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"I'm a mother, but I'm also a facilitator in her every-day life": Parents' voices about barriers and support for internet participation among young people with intellectual disabilities

Sorbring, Emma¹, Molin, Martin¹, & Löfgren-Mårtenson, Lotta²

¹ University West, Trollhättan, Sweden

² Malmö University, Malmö, Sweden

Abstract

In general, the Internet is an arena where parents (as well as other adults) have limited insight and possibilities to support the young person. However, several studies indicate that parents are one of the most important facilitators in the every-day life of young persons with intellectual disabilities. Therefore, the aim of the current article is to highlight parents' perceptions and actions in relation to opportunities and barriers for these young people when using the Internet. The empirical material consists of interviews with 22 parents of intellectually challenged young people in Sweden. The transcribed interviews were analysed using a thematic analysis, which is a method of identifying, analysing and reporting patterns within data sets. The results show that parents' views are double-edged; on the one hand, they see great possibilities for their children, thanks to the Internet, but on the other hand, they are afraid that due to their disability, their children are more sensitive to different contents and interactions on the Internet. Furthermore, the results indicate that parents believe that the Internet can facilitate participation in social life, but that it precludes young people with intellectual disabilities from being part of society in general when it comes to community functions and services. This article will discuss barriers and support in relation to the individual and her or his support system, which brings into focus the parent's responsibility and support for young people, helping them to surmount barriers – instead of avoiding or ignoring them – and find ways to take action to do so.

Keywords: internet; intellectual disabilities; young people; barriers; support

Introduction

Many people with intellectual disabilities live socially isolated lives and are often in need of more contact with the surrounding community. The Internet has the potential to offer them an arena for greater participation in social life and society in general. However, research has shown that from time to time young persons with intellectual disabilities experience barriers when using the Internet and that they are in need of support (Caton & Chapman, 2016). Parents have been shown to be the primary source of support for young people in their every-day lives (Björquist, 2016; Palmer, Wehmeyer, Davies, & Stock, 2012). Previous research has mainly focused on parent support in every-day life; however, parents' role in their children's Internet use has received less attention, and – especially when it comes to parenthood and intellectual disabilities – this constitutes a gap in

our knowledge. The aim of the current study is to reduce this gap by examining the following questions: How do the parents of young people with intellectual disabilities perceive opportunities and barriers to their children's use of the Internet? In what ways do parents describe their own actions in terms of their ambition to lower the barriers and support opportunities, both in relation to the Internet as an arena for greater participation in social life and in society in general?

Participation and the Internet

Participation is a concept that is often discussed when we talk about children and young people with intellectual disabilities. For the individual, it is important to create the conditions for participation, both in society and on an interpersonal level. The UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) states that participation is important for strengthening the individual. Full and effective participation in society is seen by the convention as: 1) a general principle, 2) a general obligation, and 3) a right. Despite the UN Convention, many people with disabilities still lack a context for participation, especially regarding education and the labour market. It can be assumed that young people with intellectual disabilities may experience more difficulties, compared with others. For example, it is hard for them, by themselves, to take contact with various agencies and organizations, to assimilate written and verbal information, and to receive adequate health care. In addition, research shows that many young people with intellectual disabilities live socially isolated lives and feel that in comparison to their peers they are lonelier (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006; Sharabi & Margalit, 2011). Recent Swedish studies have shown that a new generation of young people with intellectual disabilities strives to increase social participation and develop alternative identities. In this sense, the Internet could play an important role as a social venue where young people can free themselves of labels that categorize them (such as "special needs student") and find new "free zones". This is a free zone, in that it is a space without parents' or other adults' oversight, but also in the sense that the disability is not in focus or visible to others (Löfgren-Mårtenson, Sorbring, & Molin, 2015; Molin, Sorbring, & Löfgren-Mårtenson, 2015).

The Internet can provide a forum for participation and opportunity for interaction where these children's interests and personalities – rather than their disabilities – are in focus. While some people choose the venues and sites where "everyone else" is (Löfgren-Mårtenson, 2008), others look for opportunities within the intellectual disability community (Kennedy, Evans, & Thomas, 2011). Stendal, Balandin and Molka-Danielson (2011) point out that the Internet in general, and virtual worlds (such as Second Life, a virtual world where you have your one avatar), more specifically, offer possibilities for people with intellectual disabilities (as well as other disabilities) to develop and deepen existing friendships. In virtual worlds, it is possible to spend time at a club that either targets people with the same diagnosis or a club which is not intended for any specific disabilities. Virtual worlds can also offer the opportunity to visit concerts, travel around the world and spend time with friends that the young person otherwise would never have met. In this way, young people with intellectual disabilities are also engaged in the larger multifaceted cyber culture and the rapid changes taking place on the Internet, both technically and socially.

Research on how assistive technology can support and empower people with intellectual disabilities is a growing field (Bunning, Heath, & Minnion, 2009). Several studies show, for instance, how the adoption of certain mobile technology software and support programs can provide skill development and social participation (Darcy, Maxwell, & Green, 2016). Although research points out that mobile technology could be a tool for empowerment, it is put forward that technology implementation could include both challenges and successes. In an inclusive research project Cumming, Strnadová, Knox, and Parmenter (2014) found that iPads enhanced several participation opportunities. On the other hand, increased technology use also highlighted vulnerability aspects, especially for women with intellectual disabilities.

