

CHAPTER TITLE:

Enabling people with profound and multiple learning disabilities to belong in public and community archive collections

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Abstract

Having the opportunity to access and participate in heritage is an important element of being included, on an equal basis, in society. Public archives have a role in fostering a sense of belonging, connection, recognition and accomplishment. Recently, people with learning disabilities have been recovering their history and reporting it in their own words. But amidst such progress people with profound and multiple learning disabilities have continued to be neglected from history; their lives, experiences, memories and contributions remain hidden and silenced. The Inclusive Archive of Learning Disability History Project¹ sought to address this inequality by engaging directly with people with profound and multiple learning disabilities, their families, carers and service providers, as well as the heritage sector, to explore their wishes and any barriers to their inclusion in history. We worked collaboratively with families, lawyers and archivists to tackle the legal uncertainties, safeguarding concerns and lack of experience and confidence. In this chapter we report on project methods and findings and outline the co-produced archive depositing pathway for people with profound and multiple learning disabilities.

The exclusion of people with profound and multiple learning disabilities from history and heritage

The materials that archives hold challenge, inspire and transform what we think we know of times, events and people, past and present. (The National Archives (The National Archives) 2017a: 1)

Figure 1 [insert artwork]: Gloria Ferris, published her experiences of living in St Lawrence's Hospital, Surrey, UK – a 2,000 bed long stay institution for people with learning disabilities. Gloria highlighted that stories from people like her friend Muriel, pictured above and also a former patient at St Lawrence's, were all too often missing from history (Ferris 2004).

Despite significant changes to legislation, policy and service provision in the late twentieth and early twenty-first century, the lives of people with learning disabilities remain under represented within arts, culture and heritage (Fox and McPherson 2015; Brownlee-Chapman et al. 2017). The history of learning disability has been largely documented by others (for example, through records from medical practitioners and policy makers) rather than being told from the perspective of people with learning disabilities.

The silence is pervasive. With little or no recourse to the written word their voices were seldom heard. The consequence is that much lived history in the form of personal experiences of people with learning disabilities has gone unrecorded (Atkinson 1997: 1).

The silence highlighted by Atkinson is particularly pervasive in relation to people with profound and multiple learning disabilities for a range of practical, methodological and ethical reasons. This gap in the historical research is mirrored by people's invisibility within the wider heritage picture. It also reflects the continued marginalization within contemporary social and cultural life of people with profound and multiple learning disabilities (DH 2005, DH 2009; Ledger and Tilley 2017). Without representation, there is little opportunity to challenge people's attitudes or to further understand what it means to have profound and multiple learning disabilities (Mencap 2015). Simmons and Watson (2014: 16) argue that 'a repositioning of profoundly disabled people needs to occur that reveals their social and cultural engagement in the world and allows for their personhood to emerge'.

Since 1994, the Social History of Learning Disability Research Group (SHLD) at The Open University (UK) has worked with people with learning disabilities, families, academics, historians and practitioners to enable people with learning disabilities to document their lives and experiences, using a range of inclusive approaches. Through careful archive work, alongside oral history methods, the group began to uncover previously untold stories about family, institutional and community life (Atkinson et al. 1997; Rolph et al. 2005; Walmsley and Jarrett 2019). In recent years the use of multimedia, mobile and visual methods, story sharing, and digital technology have supported people with profound and multiple learning

disabilities to play a more active role in recording, sharing and curating their own life stories and experiences (Foundation for People with Learning Disabilities 2011; McCormack this volume; Ledger and Shufflebotham 2019; Research & Media 2019). Despite these developments the experiences of people with profound and multiple learning disabilities are virtually absent from public archives. A scoping project for creating an inclusive and living archive of learning disability history (Atkinson et al. 2010) could not identify any deposits from people with profound and multiple learning disabilities in any archive collection across the UK - a finding that was replicated in 2017 following consultation with archivists (Ledger and Tilley, 2017). Some archives hold medical records and reports written by doctors, managers, social workers and teachers, but this is not the same as the stories and experiences told by people with complex disabilities, their families and friends.

