

**Creating a Living Electronic Archive With and About People With Learning Disabilities: Methodological Considerations**

**Peter Williams [[1]](#footnote-1)**

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| ***Article history:*** |  | **Abstract** |
| *Submitted:* 01.12.2021*Revised:* 15.01.2022*Accepted:* 15.02.2022 |  | This article examines the issues inherent in the construction and population of a ‘living electronic archive’ of the testimonies of people with learning disabilities (PWLD) on their experiences of ‘smartphone’ technology. It enabled a somewhat neglected cohort both to have a voice and to see their contributions displayed on a personal archive page, rather than be mere research data for an academic researcher. Project findings, in terms of smartphone uses or benefits etc., are reported elsewhere. This paper considers instead issues related to archive design and methods to facilitate the creation of testimonies by a learning-disabled cohort. Prior work has been extremely limited. Autobiographical books and a small amount of material online recounting the lives of PWLD exist. However, there appears to be no resource that includes links between contributors, is directly searchable, or ‘living’ (including a facility to update, delete or add to individual entries). Intensive meetings with various stakeholders, including PWLD, led to the adoption of various site features to ensure safety and anonymity whilst permitting easy access to other people’s testimonials. Moderation was also judged necessary to prevent inappropriate material. An innovative method was developed to create content. Participants were interviewed, but after every question they were invited to review, add to or modify their answer, as the archive testimony was gradually built-up. The common practice of including ‘non-verbal’ utterances was eschewed, so participants were not exposed to any shortcomings in their language or expression on reviewing content. This iterative technique elicited several other benefits. First, by constantly reviewing, elaborating and modifying responses extremely rich data was accrued and the participants were more engaged. It eliminated the need for participants to read through burdensome interview transcripts, post-hoc. Finally , the method could be exploited by researchers working with other cohorts who might find self-expression difficult.  |
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**1 Introduction**

Collections of the direct testimonies of people with learning disabilities regarding various aspects of their lives are rare (Keilty and Woodley 2013, and Deacon, 1974 being examples). The very few formal archives that exist are either in hardcopy or unavailable to the public. The Open University (OU, 2015) has modest amounts of material online, comprising of narratives of various individuals, and the Trinity Centre for People with Intellectual Disabilities at Trinity College, Dublin runs a project entitled ‘A story to tell’, consisting of ‘people's reminiscences about past experiences, told to another person or persons at various points in time’ (TCPLD 2020: online). The research project, its web site promises, ‘will soon be available to download and read’.

Despite these initiatives, there does not appear to be any resource that:

###### includes multimedia or links between contributors;

###### is directly searchable;

###### is dynamic and ‘living’.

This paper reports on an initiative (part of a programme of research entitled ‘The digital lives of people with learning disabilities’) to create a ‘living electronic archive’ created and developed by people with learning disabilities themselves, around the theme of mobile technology . To undertake this, participants related their experiences of using smartphones and other devices – the extent to which they used the vast array of functions/apps etc., the benefits they felt accrue from their use, the barriers they may have encountered, and how they thought the devices (and, indeed, the support they received in using them) could be improved. Findings related to these topics have already been reported extensively in the academic press (see, e.g. Williams and Gibson, 2020; Williams and Shekhar, 2019; Williams, 2019a, b). This paper discusses instead the dynamics of creating the archive and the method used to help participants create their testimonies.

**2 Literature Review**

**2.1 Learning Disabilities Defined**

A Learning Disability can be defined as ‘a condition of arrested or incomplete development of the mind that can occur with or without any other physical or mental disorders and is characterized by impairment of skills and overall intelligence in areas such as cognition, language, and motor and social abilities.’ (WHO, 2007: p101). Problems in adaptive, or social, functioning often accompany a learning disability. According to BILD, the British Institute of Learning Disabilities (Holland, 2011: p3) ‘three criteria are regarded as requiring to be met before a learning disability can be identified or diagnosed. These are: intellectual impairment (IQ), social or adaptive dysfunction combined with IQ [and] early onset’. It is common in social care or in assessments for benefits, for example, to classify learning disabilities as being ‘mild’, ‘moderate’ or ‘profound’. (NADP, n.d.) The work described in this paper was carried out with people in the ‘mild’ end of the spectrum. Such a cohort is ‘able to hold a conversation, and communicate most of their needs and wishes. They may need some support to understand abstract or complex ideas’ (Ibid: p4). People with mild learning disabilities are usually ‘functionally literate’. This has been defined as ‘reading that is used for basic survival, such as being able to read street signs’ (Deagle and D'Amico 2016: p.164).