Barriers for Participation

Although the Internet can be an important arena for finding friends, partners and experiencing greater participation in the community, some scholars question whether these possibilities that the Internet offers are really there. For example, Chadwick, Wesson, and Fullwood (2013) talk about "a digital divide," where some individuals and groups tend to be marginalized with the increased use of advanced technology in society. The authors state that several barriers are present that prevent individuals from getting access to the free zone that

the Internet can offer. The barriers can consist of both technical and individual factors, such as memory and learning skills, but there can also be factors related to societal attitudes, education, and training support barriers etc. Watling (2011) stresses that people with disabilities are often restricted to using computers at home due to the high levels of required personalization. In a society with increasingly "digital-only" welfare initiatives, this can isolate and exclude those who might have the most gain.

Normand (2016) and Lussier-Desrochers, Caouette and Godin-Tremblay (2016) describe the barriers that preclude individuals with intellectual disabilities from making use of the Internet. The basic barriers are barriers that determine whether they will ever be able to enjoy the Internet, and upper barriers are obstacles that contribute to a limited use of the Internet or even a risky use of the Internet. The most basic level *Access to digital devices*, consists mainly of a lack of finances, which does not allow the individual to acquire the technical equipment that he or she needs. In Sweden, the "digital divide" is mainly attributed to age and functionality and not financial circumstances. To some extent the financial circumstances of the individual affect what type of technology he or she can purchase, but in Sweden it is more common than in other countries that digital devices like computers are provided by the school. In many other countries financial circumstances are a central factor in determining whether the Internet is available at all. The second barrier, *Sensory motor ability*, consists of the individual's physical ability to manage the technology. It may involve limited possibilities for handling a smartphone, for example (which many times has a touch-screen), or limited ability to see what is displayed on the screen. The third barrier *Cognitive ability* and the fourth barrier *Technical ability* - may or may not be related. New technologies such as laptops, smartphones, and social media, have in many respects become an integral and natural part young people's lives. They have grown up with entirely different conditions than previous generations, and are now additionally connected online much of the day. Most young people are able to use the Internet very adeptly, while for example, young people with intellectual disabilities may experience some difficulties, possibly due to a lack of cognitive ability. The media attention surrounding young people and the Internet usually focuses on the risks of being cheated and not least the consequences of easily accessible pornography. As for young people with intellectual disabilities, the concern is many times greater. These young people are seen as more naïve than others and are many times more controlled than young people without intellectual disabilities (Löfgren-Mårtenson, 2008; Löfgren-Mårtenson et al., 2015), which leads us to the fifth barrier, *Understanding of social codes and conventions of the digital world (netiquette)*. Young people with intellectual disabilities can experience difficulties in interpreting and understanding the interaction on the Internet since it provides fewer clues than face-to-face communication (Löfgren-Mårtenson, 2008). Hence, it also becomes more difficult to understand the intentions of others. This can lead to young people with intellectual disabilities ending up in unwanted and risky situations (Löfgren-Mårtenson et al., 2015)

Chadwick et al. (2013) state that, on the one hand, the Internet has not become the "emancipatory landscape" for people with disabilities that was previously suggested; on the other hand, in the future there is a need to investigate the Internet's potential to be an arena for participation, self-determination and identification processes. They point out that most studies mainly relate to physical disabilities rather than intellectual ones.

Parents' Support

Young people with varying degrees of intellectual disabilities, need help and support in their daily lives from people in their surroundings. This means that many have practically no privacy. The bond between parents and young people with intellectual disabilities is often very close and strong. Opportunities to develop self-determination and independence can therefore be restricted in relationships that are characterized by dependency upon others. The Internet can then be a "free zone," where parents and other adults have limited insight into the lives of young people. However, research has shown that family members are often the primary sources of support for new technology used among young people with intellectual disabilities (Palmer et al., 2012). Many times parents experience ambivalence when handling both technical and moral issues that come with an increased use of the Internet. Furthermore, parents tend to exhibit strong feelings of responsibility and feelings that are often manifested through different forms of control and/or restrictions, especially about private spheres like love and sexuality (Löfgren-Mårtenson, 2005). The gender of the parent as well as the gender of the child affect how strongly they feel and which concerns parents are worried about. For example, Sorbring (2012) showed that fathers, in contrast to mothers, are more worried that their children's Internet use will result in

fewer friends. Furthermore, the study (ibid) showed that parents are more concerned that daughters, in contrast to sons, will meet dangerous people on the Internet and come into contact with stressful information.

Likewise, it is important to view young people with intellectual disabilities like any other young person without a disability, although the intellectual and maturity terms do not follow age-appropriate patterns, and life experiences may vary. The need for self-determination and participation is great among almost all young people, with or without intellectual disabilities. In the transition between being a child and becoming an adult, young people with intellectual disabilities experience a lack of autonomy, as they are lacking the skills needed to become more autonomous in relation to their parents (Björquist, 2016). Björquist highlights what is contradictory and complicated in that young people, on the one hand, strive to become more autonomous in relation to their parents and, on the other hand, need their parents' support in many everyday life situations. To be able to support a young person's Internet use, parents and other adults require some degree of access to the free zone that the Internet otherwise can offer. Without an adequate support system, the consequences may be that the individual uses the Internet in a flawed and perhaps dangerous way or refrains completely from using the Internet. New technical possibilities demand parents' and other adults' readiness to deal with not just the technical conditions, but also the ethical, moral and liability-related issues associated with Internet use. As a parent of a young person close to twenty, there might be an ethical conflict between, on the one hand, respect for the individual's privacy and, on the other hand, emphasis on the young person's needs.