Archives, belonging and community involvement

Our collections will reflect all of society, so that whether an individual, community or organisation, archives can tell us who we are and how we got here. (The National Archives 2017b: 3)

Public archives are collections of information to document and record history. Archive records come in many forms and can include photographs and films, notebooks, paintings and drawings, letters, reports, minutes, registers, maps digital files and sound recordings. Public archives, whether physical (accessed through building-based collections) or digital (accessed online) provide first-hand information relating to individual lives, community groups, historical events and organisations and buildings. The National Archives is the largest archive in the UK, but there are many smaller community archives across the country. Because today's stories will become tomorrow's history, archives actively encourage involvement from a range of community groups, including historically marginalised and disadvantaged groups.

Core and essential service standards for supporting people with profound and multiple learning disabilities emphasise the importance of every person, regardless of the complexity of their disability, being offered the opportunity to participate and contribute to their own community, highlighting that '*a sense of belonging is a vital element of the person's quality of life*' (Doukas et al. 2017: 33). Having the opportunity to access and share your history and heritage is an important element of being included, on an equal basis, in society. Understanding our personal and shared histories, and constructing an intergenerational sense of self, connects us with something much larger than ourselves, giving us a sense of belonging (The National Archives 2017a). Evidence of how archives can support a sense of belonging and community involvement for marginalised individuals is gradually beginning to emerge. In Norfolk, the Change Minds project demonstrated tangible improvements in the lives of people with mental health needs through their engagement with archive materials telling the story of their peers during the 19th century (Change Minds 2018; Scaife 2018).

Van Der Mere (2017) documents how the inclusion in public archives of embroidered story telling cloths made by South African women previously described as ‘illiterate’ and ‘uneducated’, gave these female story tellers a new form of confidence and empowerment – enabling severely disadvantaged women to make sense of their lives. For refugee communities there is interest in archiving their journeys to belonging as full and valued citizens (The National Archives 2017a).

Fox (2017) highlights that for many people with disabilities, the everyday experiences of their historical peers are rarely reflected in the stories that are told through local archives and heritage events. Their stories are not illuminated in our histories and generally remain hidden. Yet everyone has a story to tell and everyone is an expert in the life they have lived (Birren and Deutchman 1991). People with profound and multiple learning disabilities, and those most closely involved in their support, continue to be absent from archives despite Government policy emphasising that public archives must be representative and make efforts to ensure their catalogues include material from people who have been historically marginalised or excluded from national and local heritage collections. Policy also emphasises that while a key purpose of archives is to preserve community and national histories, they also provide a facilitative role in enabling community participation and inclusion (The National Archives 2017a, 2017b). This position is mirrored by the Archives and Records Association’s (2019) Statement on Diversity, which seeks to ensure that its ‘membership, the holdings that archives acquire and manage, and the users whom we serve reflect the diversity of our society’.

Evidence shows that individuals with profound impairments can be supported to develop their own agency, to communicate, to build relationships and become social and communicative members of their families, schools and communities (Mansell, 2010). As Grace (cited by Doukas et al. 2017) points out, the ability of a person with profound and multiple learning disabilities to communicate is not dependent on their being able to master certain skills, it is dependent on the ability of others to listen and respond effectively. Within archive settings, further thought and knowledge of communication repertoires and decision-making frameworks may be required to determine how meaningful participation of people with profound and multiple learning disabilities can be facilitated and supported.

When the SHLD Research Group secured funding to research the social, ethical, legal and technological issues that arise in the practice of making archives more open and accessible to people with learning disabilities, we made a commitment to explore the specific implications for people who may need support with making decisions about archiving, including people with profound and multiple learning disabilities. This required us to engage closely with the legal framework in England and Wales concerning capacity and decision-making, and with the families and organisations that support people with profound and multiple learning disabilities, to capture the nuanced and sensitive decision-making processes that might be triggered by a discussion of history, heritage and archives amongst this group of people.

