Internet use and digital participation in everyday life

Adolescents and young adults with intellectual disabilities

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LI.U LINKÖPING UNIVERSITY

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Title:
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There is something empowering about being asked. It sends a message that your life matters.

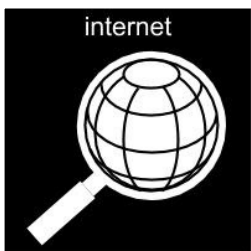Melinda Gates, *'The Moment of Lift: How empowering women changes the world',* 2017.

CONTENTS

ABSTRACT

Background: Internet use is an integral part of everyday life in contemporary society, especially among young people. It is used to perform activities in everyday life by an increasing proportion of the population. However, knowledge about access to and use of the internet by adolescents and young adults with intellectual disabilities (ID) is scarce. More knowledge is needed about digital competencies and digital participation in their everyday lives.

Aim: The overall aim of this thesis was to explore and describe internet access and use, and digital participation in everyday life among adolescents and young adults with intellectual disabilities.

Designs and Methods: The thesis is based on results from three studies. In study I, the focus was on access to and use of the internet in the everyday settings of school/work, at home or during t free time. Data was collected through observations, conversations, and follow-up interviews with 15 participants with ID, aged 13–24 years. The data was analysed using qualitative content analysis. In studies II and III, the design was cross-sectional and comparative, using national surveys on media and internet use from the Swedish Media Council, from which comparative data from reference groups could be gained. In study II, the national survey of adolescents on internet access and use was cognitively adapted for adolescents with ID in several steps. This made it accessible to a total selection of pupils with ID, aged 13–20 years, from all the special schools in four diverse municipalities in two different regions of Sweden. In study III, the national survey of parents about opportunities and risks of internet use by their adolescents was used. The surveys were sent to a sample of n=318 adolescents with ID and their caregivers/parents. The responses were higher for the adolescents (n=114) than for the parents (n=99), and the response rate of the adolescents with ID was equivalent as that of the reference group, at 36% and 38% respectively. In study II, chi-square tests were used and, when necessary, Fisher's exact test to analyse the data. In study III, analyses were carried out using Fisher's exact test and logistic regression to control for confounding factors.

Results: This thesis show that access to internet-enabled devices is lower for adolescents with ID than for the general population, except for tablets

(study II). All internet activities, except playing games, are performed by fewer adolescents with ID compared to the reference group (study II) and the time spent on the internet activities is less (study III). Both environmental challenges and personal abilities present difficulties in internet access and use (study I) and affect digital participation for adolescents and young adults with ID. Furthermore, a significantly higher proportion of parents of adolescents with ID perceive opportunities associated with internet use and playing games, and a lower proportion perceive risks with negative consequences, or have concerns about online risks, compared with the reference group (study III). Significantly more parents of adolescents with ID state that their adolescent never uses smartphones or social media compared with the reference group. Strategies used to handle the digital environment and take part in internet activities were found and described, such as getting support from others, reducing the number of internet-enabled devices used and personalising them. Gaining access to internet content and performing internet activities was facilitated by picture-, word- and voice-based strategies, which were used by adolescents and young adults with both mild and moderate ID (study I).

Conclusions: The conclusions are that the results show a lag in internet access and use and in digital participation by adolescents and young adults with ID. Adolescents and young adults with ID were accessing and using the internet in similar ways to the reference group, but to a lesser extent. The impact of the participants' environment, together with their lack of certain abilities, make the development of digital competencies difficult for them. The result that parents of adolescents with ID perceive more opportunities and fewer risks associated with the internet provides new knowledge to support positive risk-taking in internet use and enable digital participation by adolescents and young adults with ID. Support can be developed in collaboration between the adolescent/young adult, their parents and teachers, and staff in community-based services and should involve physical, social and digital environmental adaptations. These can enable the development of digital competencies and minimise the lag in digital participation in everyday life, which is needed for participation in today's digitalised society.

SVENSK SAMMANFATTNING

Bakgrund till avhandlingen: Internetanvändning är en integrerad del av vardagen i dagens samhälle, särskilt bland ungdomar. Internet används för att utföra en mängd aktiviteter i vardagen av alltfler personer. Dock är kunskapen om tillgång till, samt användning av internet i vardagliga aktiviteter för ungdomar med intellektuell funktionsnedsättning (IF) bristfällig. Ökad kunskap behövs om digitala kompetenser och digital delaktighet i vardagen för ungdomar och unga vuxna med IF.

Syftet med avhandlingen: Det övergripande syftet med denna avhandling var att utforska och beskriva tillgång till och användning av internet och digital delaktighet i vardagen bland ungdomar och unga vuxna med IF.

