THE DIGITAL LIVES OF PEOPLE WITH LEARNING DISABILITIES: METHODOLOGICAL CONSIDERATIONS

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Mobile technology is becoming ubiquitous, with usage ranging across such diverse activities as direction-finding, music storage, photography, texting, checking social-media, accessing newspapers and watching TV. This paper describes a major study examining the use of such technology by people with Learning Disabilities (LD). It concentrates on the issues related to undertaking research with this specific cohort – such as difficulties participants may have in generalising, abstract thinking, and the possible tendency to simply agree with comments or questions made by the researcher (known as acquiesce bias) - and methods being adopted to minimise or obviate these completely.

Keywords: Learning disabilities, Mobile technology, Methods.

Introduction

Digital Technology is becoming ever more used by people with Learning Disabilities (LD) for entertainment, to socialise and enjoy self-expression (Holmes and O'Loughlin, 2014; Alper, 2014). Despite this, there has been very little research into the experiences of such technology by this cohort, it's role in articulating personal identity and self-advocacy (Kwiatkowska et al, 2012), and the barriers encountered in negotiating technology in everyday life (Williams, 2011). Considering how important and all-embracing smart phones, tablets, computers and their accompanying functionality/apps etc. are in today's society, such research is clearly needed. The British Academy, the UK's national body for the humanities and social sciences therefore funded a three-year project, 'The Digital Lives of People with Learning Disabilities', exploring this topic as part of its Post-Doctoral Fellowship scheme.

The aims of the project are to examine:

- The experiences of people with LD in using Digital Technology in their everyday lives – the benefits, in terms of entertainment, self-expression, socialising, and possible greater autonomy; and the barriers, such as accessibility or usability issues, privacy or vulnerability concerns etc.;
- How the technology, and in particular the software/apps and interfaces, can be improved to enable the greater access to entertainment, information, communication and other benefits it can offer.

By the time of its conclusion (September 2019) the project will have worked with approximately 80 adults of all ages who have 'mild' learning (or 'intellectual') disabilities. Such people can function fairly well in society and may be able to undertake supported employment, although they find everyday tasks, such as managing their finances or explaining problems to their doctor, a little challenging. For this project, participants are being chosen who are able to read basic texts and write simple sentences.

Several methods – all of them qualitative - are being adopted with the LD participants to gather data. These include interviews and focus group and activity sessions. This paper concentrates on the methodological issues inherent in data-gathering with this particular cohort. It then outlines the methods adopted, with reference to how consideration of the issues informed the conduct of the fieldwork.

Methodological Issues in Working with People with LD

There is a growing body of literature about undertaking research with people with LD (Tuffrey-Wijne, Bernal and Hollins, 2008; Goodwin et al, 2015; Kellett et al, 2010). Much of it is concerned with ensuring full participation of research 'subjects', by attempting to be as inclusive as possible (Nind, 2014, outlines research even designed or led by the cohort), at the very least by ensuring that information sheets and consent forms are accessible (Farrimond, 2013). Other papers emphasise the need to ensure the comfort and well-being of such a vulnerable group (Porter and Lacey, 2005; Rogers, 1999). Within this corpus, special considerations arising in interviewing people with LD are described by many commentators (e.g. Brewster, 2004; Booth and Booth, 1996; Shepherd, 2015).

Booth and Booth (1996) outlined the major difficulties people with LD have in engaging in an interview. These include problems in:

- Thinking in abstract terms, such as about the future or attempting to quantify their feelings;
- Generalising from experience (although this could be regarded as an aspect of 'abstract thinking'), being unable to 'reconstruct … the meaning of the past from a position in the here-and-now in order to give meaning to the present' (Ibid: p.57)
- Conceptualising time - and so having problems discussing frequency or duration;
- Articulating views and choices (It could be argued that another problem is actually enjoying 'having a choice' in the first place. Treece et al (1999) point out that many people with LD have little experience in being asked or, therefore, formulating views, preferences or ideas).

Another major issue is that of 'acquiescence bias'. This is the phenomenon of agreeing with a researcher (or, indeed, anyone in real or perceived authority) with little heed taken of the question or comment. Meisenberg and Williams (2008) found that individuals who demonstrate an acquiescence bias tend to be less educated and intelligent, and Heal and Sigelman (1995) note a tendency for this cohort to concur with closed questions – a phenomenon succinctly put by Carol Sigelman and colleagues (Sigelman et al. 1981) as 'if in doubt, say yes'. Prosser and Bromley (1998: p108) feel that, 'acquiescence is more common when the question is not understood or when respondents do not know how to answer [it], although it can also be a way of seeking social approval' With regard to the latter, 'the respondent may reply 'yes' even when he understands the question, but replies yes because he believes that a negative or other answer will displease the interviewer' (Ibid: p108, citing Shaw and Budd 1982).

Rapley and Antaki (1996), however, describe research which suggested that participants were, in effect, led to the position of acquiescence. The authors analysed interview transcripts from 'the administration of a Quality of Life questionnaire as part of a Psychological Services audit of a supported-housing network in … England' (p212), from which they conclude that research interviewees:

> 'may be shepherded into apparently inconsistent answers by: the need to formulate and reformulate responses to questions; the interviewer's pursuit of pre-existing expectations of what the "correct" answer is; the interviewer's drive to obtain an answer in the official vocabulary of the interview schedule; and the interviewer's misconstrual of the interviewee's active engagement with the task of producing careful answers by checking with back-channel responses' (p213).

