"It all sounds very interesting, but we're just too busy!": Exploring why 'gatekeeper' supporters of people with learning disabilities sometimes decline to give access to potential research participants

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Abstract

A consideration of the impact of information technology on the lives of people with learning disabilities is vital in the promotion of digital inclusion. This paper explores barriers to access to this cohort, for recruitment to research exploring this topic. Unlike prior literature, which tends to focus on potential participants themselves, it explores instead the role of 'gatekeepers' - professional or informal supporters who provide access to the cohort. Such people have the power to grant or deny researchers the right to approach vulnerable individuals, and sometimes take it upon themselves to pre-select potential participants based on their own sometimes flawed conceptions of what the research requires.

Drawing on the author's recruitment experiences in a current project; his previous projects with similar cohorts; and the existing literature, a framework-analysis of fieldnotes, interview data and other documents elicited three main overlapping and interconnected factors Protection of vulnerable people, and of self, as gatekeeper; and others; Institutional factors such as policies and relationships; and Research factors, such as mis-conceptions about its nature, and the lack of perceived benefits.

Tentative suggestions are made to help overcome these issues, although it is acknowledged that both initial non-responses, time constraints and other factors conspire against obvious most measure that could be taken (such as to liaise frequently with gatekeepers). The paper concludes by opining that the most effective policy is to make sure the research itself is justifiable in terms of aiding the lives of participants and their peers, gatekeepers themselves and the wider community.

Keywords
Learning disabilities, participation, recruitment access, gatekeepers

Introduction
Research aiming to understand and improve the lives of people with learning disabilities clearly follows the inclusive agenda admirably illustrated in the UK Department of Health's (2001; 2009) now historic White Papers on 'Valuing People', and research methods literature by inclusive champions such has Nind (e.g. 2014) and Walmsley (2014). A crucially important element to such research is, of course, access to and the recruitment of study participants. However, according to Blanton et al (2006: p647), 'participant recruitment is considered the most difficult aspect of the research process'. Although this may be a slight exaggeration, it is certainly true that there are particularly difficult recruitment hurdles to overcome in the case of vulnerable people.

This paper explores barriers to access to vulnerable people, with particular emphasis on the role and power of 'gatekeepers'. To define terms, 'access' here means access to potential participants in order to undertake the process of *recruitment* (i.e. distribute information leaflets, discuss the research and, to those who indicate that they are prepared to consider participation, offer consent forms to sign). A gatekeeper is 'someone who controls access to an institution or an organisation such as a school principal, managing director or administrator' (Singh and Wassenaar, 2016: p42). As such, gatekeepers have the power either to grant or withhold access to a research population (De Laine, 2000).

The author is currently undertaking a research project, 'Digital Lives', examining the impact of mobile technology on the lives of people with LD (see Williams, 2017a). Although this is a qualitative study, nevertheless it is hoped to recruit around 80 participants, to be interviewed in small groups and individually. The aim will be to discuss and demonstrate their mobile device activities, and for the participants themselves to create their own web page documenting their thoughts and experiences. Previous research by the same author (e.g. Williams, 2017b, 2013, 2012; Williams and Hennig, 2015) showed how difficult participant recruitment can be, and so for this present project it was decided to document the difficulties arising, with a view to making recommendations for future researchers in the field with regard to avoiding problems and enhancing recruitment. To provide a more comprehensive account, fieldnotes from previous projects undertaken by the author that also required the services of gatekeepers were also consulted. These also contained data on difficulties in this area and, thus, informed the present paper.

Gatekeepers can provide access to any potential research participant – even those with considerable power. In the past, for example, the writer gained access to national journalists through news librarians working for different newspapers (Williams and Nicholas, 1997), although in many cases it was possible to gain direct access to our sample group. Problems for this project centred around the limited availability of journalists and the extent to which they were willing to discuss the issues being explored (the impact of the then fledgling Internet). However, gatekeepers assume a critical importance when potential research participants may be considered vulnerable.

Interestingly, since the Care Act of 2014 (HMG, 2014) in the UK, there has no longer been a specific definition of a 'vulnerable' adult. Instead the Act defines people in terms of whether safeguarding duties apply to an adult who has care and support (whether or not the local authority is actually meeting any of those needs); is experiencing, or at risk of, abuse or neglect; and is unable to protect themselves from either.

