Smartphones and people with intellectual disabilities: an international comparison of contextual social barriers for effective usage

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ABSTRACT

Mobile devices are becoming ubiquitous. However, very little research has been carried out on the use, benefits or barriers of this technology by people with Intellectual Disabilities (ID), either in an educational or social context. This paper explores self-reported constraints upon usage of smartphones by ID in a study conducted in the UK (with 59 participants) and replicated in a smaller scale in Brazil (23). The studies explored these issues via in-depth group and individual interview and observation. In both countries, similar 'self-imposed' barriers were elicited, with different emphasis. The categories 'reluctance to reveal oneself online' and 'concerns about factors beyond one's control' (viruses, unreliable hardware) were more evident in UK participant comments. Factors in the category 'burden of responsibility', specifically fear of assault were emphasized by Brazilians. Constraints imposed by supporters, in both groups, included prohibitions, restrictions and usage monitoring, especially with regard to social media. These constraints were justified as being to protect the individuals. External barriers such as usability issues, cost management were mentioned by both groups. Overall, use of the technology by this cohort can be seen as a tension between enablement and control, with emphases on different aspects of these forces related to the social conditions prevailing in each country.

Keywords: Intellectual disabilities, smartphones, technology, barriers

1. INTRODUCTION

Smartphone usage has now reached saturation point, with 96% ownership reported in the UK by 16 to 34-year olds [1]. In Brazil, by 2018, smartphone penetration was already above the global average of 115% [2]. Despite this worldwide phenomenon, very little work has been undertaken examining how people with Intellectual Disabilities (ID) use mobiles or how the technology impacts their lives or their learning. This was the motivation for the study reported here.

The paper presented here concentrates on the self-reported barriers to useful smartphone usage. Results in the two countries are compared to explore any cultural or social differences that may affect the impact of mobile devices on the lives of people with ID.

2. PRIOR LITERATURE

As with other aspects of the topic of digital technology and people with intellectual disabilities, research is fragmented and wide-ranging, with no extensive body of work built up examining any particular aspect of the subject.

Early studies include that by Bryen, Carey and Friedman [3], who surveyed people with intellectual disabilities (ID) on the extent and scope of cell phone usage. Results suggested that the cohort use the technology far less than mainstream adults, being primarily for emergencies, storing numbers, and day-to-day communication (p1). Chief reasons for non-use were expense, lack of perceived need and difficulty in use (p6).

In another early study, Dawe [4] sought to 'understand ... patterns of remote communication among young adults with cognitive disabilities and their parental caregivers' (p179). The study found that people with cognitive disabilities made 'many' of the calls, usually to solve minor problems such as those with transport. Difficulties included confusing menus and using small physical keypads.

More recently Kumin et al [5] explored the usability of touchscreen displays and virtual keyboards with adults with Down Syndrome. Participants performed a series of tasks on an iPad. These included 'social networking, email, scheduling, price comparison, and basic text entry/note-taking'. Results showed that all participants were able to complete the majority of the tasks [although] ... 'performance varied dramatically '(p.136). Some participants had problems with the sensitive nature of the touchscreen and often accidentally activated unwanted apps in the middle of a task. Participants also had problems with icons, because they were small ... 'often unrecognizable ... and often cryptic '(p137). Difficulties with passwords were also noted.

Rocha, Bessa and Cabral [6] assessed the efficacy of a mini iPad device used by people with intellectual disabilities. Participants were required to carry out tasks such as adding color to a line drawing and manipulating pieces of a puzzle. Difficulties were noted in both touch and in dragging virtual pieces. Other papers on the subject include those on mobile technologies to assist people with learning disabilities in the workplace [7]; using an app to aid travel autonomy [8] and learning generally with iPads and/or mobile apps [9], [10].

3. METHODOLOGY

The study used a mixture of group and individual interviews and participatory observation of device usage to collect data. In the UK, participants were recruited from Functional Skills' departments at Further Education colleges; attendees at adult Day Centers and voluntary groups around London and Hertfordshire, England. In Brazil, the study was conducted at the Association of Parents and Friends of Exceptional People of Belo Horizonte (APAE-BH), in the capital of the state of Minas Gerais, Brazil. This is a non-profit social organization which promotes overall development and improvement of the quality of life of people with intellectual and multiple disabilities among other goals.