The Present Study

In general, the Internet is an arena where parents (as well as other adults) have limited insight and possibilities to support the young person. However, several studies indicate that parents are the most important facilitators in the every-day life of a young person with intellectual disabilities. Research that considers parents' perspectives on the young person's opportunities to be involved and participate in social life and society in general, and how they as parents can support participation, is particularly scarce. For example, Seale (2014) highlights the need for more research concerning Internet support for people with intellectual disabilities. Therefore, the purpose of the present study was to examine how parents perceive and support the Internet as an arena that contributes to increased participation in social life and in society in general for young people with intellectual disabilities. The following research questions have been posed:

1. How do the parents of intellectually disabled young people perceive opportunities and barriers to their children's use of the Internet?
2. In what ways do parents describe their own actions in their ambition to lower the barriers and support opportunities?

Methods

Participants and Procedure

Altogether 22 guardians of young people with intellectual disabilities were interviewed (see Table 1 for participants' and their children's characteristics). 19 of the guardians were biological parents (7 fathers, 12 mothers), two were older sisters who served as supplementary parents and one was a stepmother that had known the young person since she was a toddler. In the following text they will all be called parents. The parents were contacted by letter and informed about the aim, research questions and participation and that participation was voluntary. Altogether 14 interviews were conducted, half of them were individual interviews and the other half were pair-interviews (in one interview as many as three persons took part). The interviews each lasted between 48 minutes and 1 hour and 28 minutes, with an average of 1 hour and 7 minutes. They were conducted by one of the authors, at the university, at the local clubhouse of an interest group for persons with intellectual disabilities, at a coffeehouse, or (as in most cases) at the parent's home. Altogether parents of 17 young people were interviewed. In some cases both parents took part and in others only one of the young person's parents were present.

Table 1. *Participants' and Their Children's Characteristics.*

	Parent	Family number	Parents marital status*	Daughter or son	Age of child	The child is an immigrant	Degree of disability
1	Father	1	Separately	Daughter	18	No	Milder ID
2	Father	2	Together	Son	20	No	Moderate ID
3	Mother	3	Together	Son	19	No	Moderate ID (incl. autism)
4	Mother	4	Together	Son	21	No	Moderate ID (incl. language disability)
5	Mother	5	Together	Daughter	20	No	Moderate ID (plus spina bifida)
6	Mother	6	Together	Son	17	Yes	Milder ID
7	Older sister						
8	Older sister						
9	Father	7	Together	Daughter	18	No	Milder ID
10	Stepmother						
11	Father	8	Together	Daughter	19	No	Milder ID.
12	Mother						
							Difficulties to move around by herself.
13	Mother	9	Separately	Daughter	19	No	Milder ID (plus ADHD)
14	Mother	10	Separately	Daughter	18	No	Milder ID
15	Father	11	Together	Son	16	No	Milder ID (plus ADHD)
16	Mother						
17	Mother	10	Separately	Son	19	No	Milder ID (plus reading and writing difficulties)
18	Mother	11	Separately	Son 1 (twin brother)	21	No	Milder ID (plus reading and writing difficulties and depression symptoms)
				Son 2 (twin brother)	21	No	Milder ID (plus reading and writing difficulties)
19	Mother	12	Separately	Son	20	Yes	Milder ID (plus aggression issues)
20	Father	13	Together	Daughter	20	No	Milder ID
21	Father	14	Together	Daughter	17	Yes	Moderate ID
22	Mother						
Total	Mothers, 13 (incl. one stepmother) Fathers, 7 Older sisters, 2		Together, 14 Separately, 6	Daughters, 8 Sons, 9	M = 19 Md = 19	Immigrant, 3 Nonimmigrant, 14	Milder ID, 11 Moderate ID, 6

* Parents either live together or have separated from the child's other parent.

All of the parents lived together with their sons and daughters. The children (8 daughters, 9 sons) of the interviewed parents were between 16 and 21 years of age ($M=19$, $Md=19$) and three of the children were immigrants and had moved to Sweden as young children. All of the sons and daughters went to upper secondary school, schools (two different) attended by pupils from all socioeconomic groups. In Sweden upper secondary school for individuals with intellectual disabilities is a four-year voluntary type of school that pupils can choose to attend once they have completed the nine-year compulsory school. It is divided into two programmes. On the one hand, the individual programme is primarily designed for pupils with a severe or moderate ID, and on the other hand, the national programme is mainly designed for pupils with a mild ID. There are in total nine national upper secondary school programmes for pupils with ID, spanning across programme-specific courses and assessed coursework. The daughters and sons of the parents that were interviewed were all enrolled on national programmes such as: the Health and Human Services Programme, the Hotel, Restaurant, and Bakery Programme, the Auto Mechanics Programme, and the Media Programme. The young people had

different intellectual disabilities including autism, Landau-Kleffners syndrome, Noonan syndrome, milder intellectual disabilities, moderate intellectual disabilities and undiagnosed, low general intellectual capacity. One of the pupils was also a wheelchair user due to spina bifida and several had reading- and writing difficulties as well as ADHD. We use the term intellectual disability following Schalock and colleagues (2010) who highlight the American Association of Intellectual and Developmental Disabilities' (AAIDD) definition of Intellectual disability: "Intellectual disability is characterized by significant limitations both in intellectual functioning and adaptive behavior as expressed in conceptual, social and practical adaptive skills. This disability originates before age 18" (p. 1). Furthermore, Schalock (2011, p. 228) points out that: "The term intellectual disability is increasingly being used internationally. This increased usage reflects the changed construct of disability, aligns better with current professional practices that focus on functional behaviours and contextual factors, [and] provides a logical basis for individualised supports provision."

The study followed the Swedish ethical guidelines regarding the requirements for information, consent, usage of data and confidentiality. The Ethics Board of Western Sweden approved the study (application number 048-15). To maintain confidentiality, no names, ages or other identifying information will be given when quoting parents in the presentation of the results.