Groups requiring 'safeguarding' may be children and young people, those living in adverse situations such as homelessness, prostitution or abusive relationships (McFadyen and Rankin, 2016; Gray, 2013). Also vulnerable are people having medical conditions (Hudson et al, 2017), chronic diseases (Miller, et al., 2013); or LD (Nicholson, Colyer and Cooper, 2013). As Cree et al. (2002: 50, quoted in Emmel et al, 2007) observe, 'researchers can get access [to vulnerable groups] … only with the co-operation of a number of different gatekeepers; without this, there can be no research'.

The paper does not explore issues around recruitment, in terms of the potential participants themselves. It is concerned only (unlike the focus of almost all the prior literature) on issues around gaining *access* to potential participants, via gatekeepers. Of course, some gatekeepers may take it upon themselves to not only grant access, but to undertake the recruiting themselves. Whilst this is an interesting phenomenon (and not one that is always 100% satisfactory, as mentioned in the literature cited in this paper) it does not form the focus of interest here.

Gatekeepers are essential in gaining access such cohorts, for two reasons. First, it would not be considered ethically acceptable behaviour to attempt to approach people with LD directly. Partly this is because, assuming they are not known well to the researcher, some of the potential sample may be distressed by the attention of a stranger; may not have the capacity to grant informed consent; or may have such capacity, but consent only out of exaggerated deference to authority (the famous 'acquiescence bias' problem Sigelman et al, 1981).

A second reason why gatekeepers are vital is more concerned with administrative and logistical matters. It would be extremely difficult accessing vulnerable people without any intermediary. Identifying suitable potential participants – in the case of the present project, those who have a level of literacy and notion of mobile technology – may be problematic for one thing. Early results accrued for the 'Digital Lives' project suggest that participants (although perhaps no more than other people) have a very poor understanding of their technical ability. Participants who have said they use their mobile device for several things have been unable to demonstrate their use (such as playing a music track) to the researcher.

Finally, it is also important to note that problems with gatekeepers are not confined to research around 'vulnerable' people or sensitive topics (Lee and Renzetti, 1993), but rather, may relate to any potential research where it is easier to work through intermediaries (De Laine, 2000). Nevertheless, many of the issues elicited do relate directly to the population of 'people with LD'. This is particularly true with regards to the protection of potential participants, and indeed, to the protection of the gatekeepers themselves.

Aims
Given the importance of gaining access to potential research participants, the aims of the study are to explore the factors that prevent potential 'gatekeepers' from granting such access, and possible ways in which access can be improved, to inform other researchers to help in their endeavours in the future. A less academic aim is to highlight an under-reported issue so that researchers at whatever level may be at least comforted that if they are having difficulties in obtaining access to potential participants they are not alone!

Literature review
There is a small amount of literature on the difficulties in recruiting vulnerable people – but this has been very much in terms of the views and behaviours of the potential participants themselves and the reasons why they decline to participate. There is a paucity of literature on the prevention *by gatekeepers* to the *accessing* of potential participants. Much of it (e.g. Nicholson, Colyer and Cooper, 2013) that deals with the role of gatekeepers discusses the

difficulties they have in recruiting, rather than the difficulties researchers have in recruiting *them*.

Other literature centres on the different ways in which gatekeepers might interfere with participants' decisions to consent to take part in research (Emmel et al., 2007; Sanghera and Thapar-Björkert, 2008), rather than being concerned with the flat denial to grant access. Such interference includes insisting on the inclusion of particular participants or ethical practices or even methodological approaches. Archibald and Munce (2015: p35) describe how, in institutional settings (healthcare in their case), even convenience plays a part. They state that gatekeepers may limit access to potential participants to those of their choice, such as '"key informants" or "expert patients" with an above average understanding of the [research] instead of participants with a more typical … profile or even more vulnerable participants'. They put this down to the 'relative ease' with which such people could be recruited on behalf of the researchers.

Emmel et al., (ibid) discuss difficulties gatekeepers themselves face, concluding from a qualitative study of gatekeepers' relationships with potential research participants that granting access is made difficult 'because formal gatekeepers are distrusted by socially excluded people'. Here, 'formal gatekeepers' are those who undertake professional work, including care services, with potential participants.

