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Title: Why aren't you on Facebook?: Patterns and experiences of using the Internet among young people with physical disabilities

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Abstract

There has been an explosive growth in the use of the Internet as a social networking tool and as a major venue for leisure and recreation among children and young people. It is not known whether children with disabilities are using the new medium for similar purposes. The aim of this project was to investigate the current patterns and frequency of Internet use and its impact, facilitators and barriers to use by children and young people with physical disabilities. Fifteen participants with physical disabilities with a mean age of 14.6 years were interviewed exploring the above issues. The research found the young people who participated in this study used the Internet for a variety of purposes and friends played a key role in teaching them Internet skills as well as interacting with them online. Family resources and the computer/Internet literacy skills of parents were significant factors influencing usage. The findings suggest the need for further research involving a larger cohort of children and young people with varying abilities, especially those who are currently not using the Internet, to explore reasons for not using the Internet, and to identify the supports required to increase access and participation.

Keywords: Internet, young people, physical disabilities, patterns of use, facilitators, barriers

Why aren't you on Facebook?: Patterns and experiences of using the Internet among young people with physical disabilities

1. Introduction

Participation, "involvement in life situations" [28] and in a variety of activities is important for children's physical and mental health, friendship, relationship formation, and overall quality of life [8]. Children with cerebral palsy and other disabilities worry about making friends, have fewer reciprocated friendships and are more isolated and victimised by their peers than classmates without disability [13-14].

In terms of social contact, there has been an explosive growth in recent years in the Internet's use as a social networking tool and a major venue for leisure and recreation among children and young people [5,12,21]. The Kaiser Foundation report suggests that young people have increased the amount of time spent consuming media and are increasingly using more than one medium simultaneously [21]. The report further notes that the most popular destinations among 8-18 year olds in the US are social networking and video sites. An Australian publication reports similar findings with 90% of 12-17 year olds, and 97% of 16-17 year olds, using social networking sites regularly [ACMA, 2009a cited in 5]. Social networking sites incorporate a range of features enabling users to create a profile and build a personal network that connects them to other users [10]. Examples of popular social networking sites include Facebook, Myspace, Flickr and YouTube.

A national phone survey of American teenagers aged 12-17 showed more than half (55%) of those accessing the web used an online social networking site and that these sites helped participants to manage their friendships [10]. Older teens, particularly girls, also used online social networking sites to reinforce pre-existing friendships, while boys used them for flirting and making new friends. Nearly 92% of Japanese teenagers regularly used the Internet (Ministry of Internal Affairs & Communications, 2004, Cited in [1] and Ando et al.,[1] found that higher level Internet use (including chatting with friends and family and making new friends online) had positive effects on students' loneliness through improving social support. However, the rapid increase in use of the social networking sites by young people has made parents, school staff, and policy makers concerned about the potential risks to children [12]. Concern centres on the public display of personal information and the weakening of children's "real" world face-to-face interactions, which may threaten well-being [10, 23]. Despite these concerns, recent research in Australia [27] suggests that young people are better equipped to deal with online risks than adults assume and that informal learning from peers can be a valuable way of learning how to use social networking sites safely.

For children with physical and/or multiple disabilities such as cerebral palsy, muscular dystrophy, or acquired brain injury, some of the challenges in opportunities for social interactions, and making and maintaining friendships, could potentially be circumvented through Internet use. For example, children with complex communication needs (who may have physical disabilities and limited or no speech) have difficulties in real-time face-to-face communication, which is crucial for building social networks. The Internet could provide an opportunity where they can play/interact and share their interests and stories with other children, without

prejudice and time pressure. Furthermore, today's children with disabilities are part of the "digital native" generation or "Net Generation", and contemporary research suggests they benefit not only socially but also educationally by participation in multi-modal, collaborative and connected activities (24,19). The increasing accessibility of the Internet also offers opportunities to enhance health and reduce health inequities between children with and without disabilities by addressing broader social determinants of health, for example, social inclusion, social participation and control over one's own life [6]. Increasing social networks and connecting with others may also increase self-esteem and improve overall mental health [3,22].