Interviews and Analysis

The interviews were semi-structured following a pre-designed interview guide with the following themes and examples of questions: (1) the Internet as an arena for identity formation, love, and sexuality, for example *Do you perceive Internet to be an arena where your son/daughter can be himself/herself?* (2) attitudes and experiences of young people's self-presentations and Internet relations, for example *Is your son/daughter looking for a relationship? How hard is it for him/her to find a relationship? Could the Internet be an option?* (3) the Internet and its participative opportunities, for example *What are the similarities and differences between your son's/daughter's opportunities to participate in society when it comes to the Internet and offline activity?* (4) barriers and support for Internet use and participative opportunities, for example *What opportunities for participation does the Internet provide for your son/daughter?* and, (5) parents' attitudes and coping strategies for the way young people use the Internet, for example *Do you need to facilitate your son's/daughter's Internet use and if yes, are you given the opportunities to do so?* These themes, with related questions, were mainly influenced by the pilot study prior to this study, although some themes were more developed and elaborated upon in the study compared to in the pilot (Löfgren-Mårtenson et al., 2015; Molin et al., 2015). All interviews were recorded (in total 15 hours and 32 minutes) and transcribed. The transcribed interviews were entered into the program MAXQDA. MAXQDA is software which enables the researcher to organize the material into themes, subthemes and categories and to link relevant quotes to each other, as well as group the participants and their quotes into different clusters. A thematic analysis was used, which is a method of identifying, analysing, and reporting patterns within data sets (Braun & Clarke, 2006). The first step of the thematic analysis is to get to know the data through transcribing, reading and rereading the interviews. The interviews were discussed by several researchers within the project research group. Thereafter the coding of the interviews was conducted by one researcher, and statements were highlighted in order to systematically code interesting features in relation to the research questions. Thereafter the coding was discussed with a second researcher. The second researcher did not perform independent coding. The different codes were later organized into potential themes and subthemes in relation to the research questions of the study. Finally, the themes were named in order to reflect the content in each theme. The analysis of the data resulted in two themes: (1) Society in general and (2) in Social life. For each theme, subthemes concerning Participative Opportunities, Barriers, and Support were identified (Table 2). The aim of the study is not to quantify the qualitative material; therefore the frequency with which statement or category has been mentioned by the participants has not been reported.

Findings

Below, we will present parents' perception of their children's participation in Society in general, and the barriers and support connected with participation in Society in general (Theme 1), as well as, parents' perception of their children's participation in Social life, and the barriers and support connected with participation in Social life (Theme 2). For practical reasons the subtheme Participative opportunities will be presented separately for each theme, but Barriers and Support will be presented together for each theme.

Table 2. *Themes and Categories That Emerged in the Analysis.*

Themes	Subthemes	Categories
Society in general	Participative opportunities in society in general	-
	Barriers for participation in society in general	1. Cognitive ability 2. Technical ability
	Support for participation in society in general	1. Parents 2. Society
Social life	Participative opportunities in social life	-
	Barriers for participation in social life	1. Interest and curiosity 2. Social codes and netiquette
	Support for participation in social life	1. Parents 2. School

Society in General – Theme 1

Participative opportunities in society in general. The young people of the interviewed parents are between 16-21 years of age, so most of them have very little contact with community functions and services by themselves; however, the parents try to involve them. It takes time, and parents of children that don't have very many social interactions offline are doubtful about the 24/7 society. One mother (parent 3) says about her son:

They [young people with intellectual disabilities] become isolated if they only use the Internet. They need to have this social competence to make their way in the world these days too. And if they wind up sitting in their room and everything is done on the computer, I don't believe in it. Person-to-person, it is so important. Since he turned 18 we have been teaching our son how to pay his own bills and sit and do that himself... but he doesn't want to do it himself yet. He's been doing it for a year now, but he wants us to sit next to him because he feels to unsure of himself. So he doesn't make a mistake. But time passes. But then all the other ... no. They need this social bit and to be out among people more.

On the other hand, some parents (below parent 5) describe how their children wouldn't have made any contact at all, if the Internet were not an option.

R: Yes, exactly it [the Internet] is her life-saver in some ways, at times.

I: So an even more developed Internet would benefit her then?

R: I think so. For her sake it would be fantastic. She says so quite often: "Oh why can't we email about that?" or "Why can't we send a text message about that?" So that she wouldn't have to contact people, which she finds so difficult.

Barriers and support for participation in society in general. Described below is parents' view of barriers for participation in Society in general, as well as what kind of support they think will help their children to overcome obstacles, either from the parent themselves or from society. Barriers that emerge when it comes to participation in Society in general mainly consist of the individual's cognitive and technical abilities. Parents provide significant support, but a change in society appear to be significant as well.

Cognitive ability. The parents describe how participation on the Internet, when it comes to community functions and services, can be limited by cognitive abilities, like limitations in counting or reading and writing skills. One

mother (parent 10) of a daughter tells us that she tries to get her daughter to read what she has been writing before she sends a text or posts something on her webpage. Many times her written language is so poor that misunderstandings occur, but on the other hand, she can sometimes improve her writing by just reviewing it once or twice, so the mother tries to implement this strategy as part of her daughter's use of social media: "But the thing is, she often writes so extremely poorly and often you can't understand what she is writing. [...] I tried to get her to read it out loud, I mean aloud to herself to explain what she meant." Furthermore, parents express that especially complicated, official bureaucratic language can be a barrier to participation. Some parents also describe how their children, in comparison with young people without an ID, have a hard time handling multiple things in their life. If the young people were more involved in different community functions, it is likely that this activity would need to replace another interests in the young person's life. It takes up too much time, energy and cognitive space, as the mother (parent 19) of a son describes, when asked why her son can't handle community functions:

Well... time and energy. So, there, are many things, both practical and such, that he doesn't do because he is so busy with what he is doing. So I think that he isn't like others his age [...]. But of ten things that someone his age might manage to do, he can get three or four done, because then he is so exhausted and time has passed. [...]. So I think that it has to do with intellectual ability. It is not that he can't do anything, but he can only manage a certain amount and that amount has been reached. And if you add something else to that, you have to take away something.