The same writers, however (Emmel et al., 2007) also describe how informal gatekeepers (who have roles more related to 'befriending, supporting, and protecting those that they see as vulnerable' rather than undertaking formal and more officious duties) were themselves distrustful of researchers, and so did frustrate research efforts. They tended to see researchers as proxy service providers but who were unable to deliver services to meet appropriate needs.

Swaine et al (2011) discuss legal guardians who (albeit not so termed in the article) might be considered to be a third kind of gatekeeper. The authors discuss issues related to the recruitment of participants for a randomised controlled trial testing an intervention designed to promote cervical and breast cancer screenings. They explain that 'The US Code of Federal Regulations … has specifically designated people with ID [Intellectual Disabilities] as a vulnerable population. As such, when individuals with ID have legal guardians, it is the decisions of these guardians that "trumps" the decisions made by people with ID themselves' (Ibid: p481). They describe how, although succeeding in gaining access through recognised professional gatekeepers, they were denied consent by guardians even though, in an apparent attempt to obviate this, they had first obtained consent from the potential participants themselves. They note that 'once a guardian declined to consent, the research team was not permitted to have further contact with [potential participants]' (Ibid: p481)

Lennox (et al, 2005) points out that some of the usual participant recruitment methods (see Hennink, 2007 for a comprehensive annotated list) are not appropriate for a learning-disabled cohort, due to possible lack of the necessary literacy or oral language skills. These may include using online or hardcopy advertisements, telephone recruitment. The first two clearly require literacy skills, and even if targeted at websites (for example) likely to appeal, and written in 'accessible' language, may not be read, or the contents understood

completely. Any required response may be confusing too – such as emailing or telephoning the research team.

Finally, there is the question of convenience, too, although seemingly barely mentioned in the literature. Braun and Clarke (2013: p57) describe how it is easier to recruit (participants rather than gatekeepers) with regard for certain topics, and also discuss convenience sampling. 'a sample selected because it is accessible to the researcher'. Selecting locations (rather than individual participants) may sound somewhat trivial, but having access to a network of, for example, voluntary centres for people with LD and a potential sample of 20 to 30 or more is far more efficient than attempting individual recruiting, possibly using a snowball technic from one known respondent. There are possible problems, of course, in terms of the sample all coming from the same environment where they may have very similar experiences, peer pressures etc., but in the experience of the writer, this effect is manifest only in the functional skills departments of Further Education Colleges, where people are undertaking the same or similar course in, say, information technology. In day centres or care homes, use of technology may be very varied, as the focus tends to be on other life skills, such as shopping, cooking or handling money.

In sum, there is a lack of literature on the recruitment of gatekeepers and, in particular, reasons for their denial of access to potential research participants. Some literature covers exigencies of gatekeepers with regard to choosing participants, practices and methods. Other literature describes their influence on participants, and the difficulties they have recruiting on behalf of researchers. One paper was found that approached the issue of the problem of relatives (parents in this case) blocking participation. Literature was also examined the importance of gatekeepers and the necessity to work through them rather than – in the case of vulnerable people – attempting direct access.

Methodology
Data sources and sample
Data were gathered from three sources to inform the issue. These were:
- Fieldnotes and other outputs, notably published journal articles (Williams, 2005; 2011; Minnion et al, 2006, 2008) from previous projects requiring the recruitment of people with LD. These were revisited, being examined for evidence of
  reasons for non-participation and obstacles met and overcome by those gatekeepers who did facilitate participation (the latter being considered as barriers preventing others from doing so);
- Statements from gatekeepers relating to the 'Digital Lives' project, giving reasons for declining access to potential participants;
- The views of gatekeepers who did participate in the 'Digital Lives' project, opining on why others had declined and outlining any barriers they themselves had to overcome.

Historical context
The relevant 'historic' projects are listed below.
- 'Pete's Easy Read': Comparing the effectiveness of different website designs in facilitating information retrieval for people with LD (Williams, 2012; 2013, 2017b; Williams and Hennig, 2015).