The Inclusive Archive of Learning Disability History Project

In the Inclusive Archive of Learning Disability History Project we investigated how people with learning disabilities can engage with their cultural history and heritage more easily and effectively, and how they can be enabled to tell, share and deposit their own stories and artefacts, to ensure the lived experiences of people with learning disabilities today are captured and represented in the historical record. The project had two key strands. The first involved working with people with learning disabilities, their families and supporters to co-design and test an accessible prototype digital archive of learning disability history. This was the first key step in enabling people with learning disabilities and other stakeholders not only to access the history of learning disability but to actively contribute to curating and shaping that history, through the online depositing of their own stories, memories and digital artefacts. The second strand involved working with the wider heritage sector (specifically archivists across England) to explore how public archive collections can become more open and accessible to people with learning disabilities, both as users and potential depositors. Our research with people with profound and multiple learning disabilities was focused on this second strand: access to and participation in public archives.

A key project aim, in keeping with human rights and equalities legislation, was to ensure that the experiences and stories of people with the most complex needs would not be discriminated against, excluded or forgotten in public archives. Following an extensive consultation with stakeholders to help us understand why people with profound and multiple learning disabilities continue to be excluded from heritage and the historical record we explored potential solutions to the barriers identified. This involved a period of highly intensive case study research with one individual with profound and multiple learning disabilities and their circle of support, in collaboration with a local public archive. Our findings, coupled with the supported decision-making process that emerged from our research, were then reviewed by an expert legal team.

Phase One: Exploring perspectives and experiences

The first phase of research seeking perspectives on including people who may not have capacity to consent in archives, focused on three research questions:

1. What are the reasons for offering people with profound and multiple disabilities the opportunity to share their stories and experiences through involvement in archives?
2. What are the barriers to people with profound and multiple learning disabilities depositing their stories and experiences in archives?
3. What would help us overcome these barriers?

We used a range of research approaches to address these questions. First, we facilitated workshop discussions with our two project partner organisations, The Woodbine Day Centre

History Group and Carlisle People First Research Team. Both were groups of people with learning disabilities experienced in learning disability history and life story research and most self-advocates had been at school or day centres with children with profound and multiple learning disabilities and so were knowledgeable about barriers encountered and how these could be overcome. Then we interviewed leading experts in the field of consent and capacity, inclusive methodologies, community archives, mental capacity and the social history of learning disability. Finally, we facilitated two inclusive workshops with stakeholders to share ideas and map a way forward. These included people with learning disabilities, their families and supporters; social care providers; health and social care practitioners; archivists; heritage specialists; disability arts and theatre organisations; academics, educationalists; and technologists. We used a range of creative and accessible methods to gather people's views. The data – comprising recorded discussions, participant workshop notes, photographs, drawn images and researcher field notes – were thematically analysed (following the method outlined by Ziebland and Macpherson 2006) to extract themes and patterns in the data within the structure of our research questions.

Figure 2 [insert artwork]: To support our exploration of issues for people who may wish to deposit in a public archive the team, we made mock depositing boxes with sample artefacts from a fictitious person with profound and multiple learning disabilities

Figure 3 [insert artwork]: The sample box pictured contained care records, CD, pottery, artwork and photographs

Figure 4 [insert artwork]: Stakeholders worked together to identify potential barriers to their inclusion and how these may be addressed

In relation to our first research question, participants identified that it was important for people with profound and multiple learning disabilities to share their stories publicly as part of the historical record to help others understand their experiences and life worlds. Participants also argued that it was important to capture the experiences of families as these often go unrecorded. They suggested that depositing in archives also had the capacity to support individuals and their families to make local connections and meet new people. This was seen as significant in the wider context of people's systemic isolation from their local communities and as a way to enable people to experience a sense of belonging.

In terms of barriers to the inclusion of people with the most complex needs (research question 2), participants emphasised the importance of having the right legal paperwork in place. There was considerable confusion about documenting consent, particularly in relation to the Mental Capacity Act (MCA) England and Wales (2005), which appeared to be serving to keep people's stories hidden. Some participants queried whether a public archive would accept materials about the lives of this group, in that their experiences could be considered too 'niche' or unimportant. Participants identified that securing a consensus within a person's circle of support about depositing in archives could be complex, which might discourage people from exploring the issue further. They also raised concerns about sharing confidential information in archives and how this would be managed.