Population and sample
Participants were sought who had 'mild' intellectual disabilities and who, as such, were 'functionally literate'. That is, they were able to read street signs and simple sentences, follow simple instructions, and use a simple list. However, a small minority of participants did not fill this criterion but were included at the request of support or care staff, usually as they were interested in the topic and/or did not wish to be excluded.

In the UK study, participants were adults, ranging from 18 to 64 years. Fifty-nine people participated as shown in Table 1 below:

Table 1. Age ranges of participants - UK

Age range	Number
18-19	15
20-29	22
30-39	12
40-49	4
50-59	6
60-69	15
Total	23

Five supporters were also interviewed, including two college tutors, two Day Center workers and a personal carer.

In the Brazilian study, 23 adults who attended APAE-BH activities participated. Six supporters, who were mothers of the participants (in one case, of an attendee that did not participate) were interviewed. Three other supporters participated in the interviews, acting as facilitators of communication. Ages of participants ranged from 17 to 40, as follows:

Table 2. Age ranges of participants - Brazil

Age range	Number
17-19	5
20-29	12
30-39	5
40-49	1
Total	23

As can be seen, most (54/82) participants in the study were below 30.

Data Collection
The interviews explored themes such as the experiences, benefits and difficulties of using both the hardware and software, and how the technology could be improved. Light probing on topics such as agency (i.e. who had control) and support, the impact on social interaction and other relevant topics were covered, depending on the group dynamic and interests. This paper concentrates particularly on barriers encountered, of whatever form.

The data gathering then began in groups. After the group sessions, most participants were also interviewed individually, depending on time, availability and interest.

Interviews with supporters were very open and centered around interviewees' experiences of the use of mobile devices by and with the people they support. Benefits, barriers of whatever form and how to make devices more accessible were all mentioned with little prompting.

Data analysis
For qualitative data analysis categories were created that describe the content of the interviews. The material was coded, and comments were categorized and classified through grouping comments according to their content. The main categories were mobile phone usage; the role of mobile technology; levels and types of support, and the various barriers encountered.

4. FINDINGS

In both studies, a large number of constraints, were elicited from the fieldwork. Barriers were grouped in three categories self-imposed, support-imposed, and externally imposed.

Self-imposed barriers
Constraints that the participants placed upon themselves included three subcategories: Reluctance to reveal oneself online; Factors beyond one's control and The burden of responsibility. Table 3 summarizes the comments in each

sub-category. As the number of participants in the Brazilian study was necessarily lower, fewer comments were accrued from the fieldwork.

Table 3. Self-imposed barriers

Sub-category	UK	Brazil
Reluctance to reveal oneself	Self-awareness, fear of being ridiculed, worry about spelling or grammar, reluctance to post written comments, some participants did not wish to upload photos.	Not wishing to misspell
Factors beyond one's control	Technical problems (virus, battery run out, software not functioning) Non-technical (fear of unscrupulous users, fear of high costs	Fear of high costs
The burden of responsibility	Fear of phone being stolen or damage	Fear of assault

Reluctance to reveal oneself online. This sub-category had more comments in the UK group, related specifically to the use of social media. A small minority of participants indicated that they were worried about spelling or grammar and one person indicated he would not like other people to see his writing. This was apparent in the Brazilian group also. There was, however, a difference between the two groups. About half of the Brazilian participants, tended to obviate this problem by using the voice-to text facility to write or the microphone to send audio messages avoiding the need to write.

In addition to a reluctance to post written comments, some UK participants did not wish to upload photos either - particularly of themselves. No reasons were given, except in two cases, where participants described themselves (sadly) as 'ugly' in one case and 'fat' in the other. No Brazilian mentioned this kind of problem.

Factors beyond one´s control. Comments in this category were principally from the UK participants. They were nearly all related to technical problems. One participant worried about 'getting a virus'. Also, in this category were anxieties about phone batteries running out of power. Finally, with regard to technology, there seemed to be a general fear of software not functioning in the way expected. Indeed, for many participants, far from enabling communication or independence, the technology seemed to be instead something of a mysterious force that was too powerful or unpredictable to use.