- 'Beyond the Road Ahead': Providing accessible information around independent living on the Internet for (and, crucially, by) people with LD (Williams, 2008; 2011) and
- 'Project @pple' (Access and participation in ICT for people with LD): Developing an ICT systems to help adolescents with LD in their learning and self-advocacy (Williams, 2005, 2006).

In the case of the first project listed ('Pete's Easy Read') the participant cohort were people with 'mild' LD, as is the case with the current 'Digital Lives'. Such people experience a slower rate of language, motor, and social development than those without the disability. However, they enjoy basic literacy skills, and can undertake supported employment s (Beirne-Smith, Ittenback and Patton, 2005). Regarding the other projects, people with 'moderate' or (in the case of 'Project @pple') 'profound' disabilities were also sought (see BILD, undated, for practical definitions and commentary). Depending on the project, in some cases basic knowledge about or use of computers or other information technology was a pre-requisite (especially 'Pete's Easy Read').

For all the research (including the current 'Digital Lives') except the final one listed ('Project @pple') target recruitment location types included Further Education colleges (with Functional Skills units), Local Authority day centres and voluntary groups. Thus, potential gatekeepers were:
- Heads or senior staff of Functional Skills departments at Further Education colleges
- Learning Disability Outreach & Development Workers
- Inclusive Learning Tutors
- Day Service Managers and other care or support workers

Several methods were used:
- Direct contact with colleague worked with in the past
- Direct email contact with known or found organisations
- Messages on various fora (such as UK Health Forum; Choice Forum UK etc.)
- 'Fliers' distributed by colleagues, organisations and fora
- Snowballing – obtaining contacts via organisations whose gatekeepers became involved in the project
- Messages sent via University College London outreach and voluntary services offices ('Digital Lives')
- Recruitment via Newham Borough Council (part-funder of 'Beyond the Road Ahead')

In some cases, staff passed details on to colleagues who were more suited to deal with the request, usually by virtue of being more involved with potential participants or in a greater position of authority.

For the last mentioned, 'Project @pple', recruitment was only from Education Authority Special Schools, via the charity Mencap.

Method
For the historic (previous projects) data, fieldnotes were revisited, with the emphasis on eliciting data specifically regarding obtaining access to potential participants. This proved extremely fruitful, as these highlighted many barriers to the adoption of Information

Technology by supporters of people with LD (see Williams, 2011), many of which (lack of access to computers and software; time constraints; poor support by managers etc.) played a part in non-participation and thus inform the present study.

With regard to investigating gatekeeping behaviour during the present 'Digital Lives' project, those invited to take part in the main study but who declined or did not respond to an initial or follow-up letter were re-contacted with regard to the current investigation into gatekeepers. This represented 12 individuals, from nine organisations (four regional offices were contacted of one large charity). Of these only three responded. Ten people who did decide to permit access to participants in the 'Digital Lives' study also participated in this aspect of the study, being informally interviewed about why their peers may have declined. For this exercise, no formal interview schedule was adopted. This very open-ended approach is unlike, for example, prior work by Nicholson, Colyer and Cooper, (2013) who adopted a very rigorous semi-structured interview schedule. This comprised a series of guided questions … Examples of [which] included … "Was it helpful if [one of the researchers] had met the participant beforehand?"' (p649)

The more open-ended method was because it was decided that the possible reasons for gatekeepers not wishing to grant access to potential participants were so wide-ranging that a more open approach was considered more likely to elicit the thinking and reasoning behind decisions rather than formulating speculative (albeit open) questions as a data gathering instrument. Thus, those approached because they had declined to facilitate participation were simply asked, via email, to provide a reason, either via an email reply or in a telephone conversation. Such emails were sent to all those who had originally been invited to participate in the project and had not replied after the initial and one reminder message or (only two cases) who had formally declined. It was – of course – impossible to know the reasons why those who did not respond even to the message about non-participation. It would be interesting to speculate whether or not their reasons differed from those who were prepared to indicate why they did not wish to participate.