Parents describe over and over how they sit next to their children and help them out by showing and explaining. Many times instructions are too complicated and need to be explained. Another mother (parent 18), whose son just moved to his own flat, describes how the son films himself when he is paying bills on the Internet, so that the mother can give him instant support. If instructions are verbal instead of written, they are easier to understand, and parents call for more verbal instructions from different community services.

Technical ability. Another complication is the technology. Most adolescents and young adults manage the basics of using the Internet and more, but according to their parents, they do need help in understanding the nature of new apps, webpages and other technology on the Internet. Parents fear that in the future when more and more aspects of society are moved to the Internet (e.g. 24/7 society), the difficulties these young people have with the technology will result in less participation in society in general. Situations and roles that they can cope with today in traditional ways will be hard to handle in a 24/7 digital society due to the technical skills that are required. One father of a daughter (parent 1) revealed that:

If the Internet is not developed in a way that it will be easier to handle, persons with intellectual disabilities will have a harder time taking part in society. [...] I think that other people pick up and use the technology much quicker, but she needs more time to pick up and be a part [...] I mean when society gets more and more Internet-oriented, it will be more disabling for them [people with intellectual disabilities].

Parents are their children's everyday support when it comes to practical issues concerning the technology. One mother (parent 13) says about herself that she is her daughter's every-day support: "We have had a lot of discussions about me being her facilitator. I am a mother also, but I am a facilitator in her every-day life," meaning that she considers herself to be an important support for her daughter's everyday life. The same mother (parent 13) highlights the need for simpler technology that is possible for everyone to handle and the limited knowledge that society seems to have concerning this issue:

If we had more user-friendly systems, more consideration for the fact that there are people who are mentally challenged, it would have been much better. You learn, again pardon my language, so damn much, from living with a person who is not like everyone else. So it would've been good if life in general were not geared toward all of us who know and understand.

Mainly parents help their sons and daughters with technical support when it comes to participation in society in general, like community services, but some also help with participation in social life. Some young people, for example, need help to upload photos on Facebook.

Social Life – Theme 2

Participative opportunities in social life. The majority of the parents described their children as users of some kind of social media, although there were also many parents who thought that their children use the Internet mainly for listening to music, watching movies and YouTube clips. Parents also described the use of several social media, which mostly were used by their children to maintain contact with friends and family. It was not uncommon for young people to have not only peers and relatives as friends, but also their parents' friends or friends' parents as friends on social media, which the mother of a daughter (parent 14) describes as positive:

M: Many of her peers, but she also has some cousins in town that she keeps in touch with and, yes, even the parents [of her friends], you could say, but then they are people we know. I think, maybe it's a little strange, but well I notice that kids, they have a more natural relationship with other adults than maybe I had when I was the same age.

I: Yes, exactly.

M: Back then there was so much more distance between adults and children, like no one had contact with their friend's mum.

I: No, I agree with you about that.

M: I feel it's sort of good, because then they [the young people] have more adults that can help them if there is need.

Most parents described how their youngsters mainly surf around to look at what others have posted to have an idea of what is going on among their friends, but they rarely post anything themselves. Others are more proactive and post their own messages and also took contact with other people they either know in one way or another, or that for them were unknown. For a couple of the young men, it has mainly been about contact with other car enthusiasts, so even if they did not know the person they were interacting with, they contacted them because of a shared interest. A couple of the girls' parents described how their children seek out people they know at a distance or used to know many years ago and establish a new contact. Sometimes the young women took the initiative to ask their new contact if they could meet offline. A mother (parent 5) describes the Internet as a prerequisite for her daughter to dare to ask questions:

Yes... she can express herself so much better on the Internet, she dares to say things that she might not have said face-to-face [...] for example to ask "I'd really like to go out to a café with you." She would never have the nerve to ask someone that face-to-face and above all not call the person up. But then [on the Internet] she can ask those questions.

The parents in this study believe that the Internet offers many opportunities for young people to maintain friendships and make new friends. Especially those parents with children who have limited contact with classmates outside school, and therefore were perceived as relatively lonely when not in school, would have preferred that their youngsters used the Internet more frequently to maintain contact with friends. Many times the family, and possibly a personal assistant, are the only friends they have when they are not at school. There is an ambivalence among parents: on the one hand, they mainly wish their children would acquire more friends to hang out with offline, but on the other hand, they recognize the Internet offers an opportunity to make friends. The parents' ambivalence is expressed by the mother of a son: (parent 3)

Our son does not use Facebook. When he's on the Internet he's on YouTube and that sort of thing. I haven't wanted to help him get started on Facebook because he has difficulties, he often needs to see the person to understand what they mean. Facial expressions. On the other hand, I can see that it might be good for him to have Facebook since he doesn't have any friends outside school. That's where he has his friends and at home he doesn't have any besides his personal assistant that he sees about three hours a week. Otherwise we're his closest friends, so to say. That's why I wish that he had it [Facebook], to broaden his horizons and make some friends on the Internet. He could set up a meeting with someone and that sort of thing. So, it's not all bad, Facebook. For those who are at home a lot and might have trouble getting out on their own to find friends.

Parents who have youngsters who have a rich social life offline, or even both offline and online, are not as keen for their children to spend time on the Internet to meet friends, whether they are new or old acquaintances. These parents care almost exclusively about the interactions offline, and argue that this enriches their children's lives more than the online interactions do. One mother and father (parents 9 & 10) describe their daughter's active Internet life:

I: Do you think she is active enough on the Internet or would you like her to be more active?