In Australia in 2006 there were 41,000 children aged 10-18 years with a disability or need for assistance in core activities, and 75% of these already had an Internet connection at the place of residence [2], highlighting the potential to conduct Internet-related research with this group. However, there is emerging, but very limited research into the use of Internet patterns and their impact on adolescents with disabilities. Preliminary US research indicates that 5-17 year-olds with a disability were significantly less likely to use computers and the Internet than their peers without disabilities [15]. Barak and Sadovsky [3] found that 114 hearing-impaired adolescents actually used the Internet more than hearing adolescents. Intensive Internet-using deaf participants had similar levels of well-being to hearing adolescents, whereas hearing-impaired adolescents who used the Internet less had lower levels of well-being. A recent Dutch study [9] examined Internet access and use by 97 adolescents with a physical disability, such as cerebral palsy (CP) or traumatic brain injury, compared with 1566 non-disabled teenagers. While both groups had a high level of Internet access and the most common online activities were similar for both groups (i.e. email), parents of adolescents with a physical disability warned their children more about risks of Internet use and had more home rules. However, the adolescents with disabilities lived in residential care and the study did not investigate the effects of Internet use on wellbeing. A recent qualitative study with 14 young adults with cerebral palsy examined reasons for online social networking use/non-use, whether assistive technologies were needed, and advantages and disadvantages of use [11]. The study identified online social networking as vital for reducing social isolation. However, the changing technology provided challenges, with slow text input and poor interface features. Participants were also concerned about privacy and trust in publicly displaying their information.

A recent evaluation of Livewire, which is an Australian online site for young people with chronic illness or disabilities (www.livewire.org.au), found that Livewire members used the moderated chat extensively and formed friendships through the online site. The young people also reported that they could experiment socially in a safe environment and valued the high level of peer support amongst the members [26].

In summary, there is very limited research investigating whether children and young people with disabilities are using the Internet, reasons for using or not using it, and the facilitators and barriers to use. It is critical to examine these factors so as to inform ways of facilitating the use of this communication medium for increasing social participation, leisure and recreational and learning opportunities for young people with disabilities. The aim of this project was to explore the perceptions of young people with physical disabilities regarding their current patterns of Internet use, its impact, and facilitators and barriers to use.

2. Method

2.1. Design

This study employed a qualitative design with semi-structured interviews to explore the perceptions, views and experiences of young people in Australia with physical disabilities in using the Internet. Ethics approval was obtained from Children, Youth, Women's Health Services Human Research Ethics Committee prior to commencement.

2.2. Participants

15 participants with physical disabilities ranging from 11-18 years of age, with a mean age of 14.6 years, were recruited using purposeful sampling. This is a non-probability sampling approach employed when special cases are the major focus of investigation [25]. Participants were recruited from a previous questionnaire survey on Internet use by children with a physical disability [20] in which respondents had been asked to indicate their willingness to be interviewed in a subsequent stage. Of the 50 returned survey questionnaires, 31 indicated willingness to participate in a subsequent interview. From these 31, 15 who met the following criteria were selected; aged 11-18 years; proportion of boy and girls as represented in the survey; living in rural or metropolitan areas; have complex communication needs; nature and extent of use of the Internet varied from little to extensive as reported in the survey. All 15 agreed to an interview.

Table 1 provides participant demographic information. The classification of participants' level of physical disability was based on the Gross Motor Function Classification System (GMFCS) which ranges from Level I where adolescents walk without limitation and can perform gross motor skills (eg running and jumping but with limited speed, balance and coordination) to Level V where adolescents are transported in a manual wheelchair in all settings and need assistive technology to participate in physical activities including physical assistance [17]. All participants used natural speech for communication, except one who has CCN and used a speech generating device. This participant's age, sex, diagnosis and school details are not mentioned as it would make them easily identifiable. Five had mild to moderate dysarthria requiring some assistance from parents in repeating or clarifying responses. All attended mainstream school with four of them attending special classes in mainstream school.

2.3. Procedure

A semi-structured interview was used following protocols suggested by Patton [18], with an interview schedule developed incorporating general questions on Internet use and specific questions informed by responses to the previous survey. For example, participants who had mentioned that they were using Facebook every day to talk with their school friends were asked if they were still using Facebook to the same extent and manner (see Appendix A for an example of interview questions). Two members of the research team conducted the interviews individually. Eleven participants were interviewed face-to-face at home, except for one rural participant interviewed at the research organisation. Four who lived away from the city were interviewed by phone. All had one parent nearby during the interview; generally the parent did not remain for the entire interview but was available if needed. Interviews lasted from 14-55 minutes, with the average lasting 36 minutes.