As mentioned, others who had chosen to participate in the main project were asked to also consider why others had declined. The issue was mentioned in pre-fieldwork visit emails, allowing respondents time to consider possible factors, and discussed during face to face meetings within the full 'Digital Lives' project. Although this method is not ideal, interviewees at least had 'inside knowledge' of conditions 'in the field', including the attitudes of colleagues and of potential participants, workloads, relationship dynamics etc. and so were at least able to offer informed assessments as to the reasons for a disinclination to engage with researchers. This 'hearsay' evidence has been used previously in the literature on the subject. For example, in their exploration of the informed consent of women with intellectual disabilities in recruitment to a cervical and breast cancer screening information programme, Swaine et al (2011) admit that they 'could not track why the women or their guardians declined the study' but obtained 'anecdotal' information from women and gatekeepers who did elect to participate.

Data analysis
Data were analysed by loosely using the 'framework analysis' approach of Richie and Spencer, 1994: p176). It involves a process of familiarisation, identifying and indexing key

themes, 'charting' ('lifting the [indexed] data from their original context and rearranging according to … (theme)' (Ibid: p182). Meta-data is added giving the source of each entry. 'Charted' data is further examined to complete the research, by eliciting concepts, finding associations (between circumstances and motivation; attitudes and behaviour etc.), assessing the strength and extent of elicited views and behaviour, and seeking explanations.

Data for the present project was unusual in that much of it was collected for other purposes – those relating to the actual projects and not specifically around access issues. Even that created for the project did not require much detailed scrutiny, with very brief comments (such as that used for the title!) constituting many responses. Even the comments of gatekeepers who did offer access tended to be brief. Thus, although the process appears rigorous – and daunting - the content of each document, and their small number actually made the analysis fairly straightforward, and free of many of the nuances often inherent in the analysis of interview data (e.g. Liamputtong, 2013).

Findings
Several interweaving and overlapping factors emerged, which can be categorised under the following main headings: Protection of self and others; Institutional factors, and Research factors. These are discussed in turn.

Protection of self and others
The need to protect vulnerable people
Not surprisingly, this factor permeates through the work of those who care for this cohort. Apart from potential gatekeepers in Further Education, the targeted locations are monitored by The Care Quality Commission (CQC, 2017). This inspects and regulates the provision of care services to make sure they meet fundamental standards of quality and safety (CQC, 2017). Unsurprisingly, the areas of interest to the CQC includes safeguarding and protection and risk assessment. Wellbeing and safety are, of course, given high priority.

In the sphere of education, OFSTED (The Office for Standards in Education) inspectors monitor safety, and 'always have regard for how well … learners are helped and protected so that they are kept safe' (OFSTED, 2018: p38). OFSTED requires institutions to 'identify responsibility and accountability for safeguarding arrangements …; and to ensure that [the workforce] is well equipped to promote safeguarding in a sensible and proportionate way' (OFSTED, 2011: p6).

In both the care and education sectors, staff and others working in the various locations are required to obtain a Disclosure and Barring Service (DBS) Certificate. The DBS is a UK Government-run organisation which searches police records and, in relevant cases, barred list information, and then issues a DBS certificate to the applicant showing that he/she does not have a criminal record (and not on the UK sex-offenders list) that would debar them from working with vulnerable people. (DBS, undated)

Thus, potential gatekeepers are steeped in an environment where they are not only made acutely aware of the need for protection, but under a very strong obligation to ensure the safety and wellbeing of the people they support. Examples were given of measures required to be undertaken on a day-to-day basis by staff – even including noting the colour and type

of clothing worn when on a trip, in case people become detached from the group. Of course, the difficulties, although 'bureaucratic', are also borne out of genuine concern for the individuals in their care.

The fact that a university ethics committee had given permission for the study was described by one participant as 'probably not being a factor'. Such documentation did not seem widely known by professionals – partly because they were not operating within an academic context or within the NHS (the latter requiring NHS Ethics Committee approval). No representative from any of the participating organisations asked to see the Ethics documentation (although, of course, participant information sheets and consent forms used by the researcher were an integral part of the Ethics submission).

Concern was also expressed about upsetting a routine. It is well-known that people with LD enjoy routine (Cimera, 2007), and that disruption to a normal schedule can cause distress. Clearly, the presence of 'an outsider', especially one attempting to engage with people and seek their participation, represents quite a change from a routine – and one to which gatekeepers may be reluctant to expose the people whom they support.