**2.2 Prior Work in the Area**

Much work in this area has concentrated on supporting people with learning disabilities relate their life stories. The oral historian Dorothy Atkinson (often together with Jan Walmsley) has undertaken extensive work on such autobiographical endeavours (e.g. Atkinson 1997, 1998; Atkinson and Walmsley, 1999). The driving force behind this work is that of making it possible for people with learning disabilities to represent themselves. She views the process and product of an autobiography as giving a voice to ‘marginalised and oppressed groups’ (Atkinson and Walmsley, 1999: p74). ‘Telling of one's [own] story’, the writers continue, ‘whether as part of an oral history project or as sole auto-biographer, means recognising [the past], claiming it and, ultimately, being 'authenticated' and 'empowered' by it. The auto- biography gives substance to the life, and the social world, of its subject.’

Atkinson (see, e.g. Atkinson et al, 2000; 2005) and Jan Walmsley (see e.g. Walmsley, 2000) run The Social History of Learning Disability (SHLD) Research Group, based in the School of Health, Wellbeing and Social Care at The Open University (OU) which also carries out a great deal of autobiographical work (e.g. Mitchell et al [Eds.], 2006; Walmsley [with Changing Our Lives], 2012) . The group’s website contains links to two autobiographical accounts by people with learning disabilities about their lives and their experiences of being cared for (See SHLDG, n.d.)

Atkinson (2010:p7) uses the term ‘expert witnesses’ in arguing that testimonies by this cohort are both valuable and useful (e.g. to service providers), and argues that despite problems in articulation, those providing testimonies know more about their own experiences than professionals or academics, and ‘are not simply sources of data for researchers’. Grant and Ramcharan (2009: p29) describe this as being ‘expert by experience’. Whilst aspects of this approach may be questioned - including by the present author (Williams, 2020) – it is, nevertheless, a useful guide to follow when eliciting testimonies from vulnerable (or indeed, other) groups.

In addition to pure autobiographical accounts, testimonies relating people’s experiences with, and evaluations of, service provision are common. For example, Richardson (2000) examined people with learning disabilities’ views on their lives and experiences of living in nurse-managed community homes’, and Head et al (2018) looked at the experiences of people moving from hospital to supported independent living. Researchers have also looked at various other topics, such as stigma (e.g. Ditchman et al 2016), employment (e.g. Romualdez, Yirrell and Remington, 2020), advocacy (e.g. Duffy, 2007), the impact of technology (e.g. Seale, Choksi and Spencer, K (2019) and relationships (e.g. Bates, Terry and Popple, 2017) including parenting (e.g. Franklin et al , 2021).

Despite this apparent abundance of material, the latter works all comprise edited accounts from research participants, where academics have used answers to interview questions to explore their own research agenda, where the participants (the ‘subjects;’ of the research) cannot not normally possess their testimony, (although in many cases they may be able to review and amend it) and have no access to those of their participating peers. Non-participants (including the academic community) see only quotes from it that are selected by the researcher for inclusion in an academic paper, rather than full, original accounts. The Digital Lives project, to which this paper now turns, attempted to redress this balance somewhat, by giving project participants unlimited access to both their own testimonies and those of other participants, via the ‘living’ archive.

**3 Materials and Methods**

**3.1 The Digital Lives Project**

The mobile ‘smart’ phone has become ubiquitous in the western world. Statistica (2021) reports that penetration rate in the United Kingdom reached an overall figure of 92 percent in 2021. Use by people with learning disabilities in the UK is, however, significantly lower it seems. OFCOM (Office of Communication) (2019) in the UK puts the figure at 62%. One in ten people with a learning disability in a survey run by OFCOM (ibid: p7) said they were limited or prevented from using the internet, landline, smartphone or any other type of phone with and 10% of the cohort report being limited or prevented from using devices due to their disability.