Interviewers reinforced that there were no right or wrong answers and that differences in opinion between the participant and parent were acceptable. The interview began by exploring issues from the participants' survey responses regarding patterns and frequency of Internet use. Questions then probed the ways in which participants used the Internet, frequency and location of access, with whom they interacted online and any perceived barriers to use, as well as strategies which supported access or online interaction. Participants' understanding of and experience with risks such as cyber bullying were also explored, along with factors such as perceived sense of self efficacy. At interview completion participant responses were verbally summarised and presented back to participants as a reliability check, and to allow participants to add further information, retract any comments, or provide feedback on the summary.

2.4. Data Analysis

All interviews were transcribed verbatim. The data was analysed using an inductive analysis approach described by Patton [18]. The research officer then selected three interviews that were detailed, varied and yielded rich data. The research officer and a research team member who had conducted the interviews then read these three transcripts and separately open-coded the data, with codes reflecting the questions posed as well as other spontaneously raised issues. The two chief investigators then read the same three interviews, examined the codes, added other emerging codes, and developed a thematic coding framework. The two members who had conducted the interviews and had developed the initial coding then coded each of the 15 transcripts according to the framework. Then the two chief investigators and the interviewing research team member worked through five transcripts each, re-checked codes and developed a summary of themes for their five transcripts. The thematic summaries from all researchers were then combined and provide the basis for the results section.

3. Results

The findings are presented in the following sections according to major themes Identified.

3.1. Patterns of Use

This section covers what online forms and sites were used, purposes of use, locations of use, frequency and perceived efficacy of use. Participants reported using a variety of online forms, including emails, instant messaging sites (to talk to one or several people in real time), social networking sites such as Myspace and Facebook, and online games, as well as games downloaded and played offline (eg., Mousebreaker, Age of Empires). Participants also reported visiting sports sites, such as local netball and football clubs, to find information about games and scores. They reported using the Internet for various activities, including school work, leisure and recreation, and building social connections:

P13: I play Adventure Quest on the Internet... I download... music, special music, in particular TV show music, WWE which is World Wrestling Entertainment; I like wrestling.

Mother of P12: Sites you like going to are things like High School Musical sites or the netball sites or football games sites. P12: Yeah.

P15: For school, like some teachers want us to get pictures because we have to do a project or something, so we have to get pictures to put on our project.

The social networking site Facebook was reported to be used more than Myspace. On Facebook these young people reported liking to change their profile, read notifications and play games:

P14: I always change my status, like to let people know what I'm doing or what I'm thinking. You can write whatever, it doesn't really matter.

Almost all participants used the Internet predominantly at home and school, except for one who had no home Internet and used it only at school. Community access was limited. Few participants reported playing games at school due to school restrictions on the types of online activities, although some participants had managed to find a way around the rules. These young people also clearly articulated their preferences and reasons for the choice of their Internet usage. On the other hand, blogs were generally not used:

P5: I don't do those things (blogs)...Basically because I find it boring.

Participants' pattern of use appeared to be dynamic to keep up with trends. Some reported that their usage had changed since the initial survey (ie a 3 month timeframe), highlighting changes that can occur with young people's usage, for example due to starting high school or changing interests:

Interviewer: (On the survey) you are using it for things like YouTube and playing games.

P1: Don't do that so much anymore cause I'm trying to do more school work.

Some participants had either dropped off using some social networking sites or had changed their degree of use. Participants' responses suggested they were using the Internet in similar ways to their peers without disabilities, and they did not report their use as being significantly different to their peers:

Interviewer: Thinking about how other children use the Internet, do you think there are any differences in how they use it and how you use it?

P5: Not really.

Interviewer: So what would the differences be that you could think of?

P13: They might go on on-line games more maybe, play a particular game that I don't like.

Interviewer: So it might be a matter of a specific game?

P13: Yeah, like all that sort of stuff.

Frequency of use varied, from participants using the Internet every day for 3-5 hours, to instant messaging most days, using social networking sites a couple of times a week to change status, to just once a month to download music to an iPod:

P13: It depends. Like just a few weeks ago we were playing it like every day but now – for the past three weeks – we haven't been playing it at all.

P5: I normally use it [Facebook] everyday or if I'm, like, busy or have friends over or anything.

Family and school rules regarding time use of computers also contributed to differences in frequency of use (as discussed later).

3.2. Gaining skills and knowledge

Although a few participants reported having only superficial knowledge of the Internet and how to use it, it was encouraging to find that most participants reported good knowledge of the Internet, understood how to use it, and felt comfortable in using it for a variety of purposes:

Interviewer: Do you feel like you're good at using the internet?