This issue was manifest in the project Beyond the Road Ahead, where fieldwork involved engaging participants who would otherwise be occupied with a timetabled activity (such as cooking or other 'life skill'). Thus, constant reminders by involved staff and displayed posters were used. The writer always tries to undertake a preliminary 'familiarisation' visit on fieldtrips, both to avoid being an 'outsider' and to reassure potential participants that their routine will only be minimally affected.

A third theme was that of protecting vulnerable people from exploitation. At a meeting of a small group of potential gatekeepers regarding the present project, the question of participant payment arose. There was a negative reaction when the person was told that the participants would not be paid for their involvement – with the clear implication from her that this was because participants lacked the necessary linguistic skills or knowledge to argue for a fee (there were several reasons for this policy, albeit being beyond the scope of this paper).

Despite the apparent desire to protect vulnerable people (to the extent of not even offering a choice for them regarding project participation), no-one who declined to facilitate access to the cohort asked about a DBS certificate, although presumably this was because the possession of this by the researcher was mentioned in his communication about the project. Slightly surprising, perhaps, is that only two, of eight centres (as at the time of writing - December 2017) who did decide to participate asked to see the certificate.

Protection of self
Several people who chose to participate in the present study felt that their colleagues (and, indeed, themselves) were in positions which were particularly open to judgement. College tutors, carers and others in a support network have, for example, to satisfy parents/guardians and others, who might make adverse judgements about them. In addition, those in education are inspected by OFSTED, generally already considered a very

stressful experience (Brook, 2017), without the added burden of an inquisitive researcher asking about how technology is exploited.

On 'Project @pple' (Williams, 2005, 2006), teaching staff were so worried about a forthcoming OFSTED inspection that instead of allowing students to take and upload photos on an electronic 'Personal Profile', they took the quicker route (although less empowering, from the point of view of the students) of doing this themselves – sometimes choosing the content to fulfil the requirements of evidencing ability desired by the inspection team. In this case, clearly, the staff were more worried about protecting themselves from their regulatory body than by the somewhat detached researchers.

With regard to the 'Digital Lives' project one gatekeeper who (enthusiastically) provided access to participants, felt that others declined due to the fear that they themselves may be criticised for not being 'independent' - the very act of asking for participants may seem to be attempting to influence them. It is therefore easier not to get involved.

Also related to self-protection, staff involved in 'Beyond the Road Ahead' were also worried about being reprimanded over using their organisation's logo (or that of the Olympic Games – citing copyright issues) and about a supposedly sparse or unprofessional website, such as might be produced by the service users themselves, reflecting badly on themselves as staff (Williams, 2011; Minnion et al, 2008).

It is worth noting to end this section that the fear of being judged by researchers is also manifest even where people do volunteer to participate in research. This is true even with regard to professionals not working with vulnerable people. In a study in which GP researchers interviewed their peers, Chew-Graham, May and Perry, (2002) concluded that respondents felt they were being judged and so tended to be cautious in their responses. The writer's work with national journalists (e.g. Williams and Nicholas, 1997) also demonstrated this tendency. Gatekeepers at various national newspapers, although not attempting to protect themselves, apologised for the refusal of some journalists to participate in a study of the use of the Internet in their work as the latter felt they did not exploit the medium sufficiently.

Also beyond the world of LD, McFadyen and Rankin (2016, citing Gray, 2013: p73) note in the context of health (although the observation could apply more generally), that:
> 'where the research is conducted within the gatekeeper's workplace there is the possibility that the dissemination of the research findings may cause criticism … for the gatekeeper's organisation. This can put gatekeepers in a compromising position …. In extreme cases, this may result in conduct issues or dismissal for the gatekeeper'.

Institutional factors
Institutional relationships and policies must shape the perceptions and interactions between researchers and gatekeepers. However, there seems to be very little in the literature on this. The review above highlighted how institutional gatekeepers may try and make things easier by choosing only 'key' or 'expert' participants to approach. This 'filtering' or 'prejudging' potential participants (albeit with no or little connection with gatekeepers'

institutional settings) is also manifest with regard to mis-conceptions about the research, described in a later section.

Related more to one's place (or institution) of work, concerns by gatekeepers over their professional integrity overlaps with other factors that could be labelled as 'institutional'. These include those related to institutional hierarchy or power structure and simple administrative problems.

