Disability and Impairment: a Technological Fix? Conference, London Metropolitan Archive, 27 November.

Goodley, Dan. 2014. *Dis /ability Studies: Theorising disablism and ableism.* London: Routledge.

Ham, Gerald, J. 1981. 'Archival Strategies for the Post-Custodial Era', *The American Archivist* 44 (3) Summer, 207-216.

Harvey, David C. 2001. 'Heritage pasts and heritage presents: Temporality, meaning and the scope of heritage studies' *International Journal of Heritage Studies*, *7* (4): 319-338.

Heslop, Pauline, Peter Blair, Peter Fleming, Matt Houghton, Anna Marriot and Lesley Russ. 2013. *Confidential Inquiry into Premature Deaths of People with Learning Disabilities*. Bristol: Norah Fry Research Centre.

House of Lords Select Committee. 2014. *Mental Capacity Act 2005: post-legislative scrutiny,* 25 February. https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13902.htm.

Ingham, Nigel. 2003. *Gogarburn Lives.* Edinburgh, LMA.

Jarrett, Simon. 2010. ''He is a poor, foolish lad' Before there were staff-informal family and social networks of support in the 18th and early 19th Century London, and how the asylum system broke them up. Paper at the Social History of Learning Disability Conference. Open University.

Johnson, Kelley and Rannveig Traustadottir, eds. 2005. *Deinstitutionalization and people with intellectual disabilities: In and out of institutions.* London: Jessica Kingsley Publishers.

Keilty, Tim and Kellie Woodley. 2013. *No Going Back: Forgotten Voices from Prudhoe Hospital.* Sheffield: Centre for Welfare Reform.

Wilkinson, Sue and Celia Kitzinger. 2008. 'Using conversation analysis in feminist and critical research', *Social and Personality Psychology Compass*, 2(2): 555-573

Kuppers, Petra. 2011. *Disability culture and community performance: Find a strange and twisted shape.* Basingstoke: Palgrave Macmillan.

Ledger, Susan. 2012. *Staying Local: support for people with learning difficulties from inner London 1971-2007*. PhD. Diss. Open University.

Ledger, Susan and Lindy Shufflebotham. 2008. 'Developing a Visual Mapping Method to support people with intellectual disabilities to tell their life story', *Journal of Intellectual Disability Research*, 52 (8-9): 695-701.

Ledger, Susan. 2016. 'Visiting the London Metropolitan Archive with Theatre Group Access All Areas', accessed 15 August 2017. http://www.Inclusivearchive.org.uk

Ledger, Susan, Sarah Earle, Elizabeth Tilley and Jan Walmsley. 2016. 'Contraceptive decision-making and women with learning disabilities', *Sexualities*, 19 (5-6): 698–724.

Lee, Annabel. 2017. 'In the matter of The Open University and a proposal to establish a learning disability archive'.  Legal advice received from 39 Essex Chambers, private correspondence.

Malacrida, Claudia. 2015. *A special hell: Institutional life in Alberta's eugenic years.* Toronto: University of Toronto Press.

Manning, Corinne. 2008. *Bye-bye Charlie: Stories from the vanishing world of Kew Cottages.* Sydney: UNSW Press.

Mental Capacity Act 2005. London HMSO, accessed 15 August 2017. http://www.legislation.gov.uk/ukpga/2005/9/contents

Mitchell, Duncan, Rannveig Traustadottir, Rohhss Chapman, Lou Townson, Nigel Ingham, Sue Ledger, eds. 2006. *Exploring experiences of advocacy by people with learning disabilities: Testimonies of resistance.* London: Jessica Kingsley

People First. 2016. *The Campaign for Easy Read*. Available at: http://peoplefirstltd.com/policy-and-campaigns/important-campaign-areas-chosen-by-our-members/

Potts, Maggie and Fido, Rebecca. 1991. *A fit person to be removed.* Plymouth: Northcote House.

Seale, Jane, Melanie Nind, Liz Tilley and Rohhss Chapman. 2015. 'Negotiating a third space for participatory research with people with learning disabilities: an examination of boundaries and spatial practices', *The European Journal of Social Science Research*, 28(4): 483-497.

Rapley, Mark. 2009. *The Social Construction of Learning Disability*. Cambridge: Cambridge University Press.

Rogers, Matt. 2012. Contextualizing Theories and Practices of Bricolage Research. *The Qualitative Report*, *17* (48), 1-17.

Schwartz, Joan M. and Cook, Terry. 2002. 'Archives, Records, and Power: The Making of Modern Memory', *Archival Science* 2: 1–19.

Smith, Laurajane. 2004. *The Uses of Heritage.* London: Routledge.

Tilley, Elizabeth, Sarah Earle, Jan Walmsley and Dorothy Atkinson, 2012. 'The Silence is roaring': sterilization, reproductive rights and women with intellectual disabilities', *Disability and Society*, 27(3): 413–426.

Thomson, Micheal. 1996. 'Family, community, and state: The micro-politics of mental deficiency' in *From Idiocy to Mental Deficiency; Historical perspectives on people with learning disabilities,* edited by David Wright and Anne Digby, 207-230. London: Routledge**.**

Walmsley, Jan and Kelley Johnson. 2003. *Inclusive Research* with People *with Learning Disabilities: Past, Present and Futures.* London: Jessica Kingsley Publishers.

Wendell, Susan. 1996. *The Rejected Body: Feminist philosophical reflections on disability.* London: Routledge.

Zeldin, T. 1998. *Conversation: How talk can change our lives.* London: Harvill Press.

Zinn, Howard. 1971. 'Secrecy, Archives and the Public Interest', *Midwestern Archivist*, II (2): 14-27.