P12: Yep.

Interviewer: What makes you say that?

P12: Because I know how to use it.

Interviewer: Yeah why do you think you're good at it?

P13: Because I've got skill.

P15: I know how to change the background so it can be different colours and I know how to send messages and, yeah, and write comments about people's pictures [on MySpace].

Some participants were self taught, while others reported having learned about the Internet through formal education:

P4: Just like MSN, I just kind of taught myself; I like to do that. I prefer to learn things myself.

Interviewer: Did you end up learning about it, at school? Or have you just learnt off friends how to do it?

P11: I learnt about three or four years ago at school

A few stated that they could not use some functions because they did not yet have sufficient knowledge:

Interviewer: You don't use Instant messaging, so MSN and stuff like that?

P15: I don't use MSN because I don't know how. My friend does but I don't bother asking her because it is too complicated

However, most participants strongly emphasised that friends or siblings had been instrumental in teaching them Internet use. Most stated that friends or siblings had initially shown them how to set up or access and navigate sites, and they could then use the applications independently:

Interviewer: So how did you get interested in using Facebook?

P12: My friend added me, so signed me up for it.

Interviewer: Is this the same friend who got you interested in MSN?

P12: Yep.

Interviewer: The next question was the sites you use and you already told me, which was My Space and Gmail, so how did you get interested in using those?

P15: My friend. My friend showed me how to do it

In summary, most participants reported that they felt that they knew how to use the Internet and used it confidently, although while some found it very easy to use, others found some applications difficult to use. A critical factor was learning from peers and friends and family members, with the supportive role of friendship being highlighted. Not all reported using the Internet for social networking, and their frequency of use and knowledge of the Internet varied, as did the sites they use, but friends were central to both their reasons for use, whom they connected with, and how they connected or learned online skills in the first place.

3.3. Who do I connect with?

We used the Circles of Communication Partners Paradigm (CCP) [4] to represent the participants' Internet social connections. The CCP is represented by 5 circles, with Circle 1 (the innermost circle) showing the closest communication partners ie life partners such as parents, siblings, grandparents; Circle 2 showing close friends and relatives such as good friends, aunts, cousins; Circle 3 being acquaintances and friends (extended school friends and people one knows through sports, etc); Circle 4 being paid partners (teachers, hairdressers); and Circle 5 being unfamiliar people, including people who you meet online, shopkeepers, etc. The CCP paradigm gives a detailed description of one's social networks:

Circle 1. No participants in our study mentioned using the Internet to connect with parents, siblings or grandparents. This is perhaps not surprising since all participants were living with their families.

Circle 2. Online connection was often an extension of offline connections, providing additional connection which helped to maintain, strengthen and manage friendships with people at school or people already known via instant messaging, email or social networking sites.

Many participants talked about using the Internet to keep in touch with close friends and less immediate family, such as relatives interstate or overseas, particularly through Facebook or emailing. They valued these connections:

Interviewer: So who would it be mainly?

P12: Aunty, cousins, family.

Interviewer: Anyone else?

P12: (names 2)

Interviewer: Is she from school or elsewhere?

P12: They are my best friends.

Circle 3. There was a strong theme of connecting only with friends and people known through school, sporting clubs or friends of the family:

P15: I've only got seven I think, seven people that I know.

Interviewer: So you're someone who keeps it limited to people you actually know in real life?

P15: Yes.

The role of friends was particularly highlighted, especially the importance of friends showing them how to start using the Internet or particular games or sites, sharing sites, helping them and connecting with them. School friends were frequently people with whom the children connected online as well. Only a small number of participants

mentioned making new social connections with people they had only met online. One preferred this to talking to friends at school because he could easily speak to friends at school. These participants had met online friends through playing online games:

P4: I talk to both, like friends in real life and online friends together on MySpace... I mean MSN.

One participant had made friends through Facebook and said they would add people in and start playing with them:

P14: There's loads of different games that play, two players and that, and you can just add anyone and everyone that you want to add.

One who missed lot of school due to their disability had had online friendships for two years:

P4: I have got lot of friends that I made online... How I met that friend, it was on a game called Gaia... It's pretty much where you make your own avatar and you can just do phishing and that's actually how I met her, through this phishing application thing. Yeah, and we just started talking over that.