In terms of the most practical way forward in supporting more people to be included in archives (research question 3), the overriding preference was for a clear, step-by-step and legally compliant pathway that families, care staff and those working in the heritage sector could follow. Participants suggested that such a ‘decision-making pathway’ could be used when working with people with profound and multiple disabilities and their circle of support when considering whether or not to share or deposit their material as part of a public archive collection. Archivists supported this approach, arguing that it would enable more deposits from people who might not be able to consent to be accepted by local archives. With this in mind, we set about seeking ethical clearance to enable us to undertake a highly intensive and practical piece of action research to produce a supported decision-making pathway tool.

Phase Two: Co-researching a decision-making pathway for sharing stories and depositing in archives

Responding to the recommendations from Phase One, we adopted an in-depth, participatory approach which involved researching with Cherry Lane, a young woman with profound and multiple learning disabilities, her circle of support and a community learning officer from her local public archive to co-produce a decision-making pathway for use in heritage in archive settings. Our research had found no evidence of any archive having previously accepted a deposit from a person who may lack legal capacity to consent. Therefore we elected to use a person-centred (Brownlee-Chapman et al. 2017) case study approach that would enable us to respond flexibly and creatively (Becker 1998) and to invent or piece together new methodological approaches to enable the inclusion of the hardest to reach participants (Ledger 2012).

Our key research question for this phase was: How can people with profound and multiple learning disabilities, who may lack capacity to consent, be legally and safely supported to make a decision as to whether or not to deposit their stories and artefacts in an archive?

Securing ethics – breaking new ground

We secured Social Care Research Ethics Committee approval which included permission for all participants involved in this phase of the research to be recorded through film and photography and, upon completion of the research, to be offered the option of being identified in the archive decision-making pathway that we aimed to produce. Although it would have been possible to produce a completely anonymised pathway tool through the use of textual accounts and graphics, our ethics application made the case that there was potentially significant value in sharing images from the pathway research on the project website and in subsequent written outputs. This position responded to two key issues from Phase One: first, people’s invisibility and second, that decision-making practice is aided by being able to view photos and videos of decision-making in situ (Foundation for People with

Learning Disabilities 2011; Mencap 2015). Phase One participants made plain that being able to see ‘real’ people working through these issues would have significant benefit for others. This novel approach was supported by the ethics committee, which acknowledged the political and social significance of identifying participants in this way.

Recruitment and research design

Through our project stakeholder networks we identified several people with profound and multiple learning disabilities who, with their support circles, were potentially interested in depositing in a public archive and in taking part in the pathway research. Each had previously participated in recording their life story or memories as part of a research or oral history project. Cherry was selected for our pathway research as she had recently participated in a multi-media project to document her life story and had a collection of photographs, films, and objects linked to this work. As a visual artist Cherry had also reportedly enjoyed sharing her work at public exhibitions held by her local inclusive art projectⁱⁱ. In this respect, at the start of our pathway research, Cherry had a number of tangible items that were of interest to the local archive, who were keen and immediately available to work with us on developing the depositing pathway.

Consent to participation was received in accordance with MCA guidance (2005; 2007; Paradigm 2008), with Cherry’s mother Angela acting as a personal consultee. The research took place over five months and six meetings with Cherry, her circle of support and the local archivist. In line with our ethics protocol all meetings were recorded using film, photography and supplementary written notes. After each meeting with Cherry the lead researcher wrote a detailed session plan which was circulated by email to all participants (Cherry, her parents, care team and learning officer at the archive) for comments, ideas and suggestions. This process supported active engagement of all parties in shaping the direction and content of our pathway meetings. After each session, the research team reviewed with participants (including Cherry where possible) how the session had gone.