The authors conclude from their analysis that 'strategies we see people with LD use are all taken from the normal repertoire of conversational management' (p215). Any 'acquiescence bias' elicited in their study was not found to be 'automatic yea-saying', but 'a collection of various strategies demonstrating their attention to the manner and sequence of [questioning], and to [other] demands …. In spite of any

cognitive limitations …, people with LD demonstrably try to make sense of .. the interviewer …[and] respond accordingly' (p215)

This section has shown that there are several particular considerations in play when interviewing people with LD – including the need for vigilance on the part of the researcher to avoid pre-conceived ideas about participant responses. The next section examines the methods used in the present study and how these problems were addressed.

Methods Used and How Problems Were Obviated

Interviews with people with LD for the 'Digital Lives' project centre around the method of 'narrative inquiry'. Connelly and Clandinin (2006, cited in Bowler, Knobel and Mattern, 2015) define narrative inquiry as the study of personal experience as story (p. 375). It is a way of inquiring into and thus understanding experience through 'collaboration between researcher and participants, over time … and in social interaction,' (Clandinin and Connelly, 2000: p.20, quoted in Clandinin and Huber, 2010: p436).

A very small amount of work has been carried out with people with LD using narrative inquiry. Grove, (2015) explored the practice of 'storytelling', undertaken to give people with LD a voice and greater confidence and enjoyment in an institutional setting. Ankeny and Lehmann, (2010) used the method to explore the experience of students with learning or 'mild mental' disabilities in a college transition programme.

Of more relevance to the present study, however, is a study undertaken by Bowler, Knobel and Mattern, (2015). The participants in this study were college undergraduates, but the relevance is because it explored use of digital technology. In this case the focus was on cyberbullying ('a way of emotionally distressing somebody over technology' [p.1274]). Two storytelling sessions were conducted where (9) participants discussed possible 'players' in a story about cyberbullying, and then drew a series of sketches forming a 'storyboard' to illustrate their ideas. After this had been generated, design interventions were considered that would discourage or prevent the cyberbullying behaviour their accounts depicted.

For the present study, narrative inquiry is being used in both individual and group interviews, with the latter being preferred where possible. As Daems et al (2015:p76) points out, group interviews 'have the advantages of a group dynamic that can help build confidence, safe environments that are not threatening or intimidating and peer support and validation, all enabling people with learning difficulties to contribute to research discussions'. This method also, it is felt, enables discussion without the need to think in abstract terms or to generalise. Indeed, the burden of generalising falls upon the researcher, to do so using the evidence of many stories, observations and opinions. Similarly, there is no burden on participants to conceptualise time – recounting a 'story' can be considered to be a type of 'critical incident' (Flanagan, 1954), which specifically sets out to obviate problems both of accurately reporting frequency and of generalising. Finally, the method minimises the problems highlighted of the researcher 'leading' participants to answer questions in a particular manner.

The 'stories' participants describe and discuss centre around a particular themes established in discussion with parent, carer, tutor or other supporter. These 'gatekeeper' know the participants and are able to suggest which themes may be suitable (this may seem a little 'controlling', but where some participants do not own smartphones, for example, certain themes would be precluded). Themes include:

- How I learned to use (a computer, tablet, mobile phone etc.)
- The day my mobile really helped me (and on other occasions the converse, 'the day my phone didn't help')
- My digital day (i.e. a chronological narration around use of technology as the day goes on, including much prompting. Here, televisions are included (as elsewhere, in fact) in the category of 'digital technology').
- My digital friends / relatives

Where time permits and participants choose, a general discussion is initiated, usually from the narrations. The idea is to prompt explore themes such as the benefits, experiences and difficulties of using both the hardware and software. During the discussions participants who have phones are encouraged to show how they use them – the 'apps', the keyboard, the browser etc. and to say what they found difficult or were not able to do with their phones. Others are also asked for their opinions about smart phones. In this case, reasons for non-ownership are established, along with their experiences of phones belonging to their family or friends. The discussions are then broadened out to using other hardware, such as laptops, tablets or digital cameras. The discussions include light probing on topics such as agency (i.e. who had control) and support, the impact on social interaction, assistive technology and other relevant topics.

In these fieldwork sessions, Prosser and Bromley's (1998) useful 'checklist' of how to interview people with LD, is being used to aid comprehension. The list (neatly summarised by Perry, 2004), includes the following recommendations:

- Use: short words, single-clause sentences, active verbs and the present tense when possible;
- Avoid: questions about abstract concepts, jargon, figurative or colloquial language.

With regard to acquiescence bias, Heal and Sigelman (1996) approached this problem by eschewing yes/no questions in favour of either/or (in a 'quality of life questionnaire'). This was a tactic also adopted by the present writer (Williams, 2013; 2017) in examining website layout and functionality preferences. For the present project, it is important not to appear to be either in favour of or against technology. Participants are thus told it is *their* views and *their* stories which are important. Also, where possible, several visits are being made to each site, in order for the researcher to become a familiar and trusted figure, rather than someone in authority to whom it is advisable to defer.

Conclusion

This paper has outlined a major research programme in the field of LD and technology. The aims and scope of the research are described, followed by an exploration of the methodological issues inherent in obtaining data from this cohort. Several issues were elicited, including participant difficulties in abstract thinking, generalising from specific experiences and quantifying time. 'Acquiescence bias', the tendency to simply agree with what is being said (typified in answering 'yes' to the polar 'yes/no' type questions) was also explored. Deficiencies manifested by researchers, also documented in the literature, were discussed. Clearly, especially when considering the wider issues mentioned – such as ensuring the well-being of people who are vulnerable and that they understand what is expected of them – there are a large number of issues that need addressing.

This paper argues that utilising a 'narrative inquiry' approach obviates many of these problems. Few questions need to be answered - the participants are encouraged to simply tell their stories, discuss them and show what they do on their devices. 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 and contributors to a major study will facilitate digital inclusion and empowerment. The ubiquitous nature of Digital Technology will mean that an exploration of its use will provide a rich picture of 21st century life as a person with LD.

Acknowledgements

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