Circle 4. A small proportion of participants connected with their school support officers, therapists from their service-providing organisation, and hairdresser. This may be more specific for young people with a disability than with typically developing peers. However, family rules often ensured that families checked their child's online friendship list or who they talked with online, especially on the social networking sites, and this limited their child to connect only with people that the parents felt the child knew and could trust. A mother of one participant explained, for example:

Mother of P2: So we go through and check every now and again to work out who she knows, where she knows people from, because it might be someone's cousin or someone she met once at something that we don't know at all

Mother of P11: P11 only talks to who, probably who we would know. Sorry [P11] would know that we would know, if you get what I mean. [P11] would never talk to strangers [online].

Mother of P12: Every now and again what do I do?

P12: Check.

M: Do a friend list.

P12: Check it.

M: And who do we get rid of?

P12: People that swear.

M: People that swear and who else? People you don't really know.

P12: Yep.

Rules around who they talked with online limited participants to only people they knew, which families felt minimised the likelihood of online bullying and other potential harms. Protective strategies included locating computers in a central area and parents moving through to keep an eye on online use, having password protection; having protective rules, such as "no rude stuff", no online purchasing, time limits on Internet and site use, and sticking to appropriate sites.

In summary, we found that participants particularly used the Internet to maintain, strengthen and manage friendships, rather than making many new friendships.

3.4. Why do I use the Internet?

The participants in this study used the Internet for school work, to keep up with peers and for easy and quick access to friends. They enjoyed talking to friends online as well as having fun, recreation and leisure. Having a physical disability can limit active options such as cycling or walking to a nearby friend's house, and the Internet allowed participants to overcome this to some extent. Participants indicated that they liked using the Internet for instant messaging and Facebook because of the real-time instantaneous connection which these technologies allow:

P5: Uumm... well it's fast and usually they [friends] respond straight away.

Participants also reported using the Internet to update friends on what they were doing or were planning to do, and to look at other friends' status. They also reported a feeling of "peer pressure" if friends were on the Internet and wanted them to also be online. In these situations participants often did not want to be left out:

Mother: Because it's hard when everybody else is on it and you're not on.

P12: Yeah.

Mother: Because in fact if they're not on she gets phone calls, 'Why aren't you on?' 'When are you going on?'

Participants were aware of different sites and what they can do. Facebook was reported to be more popular because, as participants stated, the layout was relatively easy to navigate, applications were varied and interesting, and their friends were active in Facebook:

P3: Ummm. it's quite easy to use. It's not like, it's not like the school - complicated layout or whatever. It's easy. Simple, you get used to it and, um., a lot more people use it [Facebook] than MySpace.

For these participants with disabilities, the online social networking sites and email enabled them to stay connected particularly when they could not go to school:

P4: Because I have asthma and it's usually windy [in this area], especially in winter. So yeah – and I can't go to school if it's windy. With this, as well with my plasters... Three weeks ago – I had them on before – because I had an operation on my legs and they put a plaster on and I wasn't allowed to go to school, so like instant messaging was a good way for me to see my friends and stuff.

Therefore, one of the main benefits of the Internet for young people with physical disability was increased connectivity with existing friendship networks and family, which increased their sense of belonging to these existing circles. The expanding learning networks for school, work and future employment opportunities of using and being familiar with such technology was also highlighted:

Mother of P11: ...because I think that's [the Internet is P11's] only way of communicating, so that's why we are encouraging more technology for [P11], if you get what I mean? We're pretty lucky with [P11], as I say, that technology has just been valuable. We hope that one day P11 might be able to get a job somewhere [in computers/IT].

For this participant with complex communication needs, it was also an easy way to communicate with friends:

Interviewer: So you email a friend who lives in Melbourne, okay.

P11: Footy tips (emails regarding footy tips)

Mother of P11: You like doing that don't you? And looking at other people's, like your cousin's from interstate and those sorts of people that you don't see very often, and you can see what they're up to can't you?

P11: Yep.

Another participant said they did not want to use instant messaging, highlighting that conversations were around teenage boys' topics of "hot girls" in magazines. This participant alerted that they may talk about it for a few minutes, but then felt it was "stupid."

In summary, the main reason for using the Internet reported by participants was related to peer pressure and not wanting to feel left out because "everyone was using it", as well as wanting to stay connected with friends.

3.5. Facilitators and challenges to use

A range of factors appeared to influence the Internet use of these young people with a physical disability. Factors which they discussed in detail included the role of family and school, such as an individual or family's existing resources and capabilities (for example family support, financial resources, technical knowledge and skills, and the family's friendship network). The role of schools and assistive technology was also mentioned by participants as being both supportive and limiting. The participants' existing circle of contacts was the main facilitator for use. These factors are presented in greater detail below.