Development of the depositing pathway was overseen by a specialist steering group that included a speech and language therapist, a national MCA implementation lead, a learning disabled researcher who attended special school with people with complex learning disabilities, a lecturer in social work specializing in the MCA, two archivists and a chief executive of a health and social care provider. The steering group met three times during the pathway research to co-analyse the data with the research team, to view films and photographs to provide an independent overview of how Cherry’s communication was being supported and interpreted, and to offer guidance on MCA compliance and development of the pathway content.

The decision-making pathway format

Our aim was to accompany, support and document the journey made by one person with profound and multiple learning disabilities as they progressed through the process of making a decision about whether or not to deposit in their local archive. In England, where this

research took place, MCA 2005 (England and Wales) legislation provides a legal framework for the care, treatment and support of people over 16 years who are unable to make a specific decision for themselves. We set out to explore and practically demonstrate implementation of the MCA (2005) in relation to archival decision-making (Brownlee-Chapman et al. 2017; Graham et al. 2019). We wanted to explore and demonstrate how a person with profound and multiple learning disabilities could be supported to have as much involvement as possible in a decision about depositing their story, materials or artefacts in an archive.

The process began with initial conversations about what Cherry might be interested in depositing (and why), through to the final decision about whether or not to add her artefacts to her local public archive collection. The finished pathway uses Cherry's actual decision-making journey to document the steps taken. At the direction of Cherry's support circle, and endorsed by inclusive archive project partners Carlisle People First, the final pathway was made available as an online resource [add link]. At each stage of the pathway photographs and film clips were embedded to provide examples in addition to links to accessible proforma templates to enable evidencing of compliance with the MCA (Graham and Cowley 2015). These include a Maximising Capacity and Supported Decision Checklist; a Pros and Cons of Depositing form; an Assessing Capacity form; and a Best Interest Checklist and Decision-Making form.

Cherry – exploring the opportunity to deposit in her local public archive

Cherry lives with her family and is supported to follow a range of interests by a team of personal carers. She has a wide network of family and friends. A long-standing member of a local inclusive art group, she has contributed, as a visual artist, to several local exhibitions and to a national show at the Tate Gallery in London. Her support circle all felt that Cherry had enjoyed sharing her work at this event and in a multi-media life history project. Hence they felt that Cherry would be interested in participating in our pathway research and in potentially sharing her artwork and a selection of life story materials through her local archive collection.

The MCA 2005 states that 'a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success' (Sect.1(3)). In this way the legislative framework promotes a person-centred approach to decision-making with people with profound and multiple learning disabilities. Reflecting this, after securing research permissions, our first meeting with Cherry was at her family home where she was most relaxed, in the early afternoon which was usually her best time of day, with her family and support team present. The focus was to learn more about what helps Cherry to understand and communicate and to review what Cherry might like to deposit.

Supporting Cherry to understand information about archives and to express her wishes and preferences about depositing

The MCA 2005 emphasises that to enable Cherry to be fully involved in making a decision then information must be provided in the format she will find easiest to understand. Cherry has a progressive condition affecting her speech, movement and coordination. She communicates through eye contact, movement and facial expression. She particularly enjoys looking at film and photographs and her circle of support confirmed that these visual methods are consistently the most useful in helping her to understand new information and to express interest and choice.

In preparing materials to help Cherry understand what an archive is and what depositing means we listened carefully to Cherry and the people who know her best. Reflecting this, the completed pathway includes a short film called 'Getting Going' where Cherry's mother speaks with Cherry about what helps her to communicate. Recognising that photographs and film were the most effective ways of supporting Cherry to understand new information, the researchers worked with the local community archivist using a tablet and a set of pre-prepared questions to make a personalised film for Cherry. This simple film enabled Cherry to watch a virtual tour of the archive. The archivist on camera spoke directly to Cherry inviting her to visit and pointing out vacant space on the archive shelves where Cherry's deposits could be placed. The film also included items that the archivist felt might be of particular interest to Cherry including the work of a local visual artist. Researchers also worked with Cherry's support circle and the archive to produce a series of drawings and photographs to explain that an archive is a place to put things and to share your things with the public.