The aims of the full project were to explore aspects of the experiences of this cohort in using digital, and in particular mobile, technology in everyday life – as described in the introduction. As with the full project, the construction of the archive as a repository for the data accrued was guided by the evidence suggesting that people with LD still face ‘societal-wide exclusion and discrimination’ (Simplican et al, 2015: p22), and are used to having others speak on their behalf. Involving them as informants, contributors and, in effect, co-researchers aimed to facilitate digital inclusion and empowerment– both in eliciting, recording and disseminating their ‘digital lives’, and in undertaking inclusive, participatory research (Hollinworth et al, 2014; Cook and Inglis, 2012; Nind and Vinha, 2014). Having ones on page on the archive, self-written and constructed may have been a source of personal pride and a sense of achievement, and being permitted access to one’s peers pages on the archive enabled people to compare experiences and may have given individuals ideas and information about how they can exploit the technology to a greater level. This would be occasioned by learning about apps and services used by others that they may not have used or known about.

**3.2 Methodology**

*Population and sample:* The population from which the sample was drawn was that of people with ‘mild’ learning disabilities, as described above. The only limitation on age was to set the lower limit at 18 to restrict the study to those legally classed as adults - working with younger people would entail an added layer of ethical documentation in addition to a possible modification of protocol. Recruitment was via ‘Functional Skills’ departments at Further Education colleges; attendees at adult day centres; voluntary groups (i.e. such as Mencap) etc. around London and the south east of England. To enable supporters to identify potential participants, a participant profile was drawn up using criteria provided from a report which investigated adult literacy in England, and graded literacy levels into Pre-Entry, Entry (1,2,3) and mainstream Levels (Moser, 1999).

In total 72 people were interviewed. Due principally to technical problems with the archive, the number of people contributing to the archive was limited to 22. Thirty-two ‘supporters’ (parents, carers or tutors) were also interviewed to elicit their experiences of using mobile devices with those whom they support.

*Data gathering:* The research was qualitative in nature. Group interview sessions formed a large part of the fieldwork. Participants were encouraged to tell each other about their experiences with mobile technology, in an informal a general discussion. Themes such as the experiences, benefits and difficulties of using both the hardware and software were considered. During the discussions participants who had phones (where these were to hand) were encouraged to show how they used them – the ‘apps’, the keyboard, the browser etc. and to say what they find difficult or are not able to do with their phones. Those without phones were also asked for their opinions. In this case, reasons for non-ownership were sought, along with their experiences of phones belonging to their family or friends.

Individual interviews were undertaken after the group sessions. Here participants elaborated on any contributions they may have made in group discussions and – crucially – demonstrated how they used their phones (e.g. if they said they listen to music, they showed how they access their collection (and indeed, how it was acquired). Thus, usability was examined naturalistically, by observing for what and how participants used the technology and its constituent applications, and asking about any difficulties and noting any particular issues observed during the sessions. The way these individual interviews were undertaken developed during the project, and the final method used – discussed later in this article – became one of the project’s outputs in the form of an alternative (and in that sense, ‘innovative’) method of data gathering and recording.

As this paper is concerned with issues that arose in the construction and population of the archive, findings regarding the actual theme of the resources (the experiences of mobile device use) is not discussed. The reader is invited to explore these in Williams (2019a,b) and Williams and Shekhar, (2019). Here, the topics to be discussed are the issues that arose during the course of the research around the construction and content of the archive itself, and the methods by which the testimonies of the project participants could be elicited. These are discussed in turn, beginning with the archive construction.

**4 Results and Discussions**

**4.1 Archive Construction and Content**

The construction of the archive was undertaken in tandem with discussions around accessibility and general ease of use, privacy, different levels of permissions and various technical issues related to functionality and server hosting which are beyond the scope of this paper. Contributors to meetings where issues were discussed were various academic colleagues of the researcher, representatives from the University College London Ethic Committee (from which permission had already been granted to proceed with the fieldwork), the university’s Information Services Division (ISD) who were in charge of the provision of technical services at the university, supporters of the cohort at various fieldsites where initial visits were made. Mock-ups of the interface were also shown to members of the cohort themselves for their input. The resulting archive interface can be seen in Figure 1.

The text in the page shown (as with every page) was written by a project participant. Its production is described in detail below. Suffice to say here that posts were written in the presence of and together with the researcher. The original plan was for the research to return on two or three more occasions to talk to participants again and to enable archive contributors to add further posts to their individual pages. However, technical and other delays to the archive construction precluded this. Similar problems made it difficult for them to add posts autonomously (or with the help of a supporter) without the researcher, who had sole authoring rights. Other than this constraint, demanded by the technical support team at University College London (UCL) it would not have been appropriate for participants to be able to edit or add to each other’s posts either. Finally, the archive content contained valuable research data (albeit backed up elsewhere) and there would be a strong chance that additional unmoderated or mediated posts would stray well off-topic.