3.5.1. Family

A family's resources were an important factor helping or hindering participants in starting to use the Internet and learning to use it for various purposes. Factors included their family members' Internet and technical knowledge and skills, (such as to repair and fix problems), financial resources, and connections with other people who could provide assistance. Parents or siblings had frequently helped participants set up their computer, showed them how to download games, or set them up on social networking sites. However, some parents reported having limited computer or Internet literacy skills and knowledge, while some supported their child's Internet use because they felt it was important for the child's learning and social connection:

P7: I mean people just taught me.

Interviewer: So when you say people, was that the friends that you were trying to message with?

P7: yeah, my brother as well.

P14: My brother set up my email account but I learnt how to register it with MSN, because I asked him to how, because of the fad thing, .because you can't just do things by yourself all the time.

The biggest barrier to Internet use in this study was a family's limited resources at home. These included young people having to share access to one computer or the Internet with other family members, having limited Internet download/use quotas, experiencing time out from technical breakdowns, or having no home Internet access. Competing users was a particular barrier at home, with siblings or parents also requiring access, particularly if the family had (or could only afford) one computer:

P3: My brother's always on [the Internet]... Sometimes my dad gets annoyed. "Get off", they say they'll take 5 minutes but they'll like take an hour.

Some participants could not download as much as they wanted due to resource limits, or a slow Internet connection:

P13: I can't use YouTube too much because it takes all the Internet away.

Interviewer: Can you tell me why you don't download more?

P11: Because it takes forever.

One mother whose family had no home Internet said she felt they could not afford it, while another parent felt that a more pressing financial need might arise so that an Internet contract would be a financial risk. In some participant families there was also some uncertainty around actual Internet costs and concern that family members may overrun their quota, leading to a potentially unmanageable bill. Some parents also reported lack of trust in contracts and lack of confidence in their own ability to understand what they might agree to, due to complex contract language and their lack of technological understanding:

Interviewer: So what's behind not having the internet at home?

Mother of P15: Money. So basically if we signed up when he [Internet salesperson] came to the door that was it, we were [would have been] in a three year contract and couldn't get out and I thought, "Well what if something comes up and we need that money for something else and we can't afford it?"

On the other hand, another parent stated that she had no use for the Internet, did not prioritise social applications, and perceived a high degree of risk with home Internet access. Limited wireless connections (especially in rural areas) and problems with Internet connections were also reported as barriers.

However, even for participants with home Internet, family rules could limit the extent and nature of use. One participant wanted to spend longer than one hour per day on MSN since she felt that some of her friends were "on all the time", but her family's rules limited her to two ½ hr sessions per day. Some participants mentioned that they wanted, or their parents required them, to prioritise school work and complete this before they were allowed to use the Internet/computer:

P4: I am not allowed to stay half the night up on the computer.

Mother: Homework and work is a priority... recreation stuff is second.

Such rules could be a double disadvantage for those who needed longer time to complete homework, and therefore were unable to finish early enough to also have recreational computer time:

Interviewer: When they've [friends] finished doing their work at school then they might be playing games or MSN or stuff like that, okay. And you don't do that because? you are you more conscientious to do your work or you take longer to do your work?

P11: Longer.

When something went wrong with their computer or Internet connection, it was usually a sibling or father who fixed or took care of the problem. Some families used a professional computer repairer. Often there was one particular family member who could “fix” things. Parents also recognized that younger family members, siblings and the participants themselves could be versatile and helpful in fixing computer-related problems or using the Internet. Some families were only just becoming aware of the Internet's potential and were taking steps to learn more, either formally through courses or informally by asking their children:

Interviewer: Just thinking of the most recent time when it happened, can you tell me what it was that happened and how it got fixed up?

P11: A few days ago, my dad and ... [sister] made it – fixed it.

3.5.2. School

School emerged as a critical environment for learning Internet use, particularly for those with no home Internet. A few participants had learned through school IT classes to use emailing and how to access websites for school work. However, school rules were reported as limiting Internet use, even when established as protective factors, with particular limits on what social networking sites or recreational activities could be accessed, with some setting and monitoring Internet use quotas:

P13: [I play at] home. I don't play anywhere else because, like, most of the game sites at school are blocked because they don't like you playing games because according to library people they reckon it causes viruses. But I don't think it's the games, I think it's like the set-up stuff, like all the way they've set it up

School rules as to what sites participants could access seemed to vary between schools, and with the year/grade level. Older participants reported having access to emailing, Internet and social networking sites. Nevertheless, for participants with no Internet at home, school Internet access was critical and helpful in learning, social networking, and for leisure and recreation.