Cherry viewed the film about the local archive in her home and the researchers recorded her reaction, which was also observed by her family. Cherry appeared very interested in the content, watching the film several times and holding the arm of the researcher to keep playing the film. At one point Cherry looked away and then deliberately returned to watch the film again.

Figure 5 [insert artwork]: The archivist points out space for Cherry's story and artwork

Cherry visits the local archive

Cherry's family and supporters commented that she is often curious and enjoys visiting and looking around new places. After watching the film together several times, they felt that visiting the archive would help to involve Cherry in the decision about depositing her things. Following Cherry's positive reaction to the film a visit was arranged.

In planning this visit we thought about how to help Cherry understand what an archive is and what it might mean for her to deposit in this place in order to share her story and artefacts with a wider public. The archive officer, working with Cherry, her support circle and the research team, prepared a display of documents she thought Cherry would enjoy and relate

to. She also prepared an empty archive box with Cherry's name and photograph on it, for Cherry to physically 'try out' depositing.

Figure 6 [insert artwork]: Cherry looking at her materials in the archive setting

Figure 7 [insert artwork]: Cherry tries out depositing during a visit to the archive

During this first visit Cherry met the archive officer, had a tour of the archive and looked at a range of records from other collections. She brought a personal record to deposit and tried out putting it in her deposit box. Cherry also looked at the public archive shelves and strong room where her art work and records would be kept if she decided to go ahead and deposit.

Figure 8 [insert artwork]: Cherry visits the archive strong room where her materials would be kept

Figure 9 [insert artwork] Cherry tries out putting prints of her own artwork on the public access shelves of the archive

A series of archive visits

Cherry's mother had observed that Cherry often takes control of a new space by a process of regular visits and in this way is increasingly able to demonstrate her feelings and reactions to what is happening there and to make choices. Therefore we felt it would be helpful for Cherry to visit the archive on three occasions and on each visit to try depositing in her own box left at the archive to give a sense of building up a collection about herself in a new space. The research team recorded the visits and used film and photographs to capture and review her responses. One concern had been that Cherry might be distressed by leaving some of her things behind at the archive but the team agreed that Cherry showed no sign of distress.

A public archive means sharing your story with strangers

Sharing of information with strangers is a key part of depositing material in an archive and the team carefully considered how we might support Cherry to understand this, and to communicate her feelings about this key aspect of the decision to deposit. Cherry had not previously met the community archivist and the team recorded her reaction to sharing her potential deposits with her. The film and photos in the pathway show that Cherry seemed to be enjoying sharing her items with this stranger. As an artist Cherry had also previously shared her artwork through public exhibitions. However, the team remained unsure regarding the degree to which Cherry understood the wider concept of the general public viewing her items and, depending on the personal nature of the material being deposited, any associated risk such sharing may bring.

Figure 10 [insert artwork]: Cherry shares her artwork with the archivist on their first meeting

Pros and cons – documenting and weighing up risks and burdens

In line with the MCA Code of Practice, we involved Cherry in listing the pros and cons of depositing her things in an archive, and weighing these up in order to make a decision. We did this during our meetings with Cherry, her parents, support staff and her grandmother and the local archivist. The researcher drew out the pros and cons on a flip chart, and as we did this Cherry's archive box and potential deposits were on the table as prompts. As pros and cons were raised by the family, the presence of the archivist enabled some of these to be addressed and removed by more flexible archive practice – for example making some sensitive items available upon written request.

A functional assessment of mental capacity

The MCA introduces a two-stage test of capacity: is there an impairment of, or a disturbance in the functioning of the person's mind or brain and, if so, has it affected the person's ability to make a particular decision? The law says that a person is unable to make a decision if there is evidence that they are unable to do any of the following: to understand the information relevant to the decision; to retain the information; to weigh it up (pros and cons); or communicate a decision. Alex Ruck Keene, a leading MCA barrister, when talking about what capacity assessments look like in practice, likens them to conversations with a person – a process of getting to know someone's wishes and preferences. But there will be occasions when – after all methods to maximise capacity have been tried and all reasonable steps have been taken to support someone to be involved in the decision – it is found that someone can't make the decision for themselves. In that situation, under the MCA, a decision can be made in the person's best interests.