There were also non-technical 'Factors beyond one's control'. These related to the unscrupulous intentions of others, against which there were few protections. Both cohorts mentioned phone scams.

A prominent barrier for the Brazilian cohort was the cost. An apparently constant problem was reported by the supporters of companies contacting subscribers with offers to increase data limits, 'talk-time' or number of package-included texts for increased monthly fees. As many people with intellectual disabilities do not understand the value of money, they are likely to accept these offers without considering the financial implications. Some participants, however, were aware of cost, to the extent that there was an element of self-rationing with voice calls, to prevent large monthly phone bills.

The burden of responsibility. In both countries, there was evidence that participants felt a great responsibility to make sure their devices were not lost, stolen or damaged (possibly because this had been emphasized to them by their carers and supporters, with exhortations to keep them safe.) Thus, people either didn't carry their phones (or tablets in a couple of instances) around with them or did so, but only using them (i.e. removing them from a hidden location on their person) for emergencies.

In the Brazilian study, the problem of assault was mentioned by six of the participants and even the supporters mentioned this as the problem when using with a mobile outdoors, rather than the possibility of simply losing a phone.

In the UK study the vulnerability of mobile technology also dominated some people's perceptions of them. One participant offered this advice: 'do not keep tea or coffee near the keyboard. You are likely to damage it. Also, if you place an iPad upside down you could damage the glass.' Another even mentioned possible difficulties in having a second-hand phone repaired, due to the complexity and the cost. In fact, many actual breakages were reported, mainly by participants, but also by supporters too.

Supporter-imposed barriers
Many (overt) supporter-imposed barriers were reported, both by the supporters themselves and also by participants. Before detailing them, however, it is important to stress that no value judgement is implied regarding the 'imposed constraints'. The overriding consideration of supporters was the safety and well-being of the people in their care. Indeed, in conversations beyond the remit of the current paper, supporters discussed they can best exploit the technology to empower people with ID – and indeed, themselves – and obviate some of the problems identified.

That said, supporter-imposed constraints elicited centered around: prohibitions; monitoring and restrictions. As shown in Table 4, supporter-imposed constraints showed up in both countries, although with less emphasis in the Brazilian group.

Table 4. Supporter imposed restrictions

Sub-category	UK	Brazil
Prohibition	Ban on Facebook, prohibition after loss or breakage	Ban on Facebook, prohibition after loss or breakage
Monitoring	Use of Facebook,	Use of Facebook and YouTube
Restriction	Late night use, not carrying their phone, information retraction, use of breakage excuses	Late night use, not carrying their phones, use of breakage excuses

Prohibitions. Prohibitions were to both hardware and software, with the latter mostly consisting of a ban on Facebook. Often such prohibitions were time limited. For example, there were several instances of devices being promised as presents for birthdays, and a small number of people similarly being told they could have Facebook accounts in the future. An outright ban on this site was also reported both in the UK and in Brazil. In the UK, this was due to racist comments. In the Brazilian case, one mother prohibited use of Facebook after finding out that her son was adding transvestites' profiles. Although no-one mentioned any blanket ban on social media, per se (not even the participant who was not permitted a Facebook account at all) in the UK case those who were prohibited either never mentioned using other social media services or did not know of any other service when prompted. In Brazil, the participant prohibited to use Facebook, uses WhatsApp for chatting.

In some cases, the prohibition on usage generally arose out of the loss or breakage of a previous mobile device. The latter was not considered punitive – being explained by the need to accrue funds to by a replacement device, or as mentioned above, but here related to replacement devices, the promise of replacement on a birthday or other particular marker on the calendar. Both participants and their supporters mentioned this arrangement in the UK.

Some institutions, such as the 'Functional Skills' units at the Further Education colleges, and APAE in Brazil, also prohibited mobile phone use in classrooms on the grounds of distraction. At APAE, students do not bring their phones to the institution, and one UK location actually removed phones from students.

Monitoring. Monitoring the activities of vulnerable people for whom one has a duty or care was seen as a necessity by all supporters. Facebook was observed both overtly and covertly. This was, of course, to monitor who wanted to be a Facebook 'friend', as well as view and approve posts of existing friends. There were two (UK) instances of participants recounting how a particular family member knew their Facebook password. Both participants were grateful for this oversight. Similarly, one Brazilian mother monitors what the participant sees in YouTube.