3.5.3. Disability

Many participants mentioned factors related to their disability that made it slower or more difficult for them to use the Internet than their able-bodied peers:

Interviewer: What would stop you from playing more games on-line?

P13: There's two different things. One, as I said before, the handicap on me.

Interviewer: Yeah, so your right hand?

P13: Yeah, so I might not be able to play that game very well.

Internet use was also limited for some due to related intellectual abilities or being developmentally behind, despite their IT skills being sufficient when they were able to go on a computer:

Mother of P6: I think your friends would do more than you [on the Internet]. A lot of it is the literacy—the verbal communication—still about 2 ½ years behind in the social interaction side [but] P6 is brilliant at IT.

Using the standard mouse, becoming tired through one-handed typing and sitting at the computer for long periods were other barriers to Internet use. However, only a small number mentioned using assistive technologies to overcome these. Many reported that they were able to turn on the computer, type, read and understand the information on the screen and said they did not fatigue easily (although one had physical difficulty bending down to turn their computer on). The main disability-related access issue was one-handed typing, using a typing tutor, slow typing or using track ball or key guard:

P3's parent: We tried the quick type programs and that sort of things....

P3: They're boring...

P3's parent: But it doesn't work with (specific fingers on specific keys) ...P3 can't use certain fingers ..kids adapt which is fantastic

One participant could not type and a family member therefore typed their emails or instant messages. Some participants had been assisted at school by teachers. Nevertheless, for participants with complex communication needs, the computer/Internet became another way of communicating with a device linked to the Internet:

P15: I only use one hand... At school I have a principal, she helps me because I have got a disability. Like, I was in her class doing special English and stuff like that and when I had the special English she used, she got this disc off, I think it was from Novita, and they put it onto the computer for me. It's like one finger, one-hand typing. So she'd let me do that so I can learn how to do it quicker.

In summary, the important facilitators of Internet use were found to be family support, knowledge and skills, and the comfort level of family members. Assistive technology was used only by a few participants and only at a simple level. Barriers to use include limited family resources in purchasing an Internet connection, lack of connections at speeds suited to participants' preferred uses, inadequate time allowed by parents, parents' own limited Internet literacy, limited ability to fix the problems with computer or the Internet, and participants' disability related issues that slowed access or made it frustrating.

3.6. Cyber bullying

Participants were also asked about their understanding of online bullying, strategies that they would take if bullied at home and school, what protected them from risks, and whether they had any personal experiences. All participants reported being aware of the potential for cyber bullying and what it means, and most reported knowing at least one strategy to use if they were bullied. Some stated that they thought that bullying could happen to them and others indicated that they did not think it could. Most participants reported being aware of general risk factors and how some applications are safer than others:

P4: What my teacher says is going on the Internet is like blindfolding you and putting you in a room with like all the world, because I guess it is quite a bit like that and that's why you don't give out your details.

P5: Mmm not really. If it should happen, just delete the email or whatever and just ignore it

Interviewer: So is it [online bullying] something that you would ever think would happen to you?

P11: Yes.

Interviewer: So it's something you have thought of. What would you do if something like that happened to you?

P11: Tell my family and tell the teachers.

This participant also said they have a protective circle of school friends who would “go after” anyone who tried to bully them. However, only a small number of participants reported having personally experienced what they thought was online bullying; they had blocked the person and then talked with a parent about it. Participants indicated that protective factors at school and home included limiting access to certain sites and strictly patrolling sites, and establishing rules around when and what can be accessed:

P13: That's what they said (at school), like not to go there [on that site] for a very long time.

Interviewer: Not to visit the site?

P13: Yeah or maybe contact the police if it's getting that serious.

A few participants reported that they had experienced some risk factors, however, they had found strategies to address them. For example, one participant had experienced some people at school tricking him onto a banned site, but had now learnt to be more cautious. Another reported experiencing inappropriate behaviour when accessing the Internet at a friend's house. The participant reported that an unknown female told the participant to stand in front of the webcam and undress. The friend reported the incident to their mother and the mother told them to block the contact and delete her. Another participant stated having experienced disability-related bullying, which their school had dealt with:

I: When did it happen to you?