Institutional hierarchy or power structure
In some cases – particularly in large organisations – potential gatekeepers may not feel qualified to give permission to access the people they support. There were two cases where people mentioned a reluctance to 'bother' their superiors – one who declined to take the research forward on this basis, and the other who did participate, but claimed that others may not for that reason. There was also one case where when contacted, superiors either said no or did not reply. Another participating respondent said that big charities that operate in a large number of locations often employ a very small number of people at any given site, who may not only be reluctant to contact those with greater responsibility but may not even know who the appropriate contact might be.

During 'Beyond the Road Ahead', participants wishing to photograph the inside of a Job Centre to use on a website around transition, were debarred from doing so on the grounds that 'Head Office' would have to give permission. Unsurprisingly, perhaps, this was never given – and one wonders whether actually sought.

Administration considerations
A major factor in this category preventing access to participants is that of time constraints. One potential gatekeeper speaking at a meeting involving several professional carers, simply said "It all sounds very interesting – but we're all just too busy at [my day centre]", to nods of agreement amongst others present. The Head of a college for people with LD made a similar comment, but nevertheless forwarded project details to a colleague who did agree to facilitate participation. This problem has also been mentioned in the literature. Din and Cullingford (2004), in a study of the tastes musical of young people of a Pakistani background within a prevailing British culture, were hampered by both schools and colleges and community centres declining to engage partly due to limited time.

Even gatekeepers involved in the present study who did permit access took several weeks to reply to emails – often apologising profusely for the delay before fieldwork could finally begin. This factor was present in previous projects. During the Beyond the Road Ahead project, a situation arose in which:

> 'time constraints on staff meant that service users were not briefed about [the research]. At one site, there was clearly distress at the unexpected arrival of the project team, who were greeted with suspicion. One person actually hid her face, and others claimed tiredness when asked if they would like to participate' (Williams, 2011: p10)

Other administrative problems elicited during the Beyond the Road Ahead project also caused difficulties in obtaining access. For example, the lack of access to computers or to

space, due to activity timetabling and accommodating various groups, caused gatekeepers to decline or severely restrict participation.

Research factors
These are factors that relate specifically to the proposed research itself. 'Research fatigue'; mis-conceptions about the research, and antipathy towards it were factors elicited.

'Research fatigue'
Two organisations contacted for the present project said that they were 'always' or 'often' approached by various bodies wishing to carry out research. One did not specify further, but the other named universities and 'student projects'. The potential gatekeeper at a collage for people with LD said that having a captive and large sample, with a wide ability range very suitable for comparative studies, the location had become a 'magnet' for under- and post-graduate students and research academics. Of course, this is a factor in non-LD research as well (e.g. Clark,2008). It may be that, in some cases, a failure to see any positive outcome from past research, or even be provided with feedback from research teams (as highlighted by Nicholson, Colyer and Cooper, 2013) makes gatekeepers (and, indeed, potential participants themselves) reluctant to continue to engage with the research community.

Finally, time taken up by accommodating research can be constrained, when care staff have many pressing commitments can cause some people to be reluctant to ask their superiors to once again facilitate field visits etc. Thus, 'research fatigue' can result in organisational problems – an illustration of the interrelatedness of the factors in play.

Mis-conceptions about the research
McFadyen and Rankin, (2016: p86) opine that among gatekeepers, 'there may be misinterpretation of the study with little regard … for ethical processes and approval which can result in suspicion about [its] integrity'. With regard to the present study, the mis-conceptions were generally not as negative as described above. They concerned the:
- age or other demographic of the participants sought
- aims of the project
- proposed content of the electronic archive

Demonstrating the first two of these, three people responding to calls for participants (i.e. in professional listservs, fora etc.) for the present study, mentioned knowing or being involved with special schools which were using technology in innovative ways. The schools in question taught up to 16 or 18-year olds, although the information sheet stated, in a heading, that participants sought were 'adults, 18 plus. No upper limit'. The phrase 'young people' was used several times, appearing to suggest that technology was the prerogative of the young. Even the technical support needed to provide server space for the electronic archive held up the process, stating reservations about hosting sensitive data about children on an 'open' site – all of these three assertions being incorrect.