M: Oh God, if she were more active she would have to stop sleeping at night.

I: Okay, would you like her to be less active on the Internet?

M: Yes.

F: Mm.

M: Yes, I would have liked to see her a little more social IRL.

I: Why is that?

M: She loses a lot of that [social skills] and talking to people is a way to practice being social.

Especially for a person for whom it doesn't come naturally.

I: And then you're thinking that it would be a good thing if she practiced that more?

M: Socializing more with people, I think, would be preferable to sitting on the phone, or on the iPad, or computer, or..

A third variant of parents are the ones whose children mainly have online relationships, in addition to his/her contacts with peers during school hours, and here parents describe a more mixed picture, where they wish that the young people had more friends offline, but at the same time say that the Internet enables their children to gain entrance/an opportunity for greater participation. A mother of a son (parent 19) describes the significance: "Yes, because otherwise, if he did not have the Internet, he would surely be isolated when he came home in the evening. He never goes out to do anything." A mother and a father who have a daughter (parent 11 & 12) with both physical and intellectual disabilities say:

We've had, or yes, X has had a very hard time with so many cramps and such, so this leads to isolation at times. Yes, because it's like, you can't just go out, and that's why the Internet is a kind of door that can always be opened when you feel like it. So I guess I feel that there is something really good [with the Internet].

We can conclude that young people's participation or non-participation in social life on the Internet varies considerably. There are those that have no social interaction online, but parents that wish they did; there are those who have a broad selection of different social media through which they either view others interacting or interact with others, usually both peers, friends and parents' friends.

Barriers and support for participation in social life. Described below is parents' view of barriers for participation in Social life, as well as what kind of support they think will help their children to overcome obstacles, either from the parents themselves, the school, or society. Barriers that emerge when it comes to participation in Social life, mainly consist of the individual's interest and curiosity concerning the Internet and their knowledge of social codes and netiquette. Parents are significant supporters, but also support from school appears to be significant.

Interest and curiosity. Although many of the young people, according to their parents, use the Internet to play games or surf, the parents think that it can be difficult to get their youngsters to see the Internet's potential for social life. Some parents think that when interest occurs, they will also manage both social life on the Internet and community services. One parent, for example, thinks that his daughter will be more motivated when she moves out of their house and lives on her own.

Parents think that they as parents can promote a great interest for the Internet to some degree, but there are limits. They encourage their children to use different aspects of the Internet – both directly with suggestions about different activities and indirectly by discussing different things with their children that they may later look up on the Internet. On the other hand, the school, they believe, should have more assignments and also different kinds of teaching methods that awaken curiosity.

Social codes and netiquette. Parents describe how their children now and then get into situations where they don't understand what someone else on the Internet is saying or doing. It can be a matter of not understanding the words or not being able to read between the lines. At those times they sometimes consult the parent and ask for their advice. However, some young people sometimes need the support from their parents, but are not willing to share their "parent-free Internet zone" with the parent. One mother (parent 19) describes how her son holds a hand in front of the screen to limit her view of what is written:

Yesterday, for example, he showed me, covering [the screen] so I couldn't see what was above, and then it was the next text, sort of like Messenger. Then he covered so I couldn't see but there were some ... written in Swedish. ..."What does *selen* mean," he said to me. "Yes, *selén* is a substance" [the mother replies]. "Yes, but *sélen*?" ..."I have to see the sentence," I said. It was someone who had written "Now hang onto the harness [harness = selen in Swedish]". Well, I think it's symbolic, I said: "I think it means that you shouldn't give up, you should keep fighting and you'll manage this and so on". And it also said "the reins," so it was almost adult language, I don't know who wrote it. But it was meant well.

The parent above, as well as some of the others, know how to read their children and if something seems to be wrong they ask them about it, but they do not constantly go around asking what they are doing on the Internet and most of the parents don't feel worried. Parents' lack of interest about *what* and *whom* their children are in contact with on the Internet is not about whether or not they are paying attention to their children; it is more about not being worried about their whereabouts on the Internet. The reason is partly because they do not think the young people are interested in content that could be considered suspicious. Furthermore, their children frequently tell them about the content of what they read on the Internet, just as they share information about other things that happen or with which they have come into contact. The parents use these information-sharing situations to have discussions about what is on the Internet. One mother and father describe their daughter as being in general bad at reading social codes and expressing herself properly. The mother (parent 10) describes how she is happy that these incidents happen on the Internet instead of offline: "That if it had been in real life, so to speak, offline, then it is physical. Yes, then she could get in effing deep trouble. And on the Net it's still only talk." One mother and sister (parent 6) also describe how her son/brother might need to know some simple phrases to participate in social life online, how to take contact and start a conversation:

M: Yes, written like this: "what are you doing, how are you..."

I: He needs to learn those skills so to say, know how to do this?

S: Yes, things like that, like how you do things, yes, he can't do that. To make contact. "Hi there friend, Do you want to go out? How are you?" that sort of thing.

In general, parents guide and support their children regarding social codes and the conventions of the digital world through discussions, but also by being present in the social media (e.g. Facebook, Instagram, as friends) and if they see something that looks suspicious they talk to their children. Sometimes it's about reading the young people from a well-being perspective, and asking questions if something seems to be troubling them. But it also seems that young people sometimes have a hard time taking advice due to the cost to their autonomy.