After completing the pros and cons checklist with Cherry we needed to make an assessment as to whether, at this point in time, Cherry had the capacity to make the decision to deposit in her own right. The practice of substitute decision-making under UK law is contentious (Devi et al. 2011; Martin 2017) and has recently been challenged by the UNCRDP Committee following their review of UK disability practiceⁱⁱⁱ. However, the purpose of the pathway was to demonstrate legal compliance through a process that, in accordance with the Act, was as inclusive of Cherry as possible at every stage and we proceeded on that basis, using a supported decision-making approach to inform the best possible substitute decision making practice (Bogg with Chamberlain 2015).

The test of capacity was discussed with the group and Cherry's mother signed the capacity assessment record stating that at the point of time the assessment was made it was felt that Cherry was unable to demonstrate that she could weigh up and use the information about archives to make a decision. We agreed the decision would be reassessed in the coming year as Cherry was beginning to use eye gaze technology and this may support her to communicate further.

Best interests decision making in relation to archives

The MCA sets out a checklist that decision-makers must follow when making best interests decisions^{iv}. Our decision-making pathway contains an agenda tool, adapted from Graham and Crowley (2015), designed as a prompt sheet to help families, supporters and archivists hold a best interest meeting or discussion in the way that promotes the full involvement of a person with profound and multiple learning disabilities.

In Cherry's case, her mother made a best interests decision in relation to archive depositing after consulting carefully with several people who knew Cherry very well and taking their views into account. The best interests decision was for Cherry to go ahead and deposit her artwork and cards at her local archive, with the option of continuing to visit and add to her deposits. The best interests decision was made on the grounds that the benefits of depositing in terms of Cherry's work as an artist and her enjoyment of the archive environment outweighed any potential risks such as the risk of being traced, which had been addressed by the archivist's suggestions that any personal or sensitive elements of Cherry's collection could be available on written application. Cherry's collection of birthday cards and her artwork were then received into her local archive collection.

Co-producing a legally compliant pathway – to belonging

When we had completed our research on the decision, we began work on how this would be represented in the pathway tool. This was an iterative process with drafts exchanged between researchers, Cherry and her family, the archivist and the steering group. Cherry's support circle was involved in the selection and approval of all images and film clips used. A barrister specialising in the MCA reviewed the final content of the pathway and confirmed that it, and all attached documentation, was compliant with the legislation. They also argued that the best interest decision could be viewed through the lens of 'public interest' as well as 'personal interest', linked to notions of altruism and concern for others in the future (Lee 2017). This was a highly significant outcome for our research because it enabled people with profound and multiple learning disabilities to be viewed as potential agents in the wider political project of using history and heritage for social change. In addition, the legal advice pointed out that the Court of Protection had upheld the significance of the 'emotional dimension' of the best interests analysis. In *FP v GM and A Health Board* [2011] EWHC 2778 (COP), Hedley J stated at [21]: ^[11]_[58]“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.” We believe that the legal advice we received – citing the case of *FP v GM and A Health Board* - has significant implications for decision-making processes in relation to people with learning disabilities sharing their stories in the public domain, through archives.

Figure 11 [insert artwork]: A slide from the pathway tool showing how we worked with Cherry to weigh up the pros and cons of the decision

Figure 12 [insert artwork] A slide from the pathway tool showing Cherry was involved in the best interest decision-making process

Reflections on the pathway research process

At the end of our pathway research project we thought together about what had worked well and what we might do differently next time. We were positive about the careful documentation of some of areas that were more sensitive and difficult to approach. We also agreed that it would have been helpful for the archivist to complete an introductory home visit with Cherry at the outset and that the use of simple translucent sleeves would have enabled Cherry to handle some of art collection pieces for longer.