One person declining to offer access to potential participants named a charity at which worked 'professionals with more expertise in the field that we can offer', appearing to think that the project was about exploring innovative practice. He added that the charity he was recommending 'also use an app called Kaleido as part of the sensory art session'.

Mis-conceptions about the 'Digital Lives' electronic archive appeared to relate to the protection of the vulnerable cohort with and for whom it is being created. Questions revolved around access and editing rights, and content. In the information sheet for participants it is stated that the site would be closed, with only participants (and supporters) having a password, and only the researcher uploading information written with and agreed by the participants. However, there were still questions that assumed the site would be open and that participants would be free to add content at will.

Antipathy towards the research
This theme, in various guises, has been reported in the literature, both with regard to participants themselves (e.g. Becker et al, 2004; Iacono, 2006) and gatekeepers (McFadyen and Rankin, 2016). The latter quoted a gatekeeper who denied access to adolescent girls for recruitment to an NHS initiative 'to engage vulnerable adolescents in the research process' as saying 'these girls have enough problems to be bothered with' (pp.83, 85).

With regard to the present study, the overriding factor in creating 'research antipathy' appears to have been dislike (or mistrust) of technology either by the potential gatekeepers themselves or by the families or carers of the potential participants. A minority felt that families of people with LD were often reluctant to engage in mobile technology with them, provoking professional carers or other supporters' reluctance to participate in research around the subject. One gatekeeper said that at the supported accommodation where one of his 'Basic computing' training course students' lives, the support worker declines to provide the wi-fi password to residents. A similar antipathy with regard to previous projects was also highlighted earlier.

Recommendations and conclusion
Drawing from the above, a number of recommendations can be made. First, and most importantly, the protection of vulnerable people is, rightly, a very important research consideration. Whilst the ethical permission process can be restrictive (Swaine et al, 2011; Scott, Wishart and Bowyer, 2006) or not considered by respondents (Swaine et al, 2011, and results from this present study), strict adherence at least implies the formulation of accessible information and research protocols which have protection at their heart. it is, clearly, incumbent upon the researcher to be as clear as possible, both about all aspects of any research project (such as the aims, population, methods etc.) and about how participants are protected during the research process. Nicholson, Colyer and Cooper (2013) propose 'multiple meetings with potential participants and carers before approaching them directly about research' (p654), although it is hard to do this if the potential gatekeepers do not reply to an initial approach. Of course, where doctors or other professionals are to undertake research, a rapport can be built up before this is mentioned, although this does seem somewhat underhand.

Although the present study uses an accessible information booklet, shared before the start of the project with professionals working with people with LD and amended according to their recommendations, one suggestion from the literature (Swaine et al 2011: p482) would be to use 'multi-modal approaches to explain the study (verbal, video, written and

pictures)', although this would have the drawback of potentially requiring more time on the part of the gatekeeper to vet and approve the material.

A personal recommendation – which may sound rather basic, but proved to be very effective - is to telephone rather than, or in addition to, emailed communication. The writer prefers the latter to avoid disturbing people, possibly at busy moments, but in the (four) cases where he has only been given a telephone number or someone has made a call on his behalf (a gatekeeper helping to recruit a colleague) there has been 100% success, and three of those gatekeepers who did allow access to potential participants and were approached for this study on gatekeepers, opined that this method was more effective.

Once contact has been established, much liaising with gatekeepers is required. Detailed (oral as well as written) information about the research – emphasising both the benefits to the participants, the non-judgemental nature of the research and issues such as anonymity have also been recommended in the literature. However, although laudable, these recommendations tend to ignore time constraints on gatekeepers.

To conclude, participant recruitment may, indeed, be considered 'the most difficult aspect of the research process' (Blanton et al, 2006: p647). This paper has not only demonstrated the difficulties inherent even negotiating participant access to participants via gatekeepers (before the former even consider their own participation – also fraught with difficulties, as Nicholson, Colyer and Cooper, 2013, document) but also how difficult it is to find solutions.

The question is, of course, that of what characterises successful access cases. Perhaps the most effective policy is to make sure the research itself is justifiable in terms of aiding the lives of the cohort around whom it is centred, and that participation would be worthwhile and valuable both for those involved but also for a wider vulnerable community.

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