With regard to the actual content of the posts, an issue to resolve was the extent to which participants would be free to express themselves without being censored. It was felt that, in a sense contrary to the inclusive ethos of the study, there had to be an element of moderation. Indeed, neither the UCL Ethics Committee nor the ISD permitted the autonomous or unsupervised posting of material on to the archive, so no further consideration of that aspect of the issue was necessary. Off-limits, during interviews with the researcher that produced the archive testimonies, were comments that might be considered offensive or even illegal to express. Whilst the former is, of course, subjective, they may include discussion of acquaintances, relatives or supporters in derogatory or inflammatory terms. Examples of topic that might be considered more generally offensive (or illegal) might be homophobic, racist or otherwise discriminatory comments. An unwritten rule was that only content that does not hurt or criticise others may be allowed to be viewed by others. As it turned out, in fact, there were no cases where participants needed to be informed of this or of any form of content moderation needed.

Privacy was another important factor. Even with the ‘walled-garden’ nature of the resource, where access was limited, there were possibilities for others to copy and re-distribute images or contact details etc. Although it is good practice to try and offer as much autonomy as possible to people with learning disabilities (indeed, in the UK this practice is enshrined in the Mental Capacity Act 2006) in some respects they may be considered vulnerable. Holmes and O'Loughlin, (2014), for example, detail problems people the authors support have had using Facebook. The present author (Williams, 2019b) also elicited accounts of negative experiences on the same platform in his ‘Digital Lives’ work. Thus, it was decided to not include any identifying information on posts. This, therefore, precluded full names, and photos, both of the contributors or their circle of friends and family. Most photos uploaded were actually taken from the Internet (photos of a jigsaw puzzle, a keyboard, the ‘WhatsApp’ icon etc.) Personal photos included a pat dog, a holiday scene and (more unusually) a cereal packet.

By contrast, posts were to have a comment box underneath the main content for supporters or other participants to make observations and enrich the content of the original post. This was to be only in the presence of the researcher (who had unique access to the proposed comment box) and with the permission of the post author, but in the end there were too many logistical and other problems to make this work. The former included the need for all the players to be in one place and having the time and inclination to add comments. The latter included the ethical hurdle of permitting the practice, even given the safeguards. Thus, the aspiration of having a ‘living’ archive could not be fulfilled.

*Figure 1: Archive interface showing participant entry*

Each post had index tags assigned to it for retrieval purposes. The author of each was also tagged in the ‘back office’. Contributors were thus able to search on their own name to access their content in a continuous series of entries. In addition to a search engine (top right in Figure 1), clicking one of the tags (those of the individual post or of the ‘popular tags’ accumulated on the left-column of the page) retrieved all posts with the same tags (and therefore topics), without needing to search. Such simplified searching is, of course, of great benefit to people with learning disabilities.

Users could also read each individual post by browsing – in other words, scrolling down, as posts were arranged in a continuous feed, such as is the case with Facebook-style. The set-up configured messages so that only the first 250 words of each post were visible, with a ‘read more’ link to open the page containing the post’s full content and supporter and other comments. In practice, only two posts surpassed this threshold.

Not shown in the figure is the log-in. As mentioned above with regard to the content of posts, a major concern was privacy, and so the site was password protected, with read-only access provided to participants, including supporters and professionals and academics interested in the project who had sought access. The log-in was a very simple four-letter name, and coding in the software prevented search engine crawlers (or ‘bots’, ‘robots’ or ‘spiders’) from indexing pages and, therefore, making them visible. The URL and password were by invitation only!

**4.2 Creating Content**

The above account discussed content both in terms of the platform on which it sat and in what was permissible to include. This section discusses how that content was created. As mentioned earlier, process developed into an alternative method of gathering and recording data. This happened because of the particular circumstances of the project and its emphasis on personal testimonies and in the publication of these (at least within the participant group). It was felt that to create an authentic personal testimony it was not sufficient to simply record a ‘standard’ research interview and post a transcript. Even allowing – and encouraging – participants to read through their transcript and edit it down or otherwise modify it was considered too onerous, particularly considering the difficulties such an academic practice might incur.