Discussion

The purpose of the present study was to examine how parents perceive and support the Internet as an arena that contributes to increased participation in social life and society in general for young people with intellectual disabilities. Two research questions were examined: How do the parents of intellectually disabled young people perceive opportunities and barriers to their children's use of the Internet? And in what ways do parents describe their own actions in terms of their ambition to lower the barriers and support opportunities? In summary, the results show that many parents perceive that the Internet is an arena that can help their children to be more involved in social life. It is mainly the parents of young people who have few social interactions outside school and who are experiencing difficulties in making social contacts who say this. These young people are also the young people who are generally cautious and take fewer risks, according to their parents, so the parents do not feel the need to be concerned about their children's Internet use. Other parents believe that their children have a rich social life outside as well as on the Internet. The parents describe why the young people make contacts

with people on the Internet, which do not always proceed smoothly. These parents are more concerned that the young people are taking risks on the Internet or that they will be deceived or get into trouble. Almost all the parents in the study describe their children's shortcomings concerning reading and writing skills, which are an obstacle to active, but above all safe, participation in a social life on the Internet. Many parents believe that the young people do not have enough knowledge of netiquette, and that they find it difficult to read and interpret the subtle codes, which in turn contributes to them sometimes ending up in situations where they are either considered to be behaving badly towards others or, more frequently, not perceive when others are mean to them.

Lack of netiquette, and/or writing- and reading difficulties are less of a barrier when it comes to participation in society in general. Rather, it is the young person's lack of reading comprehension skills, and hence the inability to read instructions, which constitutes a barrier. Another way of approaching this issue is to stress that our digitalized society does not yet accommodate the variety of needs and skills that ID people require to handle the Internet. According to parents, these young people have difficulty generalizing from one situation to another, which contributes to a need for support every time they enter, for example, an official website. Parents also mention that there is a lack of interest among youth to become involved in community functions, both on and off the Internet. Many parents believe that young people do not have the ability to take on more challenges.

Parents' perception of barriers to participation are in line with Normand (2016) and Lussier-Desrochers, Caouette and Godin-Tremblay (2016) findings on barriers. The basic barriers are a lack of access to digital devices and the physical ability to handle technical devices; the more advanced barriers are limited personal skills. The basic barriers need to be eliminated so that the individual can gain any access at all to the Internet, and the more advanced barriers need to be taken care of so that their Internet use will not be limited or risky for the individual. In our study the basic barriers, access to digital devices and sensory motor ability, are not a problem for the young people of the interviewed parents. However, the advanced barriers are: cognitive ability, technical ability and the ability to understand social codes and netiquette. All three barriers are not present for each individual. In line with other researchers we argue that the extent to which barriers remain obstacles depends upon the young people's surroundings. Others' actions and values in the surrounding community can be viewed as enabling or further complicating an individual's use of the Internet. If someone (or something) in the surrounding community takes action to lower, or even eliminate, the barrier for the individual, he or she can increase the use and the safety of the challenged person's participation on the Internet.

Parents undertake several actions in their ambition to support their children, helping them to overcome and manage barriers. Support from the parents is very much on an every-day basis. They are there to provide both practical Internet support and meet their children's emotional needs. Parents describe their support to be very much about improving the young person's understanding of social codes and netiquette, as well as understanding instructions and, for some young people, also the technology. Among other strategies, several of the parents are "friends" with their children on different social media, as a means of discussing issues with their child if they write or perceive any comments on the social media that can be emotionally distressing. In a recent published review, Caton and Chapman (2016), recognize this as a strategy for many parents in several studies. Parents in the current study believe that through learning simple strategies, such as some phrases or behaviors, the young person's social interactions could improve significantly. Parents also highlight the role of the school and society in general. The school helps the child learn how to read and write, skills that increase their opportunities to participate and be safe on the Internet. Society, on the other hand, needs to simplify the way one navigates different webpages and Internet-based services by, for example, adding more possibilities to hear a voice read the text on the webpage. In the results, the parent's ambition to act as support for the young person is clear. However, it is noteworthy that the characteristics of the barriers differ depending on whether they concern participation in society in general or participation in social life.

The young person's use of the Internet can be viewed as an expression of agency. Parents describe their children as having an ambition to use the Internet in a specific way, partly to engage more in social life (and in some situations also in society in general, although this is less frequent) and partly for other things, such as pleasure and entertainment. However, the individual differences in the expression of agency can be considered as reflecting differences in resources. Kuczynski and de Mol (2015) describe three resources. *The individual resources* include the individual's skills and ambition to increase agentic capabilities. This can refer to, for

example, the young person's reading- and writing skills, but it can also be the level of curiosity and interest. *The relational resources* are an individual's access to personal relationships as a support for their exercise of agency. Examples of this are described several times in the interviews with the parents. *The cultural resources* include human rights, but also the common practice in terms of a society. In this study, the parents both describe the existence of resources in society (school), but also a lack thereof. For example, parents fear that the young person will be less capable of handling the 24/7 community services compared with traditional community services, and that this will result either in less participation in society in general or in greater dependence on their parents. Parents highlight the need for increased resources in society. The young person's effectiveness as an agent is greatly enhanced by relational resources as well as an increase in cultural resources. With appropriate relational and cultural resources the young person's individual resources will have greater effectiveness. Nussbaum (2009; 2013) argues that it is the *combined capability* of the individual's internal capabilities and the social, political and economic circumstances that constitute an individual's life conditions. By focusing on what people are actually able to *do* and *be*, we come closer to the discovery and explanation of the social barriers that prevent certain groups from achieving equality in society. For example, in the present study parents describe their children as being able to manage a website if they as parents read the instructions carefully for them; however, if the webpage offers spoken as well as written instructions, they would have been able to manage the webpage on their own. These interactions between the parent, their child and multiple media (Bunning et al., 2008) create prerequisites for communication and empowerment. Borland and Ramcharan (2000) define the shifting processes between an "excluded identity" and an "included identity," where they are said to be products of inter-related themes of "inclusion in society" and the development of "self-concept." From the perspective of human rights, a society should take into consideration people's different capabilities when constructing, for example, online community services (c.f. Watling, 2011). If this is not taken into consideration, there is a risk for an increased "digital divide," like the ones that parents in the present study reported.