This monitoring did not necessarily suggest that using social media was wrong. Several of the Brazilian mothers mentioned positive sides of the use of social media, for facilitating contact with remote people and enhancing social and cognitive growth. A UK professional supporter, for example, felt that by not promoting such services they could be blocking possible genuine friendships. She uses Facebook herself and said that she hadn't ever seen anything 'untoward'. Similarly, her organization has a Facebook page. She is 'not sure it is promoted but it is certainly not hidden', and 'families do use it to comment'. In the Brazilian study, some participants post and comment on the APAE page.

Restrictions. Restrictions on usage included those of a temporal and locational nature. The former was exclusively around the late-night use of the technology. In both countries, in addition to worries about the time and need for sleep, the restriction was to counter an excess of late-night game-playing and communicating. This was achieved by removing the devices, although it was also based on trust in three cases. In the UK case the participant was very keen to assure the researcher (and supporter, who was present!) that the trust was not misplaced. By contrast, a small minority who were not so restricted said that they played games into the night. These tended very much to be those at the 'high end' of the ability scale.

A Brazilian supporter opined that parents do not limit much, and attributes this to their low incomes and lack of knowledge about the possible harms. Only two of the mothers explicitly placed restrictions. However, the participants themselves also tended to recognize the need for restraint, at least at night.

In both countries, the 'locational' restriction consisted of participants not being permitted to carry their devices around with them, either at all or to specific places (on a bus, for example). As mentioned earlier, there were cases where people elected to leave their phones /tablets etc. at home. Having been warned of the dangers of loss or theft, there was generally acquiescence to this from those who had not made the decision themselves. This also happened in both countries.

Finally, in the UK study, there were many instances of constraints on mobile usage of which the participants themselves were unaware, elicited partly from interviews with supporters. One of these could be described as providing information on a 'need to know' basis. Thus, some participants used Facebook Messenger, because they were shown by a family member, and were unaware that to be logged into Messenger they must have a Facebook account and therefore their own 'page'. Others used Skype or WhatsApp (or other channel), their supporters preferring that medium for them, and did not know of other possibilities. A completely different and unperceived constraint was that on wi-fi usage. A supporter reported knowing of residential houses equipped with wi-fi but

where care staff chose not to divulge this fact to residents, on the ground that they might abuse it.

Also, regarding hidden restrictions, some related to breakages and malfunctions. In the Brazilian study, one interviewee complained that her sound box and cable were broken, and there seemed to be a disinclination on the part of her parents to repair/replace them – possibly because of the irritation (to the parents) of loud music playing constantly. There were also other examples of various mal functions that participants said would not be repaired or corrected, denying them access to the technology. This type of situation was also very prevalent in the full study, based in the UK. Beyond the focus of this particular article are externally-imposed constraints such as usability problems (including interaction methods such as swipe and tap; using a virtual and small keyboard; remembering passwords etc.), and cost and resource limitations (access to the devices, cost of telecommunication packages, poor or no wi-fi etc.)

5. SUMMARY AND CONCLUSION

This paper has reported on the findings from a major study in which 59 people with ID in the UK, and 23 people from Brazil were interviewed, about their use of mobile phones, the impact they have on their lives and the barriers they face in using them. Self-imposed constraints included, in the UK, a reluctance to reveal oneself on social media, due to embarrassment about appearance, a lack of anything to say or the perceived inability to express one's thoughts. In Brazil the emphasis was more on the possibility of theft, assault and cost.

Supporter-imposed constraints in both the UK and Brazil included prohibitions and restrictions (of hardware, software or services), and monitoring, particularly of social media usage. Constraints that were not perceived by the participants included teaching or installing only those apps and services perceived to be needed by the person with ID, blocking wi-fi, and not re-enabling broken devices. Constraints were imposed or adopted overwhelmingly to protect the individuals. In sum, use of the technology in both countries can be seen as representing a line between enablement and control, with the line shifting between these two conditions according to the prevailing conditions in each country.

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