As an alternative, the researcher instead made notes on his laptop as the interview progressed. However, unlike in traditional fieldwork note-taking, during which half to two thirds of data can be lost due mainly to missing certain points made by interviewees (Kieren and Munro, 1985, quoted in Tessier, 2012), after the response to every question, or after any lengthy exchange (or even when the interviewees’ comments came too quick to be accurately typed), the researcher would read back the notes to the interviewee. This enabled immediate feedback from the latter, who could therefore correct, rephrase or add to the notes made. Having agreed a final text, the interview would move on to the next point, where the process would be repeated. Thus, the personal testimony was thus developed iteratively and collaboratively over the course of the session. Although the preliminary group interviews did not produce archive pages, the method was, nevertheless, also used for these.

The final element of the method related specifically to the *archive* content, as opposed to the full content of the interviews. Participants did not necessarily wish all of their testimony to be used for it. Indeed, the majority wished to concentrate on just one topic within the answers they gave. Thus, one person only wanted his observations around his online gaming to be included. Another was keen to only alert others of the dangers of chatting to strangers online. A minority, however were happy to include everything she spoke about to be included. To edit the content down to facilitate these wishes, the researcher and participant would go through the testimony, so the latter could indicate what to delete or summarise. In the case of summarising (or, indeed, expanding a appoint) the participant would instruct the researcher who would edit the notes on his laptop. In some cases help was sought by the participant, and so the form of words was developed together. Either way, by the end of the session, an ‘archive-ready’ version and a full version of the interview notes existed. It is worth noting that the full version was retained (with the permission of the interviewee) and available for use as research data, as befits an academic research project, despite not appearing on the archive.

Undertaking the data collecting in this manner elicited several benefits. First, reviewing constantly through the interview process and encouraging elaboration and further observations arguably accrued more rich data than proceeding without referring interviewees back several times to what they had said.

Second, and related to the above, by being positively engaged at all points with the data - and even, to an extent, with its analysis (by, for example, interpreting and explaining their own comments) participants may have developed a better idea of the research process itself. Third, by this reviewing of content as part of the interview process, there was no burden on participants to have to sit and read through a lengthy transcript or audio-recording of their interviews, post-hoc. Even reviewing their final testimony in full was less of a problem, as the earlier method of iteratively producing it gave each part of it a familiarity – and, of course, due to the same practice, major changes were unlikely to be requested.

Third, the practice eliminates the practice (in the view of the writer, unnecessary anyway) of including in transcripts ‘all verbal utterances … both actual words and non-semantic sounds – such as “erm”, “err” [and] …”mm”’ (Braun and Clarke, 2013: p163, who recommend doing so) and by doing so, potentially humiliating participants in the course of their reviewing their contributions. Carlson (2010) writes with feeling about how her interviewees reacted in embarrassment and shame when faced with evidence of the inadequacies of their speech such verbatim transcripts had exposed.

**5 Conclusion**

This paper has described a research project which explored how mobile technology impacts on people with learning disabilities. Rather than discussing the findings, however (available elsewhere, as indicated) its focus has been on the method of data gathering and the construction of a living electronic archive consisting of the personal statements of participants around the issues. The paper has shown how it is possible, when researching with this cohort (and possibly with others, in fact) to positively engage the ‘subjects’ of any study in the research process itself, to make their contributions tangible (in the form of their own archive page) and to avoid the burdens that constitute transcription checking, including the intellectual effort, time taken and (of more importance) confronting, in print, the inadequacies of their articulation.

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**Biography of Authors**

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|  | Peter Williams is a Post-doctoral Research Associate, based in the Department of Information Studies at University College London, UK. He is currently working on the MIRRA+: Memory – Identity – Rights in Records – Access (phase two) project. Prior to this he completed a three year full-time Post-doc Fellowship from the British Academy, entitled ‘Digital Lives’,  investigating the role of ‘digital technology’ in the lives of of people with learning disabilities. This culminated a long period of researching the use and value of Information Technology (in particular, the Internet) by people with learning disabilities. He completed his PhD in this area in 2013. In addition to his learning disabilities work, Pete has investigated the use of the Internet and other ICT applications in the fields of education, health, scholarly communication/research, and the news media. *Email: peter.williams@ucl.ac.uk* |
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