P8: Oh last year. They were sending me these rude words which I wasn't impressed by and it got dealt with then; its over now. But they were saying stuff like “Oh you're in a chair” and all this stuff. I was going “This is not right”.

Protective factors to prevent bullying included family rules about the location of computer, not talking to strangers, rules on appropriate sites, school rules and good relationships with parents and teachers.

4. Discussion

This study investigated patterns of Internet use, facilitators, barriers and benefits of use by young people with physical disabilities. The most important finding from this study is that this group of young people with varying levels of disability, from mild to moderately-severe physical disability, with a wide age spread were using the Internet for a variety of purposes. However, the frequency and extent of use was found to be limited compared to the general population of young people in this age group [see e.g. 5,10,12,21]. Even though most participants reported that they found it easy to use the Internet, a few needed help with certain applications.

Training, support and appropriate assistive technology should be provided to ensure that all children and young people who want to use the Internet are able to.

The study also found that friends and siblings played a significant role in supporting participants to get set up on social networking and other Internet sites. Friends were also the main people participants had contact with online. Family resources and literacy seemed to be more of a barrier than the disability per se in this group. However, typing speed was a limiting or frustrating factor for some, particularly for live interactions such as games and instant messaging which require quick responses. In relation to the finding that at least one participant's family typed email or instant messages for them, due to their disability preventing them from typing, it will be important to conduct further research on how acceptable this is to a young person and what the likely impact could be on their online relationships and their ability to socially connect.

Using the Circles of Communication Paradigm we found that Internet use can increase the social participation of children with a physical disability, because it provides an additional medium through which they can strengthen their offline friendships and increase contact with more remote family members. These findings therefore reflect other research with young adults without disabilities which shows that most relationships formed via social networking sites are with existing friends [23]. In this study, the social circles were not much extended to new people through being online. Nevertheless, for those with less social contact offline, the Internet did offer a way to extend their social circle to new people or as an alternative social circle. It is important to examine how this could be more supported so that online social circles are developed or extended safely to new people.

In this study, the limitation of most young people to online connection with known others was found to be at least partly related to parental rules. The limitations of parental rules were also highlighted in a Dutch study by Lathouwers et al., [9]. Due to emphasis on cyber safety, rules may not be specific to young people with disabilities. However, the degree or enforcement of parental rules may be different for this group and this should be explored further, particularly since a recent study has found that young people are better equipped to deal with online risks than adults assume [27]. Similarly, in our study most participants were aware of cyber safety issues and knew and/or had used strategies to safe guard themselves. To support Internet access, it is therefore essential that all young people continue to be supported and reminded about privacy and to ways to protect themselves online.

The benefits of using the Internet for social networking were highlighted by many participants. This finding is consistent with Third and Richardson's findings [26] where young people with a chronic health condition or disability found the online community supported their health and wellbeing. In several families in our study, participants and their siblings knew more about computers/Internet than their parents and so were a source of knowledge and expertise in managing the family's information technology resources. This gives children with disabilities, who may be dependent in more ways than a typically developing child, a rare and important opportunity for role reversal.

Limitations to online connection, such as families' resources and capabilities with information technology, including fear, lack of skills, and mistrust of contracts, were also found in a study of adults from disadvantaged and low-income backgrounds [16]. Since children with a disability are more likely to live in families

with these backgrounds [7], this has significant implications for equity in Internet access.

5. Conclusions

It was encouraging to note that the 15 children and young people with physical disabilities who participated in this study used the Internet in a variety of ways. Friends and family played an important role, similar to children without disabilities. The disabilities per se did not play as central a role in the nature and extent of use as family resources, family rules, and knowledge of the Internet.

The sample size of 15 participants with varying abilities was adequate for the purpose of the study, which was to explore relatively new issues with this population. Future research should explore these issues with children with more severe disabilities, and investigate the influence of different residential locations (rural vs. metropolitan), gender, age groups and the impact of supports provided to families in terms of becoming computer/Internet literate.

Future research should also explore the impact that parental support with messaging (eg typing messages) and family rules have on the formation and maintenance of relationships online, and whether this differs between children with and without disabilities. Future studies can also examine how young people should be supported in ways which do not undermine other aspects such as privacy, personal safety, and cyber safety for young people from "high risk" populations. This study adds to the growing understanding of patterns of use of social networking sites by young people in general, and young people with disabilities in particular, the implications for informal learning, and for health and wellbeing through social participation.

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