The final content of the pathway was agreed by all members of the team and shared with Cherry by her mother who reflected on the process of our pathway development:

What was nice is that we all were able to feel heard and that we took enough time to really change our minds if we wanted to or to think about things in a different way... To try things out that maybe worked or didn't work – not getting it right but getting it to start to happen. You learn from that don't you? You don't learn about it ahead when it's such a new, undone thing.

Figure 13 [insert artwork]: An example of Cherry's painting with Project Art Works that was deposited in her local archive

Figure 14 [insert artwork]: Self-portrait, by Cherry Lane, with Project Art Works. Photo credit: Layton Thompson, at www.laytonthompson.com

Conclusion

Doukas et al. (2017) emphasise that for people with profound and multiple learning disabilities and their families, having a fulfilling social and community life is more than simply being present – it is about enjoyment, thriving, and being visible. It is also about being actively involved, welcomed and accepted within local communities. The aim of our work with Cherry was to demystify and show what legally compliant decision-making looks like in practice for one individual with profound and multiple disabilities, specifically in relation to archive depositing. The archive learning officer who was working alongside the research team reflected that her practice with Cherry was similar to what she would do for any other visitor to the archive. In essence, this involves getting to know the individual and what they are interested in, finding items in the collections that relate to them or their experience, and showing the person how their deposit would be looked after.

Participation in heritage – specifically in public archives – is one way in which the visibility of people with profound and multiple learning disabilities can be heightened within local communities. As our research with Cherry showed, it also has the capacity to support people with profound and multiple learning disabilities – and their families – to visit new places,

spark new conversations and forge new social connections. Stereotypes can also be challenged, for example, Cherry's depositing of her work as a local artist. Representation in public archives is also fundamentally about having one's life and contribution acknowledged and valued. For these reasons, extending opportunities for people with profound and multiple learning disabilities to participate in public archives speaks directly to issues of belonging.

The legal advice we received during the course of our research emphasised that mental capacity legislation need not prevent people with profound and multiple learning disabilities participating in archives. The emotional dimension of the decision to do so – intimately linked to questions of representation, connectedness, value and legacy – means that people with profound and multiple learning disabilities have emerging opportunities to be more active participants in heritage.

The final word goes to Catherine de Haas, a parent and participant in Phase One of the research:

My daughter Johanna and I attended two workshops in which the research team were asking for our views and ideas on the involvement of people with profound and multiple learning disabilities in archives. Johanna has profound and multiple learning disabilities and we are used to communicating with her without words and to making decisions together, so we felt we had a lot to contribute. We were both very excited to be in a venue where we were treated equally.

I am pleased that a pathway has been created to deposit our story for ordinary people to learn about families like ours. During Johanna's lifetime I have learnt the importance to our quality of life of helping extended family, friends and potential friends to feel comfortable communicating with Johanna. She is unable to speak to them. I believe increased knowledge of profound and complex disabilities through archived material will help families like ours to have a better life story. It's hoped it will help society in general to understand us and offer appropriate support and inclusion.

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ⁱⁱ Cherry worked with Project Art Works. The technique of filming Cherry with a mini camcorder and projecting it on a wall for her to watch, before freezing and painting over the projected image, is one that Project Art Works have used often with artists with Profound and Multiple Learning Disabilities.

ⁱⁱⁱ Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), as interpreted by the Committee on the Rights of Persons with Disabilities, offers a vision for the law's response to capacity impairments which differs in crucial ways from that contained in the Mental Capacity Act 2005 (MCA) that applies in England and Wales. The Committee rejects both differential treatment on the basis of an application of a functional test for capacity and the use of the Best Interests standard for decision-making. Instead, it requires that the "will and preferences" paradigm must replace the "best interests" paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others.'

^{iv} Under the Mental Capacity Act 2005 (England and Wales) if a person has been assessed as lacking capacity then any action taken, or any decision made for or on behalf of that person, must be made in his or her best interests. The Act provides a non-exhaustive checklist of factors that decision-makers must work through in deciding what is in a person's best interests. A person can put his/her wishes and feelings into a written statement if they so wish, which the person determining capacity must consider. In addition, people involved in caring for the person lacking capacity have to be consulted concerning a person's best interests.