Limitations of the Study

While the study has several strengths, it also has some limitations. One limitation is that about twice as many mothers chose to take part in the study as did fathers. In some studies, and in some areas, fathers, in contrast to mothers, report more liberal attitudes towards children's Internet use. Yet in other studies they report less liberal attitudes (Sorbring, 2012; Sorbring, Hallberg, Bohlin, & Skoog, 2014). It is therefore difficult to say in what way, if any, the results of the present study have been influenced by the skewed distribution between mothers and fathers. Another limitation is that the parents all had children in the same upper-secondary special needs school. It is therefore possible that parents' perception of the Internet as an arena for greater participation in social life and society in general, has been colored by similar off-line experiences connected to their children's school. A great concern is that the parents were all parents of young people with mild or moderate intellectual disability. All of the young people of the interviewed parents were taking the national program, which is mainly designed for pupils with a mild intellectual disability, and none of the parents had youngsters that were taking the individual program, which is primarily designed for pupils with a severe or moderate ID. Based on the results of the present study, we suggest that parents' perception of the Internet as a possible arena for greater participation in social life is connected to having a child with difficulty finding social interactions offline in combination with being a young person who does not take very many risks. In the current sample, young people (of the interviewed parents) that seemed to have difficulties with offline relations also had moderate or less mild ID and seemed to exhibit less risky Internet behavior. Therefore, one can presume that a sample with greater variation in the level of intellectual disabilities would have given a clearer result or at least greater variation in the result.

Conclusion and Future Studies

The parents of young people with intellectual disabilities recognize the Internet as an arena for greater participation in social life and in society in general. However, participation in social life can be risky in relation to the person's limited abilities, but for some young people it might be the only or close to the only social arena, except those social interactions they have with family and relatives. Parent's support is one way to lower the barriers for young people's safe participation on the Internet. Parents promote support in the form of cognitive social strategies that could help the young person to handle every-day situations on the Internet more adeptly in

combination with a supportive parent or other family members (Palmer et al., 2012). To increase young people's participation in society in general, parents think that education in combination with developed technical tools and interface is essential. But participation in society in general is many times also dependent on support from the parent, according to the parents.

From this study we have learned that parents are important facilitators in the young person's every-day Internet use, both when it comes to practical matters and emotional ones. The relationship with an Internet-savvy parent enables the young person to get not only practical technical support but also emotional support concerning emotions related to Internet use. However, Sweden is a country with high Internet use and most people who are the same age as the parents in the study (about 55 years of age) are very present on the Internet themselves and very knowledgeable about Internet use, both concerning practical technical issues and concerning the use of social media. In a review (Seale, 2014) it is shown that the ability to support young people with intellectual disabilities in their Internet use, is linked to levels of technology skills and familiarity with technologies of the supporter (e.g. parent). Therefore, future studies should be conducted outside Sweden, in countries where parents might not have in-depth knowledge of the Internet.

Although the Internet can be a "free-zone" where the young person can develop social bonds and construct their identity away from adult oversight, parents are highly present. In a review, Caton and Chapman (2016) highlight that the perception of risk and barriers might differ between the young person and for example a parent. Young people mostly feel confident and in no need of support. Therefore, future research should examine how parents' every-day support concerning the Internet is perceived, both by the parent and the young person, from the standpoint of autonomy.

This article has discussed barriers and support in relation to the individual and her or his support system, which brings into focus the parent's responsibility and support for young people. The result suggests that support for parents as facilitators of their children's every-day life on the Internet should be developed and evaluated. Seale (2014) suggests that parents (as well as professionals) more often should ask themselves the question "what if something goes right?" instead of "what if something goes wrong?" when supporting young people with intellectual disabilities. This so-called positive risk-taking involves developing strategies so that the risks of an activity or option are balanced against the benefits. This might require an element of creativity in terms of how risks, problems, possibilities and opportunities are conceptualized or reframed (Seale, 2014, p. 228). Through discussions with the young person from a positive risk-taking perspective, the parent can provide support, helping him or her to take action to manage and surmount barriers – instead of avoiding or ignoring them.

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Correspondence to:

Emma Sorbring
Centre for Child and Youth Studies
University West
SE-461 86 Trollhättan
Sweden

Email: emma.sorbring@hv.se

About authors

Emma Sorbring, Professor of Child and youth studies and Research director for the Centre for Child and Youth Studies at University West, Sweden. Her research and teaching interests lie in the area of children, adolescents and families. Her projects focus on: Teenagers' Internet use and parental strategies, Sexual development in traditional and new settings (the Internet), Dating violence, Parental behaviour and children's adjustment, and Young people's decision-making.

Martin Molin, Associate professor of social work at the Centre for Child and Youth Studies at University West, Sweden. His research and teaching interests relates to the area of: Participation and exclusion in upper secondary special programme for pupils with intellectual disabilities, Identification processes and adulthood, as well as, Transition between school and work-life for young people with intellectual disabilities.

Lotta Löfgren-Mårtenson, Professor in Sexology and Research director for the Centre for Sexology and Sexuality Studies at Malmö University, Sweden. Her research and teaching interests lie in the area of: Sexual health, Sex education for young people with intellectual disabilities, Sexual risk taking among young people in compulsory care, Sexologists as professionals, Love and sexuality on the Internet.

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