Hur studierna genomfördes: Avhandlingen bygger på resultat från tre delstudier. I studie I samlades data in via observationer av och uppföljande intervjuer med 15 deltagare med IF, i åldern 13–24 år. Fokus låg på tillgång till och användning av internet i deras vardagliga miljöer: skola/arbete, hemma eller på fritiden. Data analyserades med kvalitativ innehållsanalys. I studie II och III var designen jämförande tvärsnittsstudier. Nationella enkäter från Statens Medieråd om medie- och internetanvändning användes där jämförande data från referensgrupper kunde erhållas. I studie II gjordes kognitiva anpassningar av den nationella enkäten om medie- och internetanvändning i flera steg för målgruppen ungdomar med IF i åldern 13–20 år. Anpassningen till en lättläst version av enkäten, med bildstöd för de som behövde det, gjorde den möjlig att skicka till ett totalurval av elever från alla särskolor i fyra olika kommuner i två olika regioner i Sverige. I studie III användes den nationella enkäten till föräldrar om möjligheter och risker med internet- och medieanvändning för deras ungdomar. Enkäterna skickades till ett urval av n = 318 ungdomar med IF och deras vårdgivare/förälder. Antalet svar var fler från ungdomarna (n = 114) jämfört med föräldrarna (n = 99), och svarsfrekvensen för ungdomar med IF var i paritet med referensgruppens, med 36% för ungdomar med IF, jämfört med 38% i referensgruppen. I studie II användes chi-två tester och vid behov Fisher's exakta test, för analys av data. I studie III genomfördes analyser med Fisher's exakta test och logistisk regression för att kontrollera för confounding faktorer dvs övriga faktorer som kan påverka.

Resultaten som framkom i studierna: Resultaten av studierna visar att tillgången till enheter för internetanvändning är lägre för ungdomar med IF än för ungdomar generellt, med undantag för surfplattor (studie II). Alla internet-aktiviteter, utom att spela spel, utförs av en lägre andel ungdomar med IF jämfört med referensgruppen (studie II) och tiden som spenderas på internet-aktiviteterna är lägre för ungdomar med IF (studie III). Utmaningar i den omgivande miljön, såväl som personliga förmågor leder till svårigheter med internetuppkoppling och internetanvändning (studie I), och påverkar digital delaktighet för ungdomarna och de unga vuxna med IF. Möjligheter och risker med att använda internet visade att en signifikant högre andel föräldrar till ungdomar med IF uppfattar möjligheter förknippade med internetanvändning och att spela spel, och en lägre andel upplever risker med negativa konsekvenser, eller oroar sig för risker med internet jämfört med referensgruppen (studie III). Signifikant fler föräldrar till ungdomar med IF uppfattar dock att deras ungdomar aldrig använder smartphones och sociala medier jämfört med referensgruppen. Strategier, som ungdomar och unga vuxna med både lindrig och måttlig IF använder för att hantera den digitala miljön och delta i internet aktiviteter identifierades (studie I). Strategierna innebär; att få stöd från andra; att minska andelen enheter som används för internetanvändning och att främsta använda enheter som är utformade för/av person; samt att använda stödstrategier som är baserade på ord- bild- och röststöd för att kunna utföra internet-aktiviteter.

Kunskapen som avhandlingen har bidragit med: Sammantaget visar resultaten en eftersläpning i tillgång till och användning av internet, liksom i digital delaktighet för ungdomar och unga vuxna med IF. Även om deltagarna har tillgång till och använder internet, är det i lägre utsträckning än referensgruppen. Faktorer i miljön tillsammans med deltagarnas personliga förmågor gör utvecklingen av digital kompetens svår för deltagarna. Resultatet att fler föräldrar till ungdomar med IF uppfattar möjligheter och färre uppfattar risker med internet är ny kunskap som kan stödja positivt risktagande i internetanvändning och möjliggöra digital delaktighet för ungdomar med IF. Stöd kan utvecklas i samarbete mellan ungdomar, deras föräldrar och personal, i både skola och kommunal omsorgsverksamhet, och involvera anpassningar av såväl fysisk, som social och digital miljö för utveckling av digitala kompetenser. Genom detta kan eftersläpningen i digital delaktighet i vardagen minimeras, vilket krävs för delaktighet i dagens digitaliserade samhälle.

LIST OF PAPERS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals.

I.   Alfredsson Ågren K, Kjellberg A, Hemmingsson H. **Access to and use of the Internet among adolescents and young adults with intellectual disabilities in everyday settings.** *Journal of Intellectual and Developmental Disabilities* 2020, 45 (1): 89—98.

II. Alfredsson Ågren K, Kjellberg A, Hemmingsson H. **Digital participation? Internet use among adolescents with and without intellectual disabilities: A comparative study.** *New Media & Society*, e-published ahead of print November 2019. https://journals.sagepub.com/doi/10.1177/1461444819888398

III. Alfredsson Ågren K, Kjellberg A, Hemmingsson H. **Internet opportunities and risks for adolescents with intellectual disabilities: A comparative study of parents' perceptions.** *Scandinavian Journal of Occupational Therapy*, e-published ahead of print June 2020.

     https://www.tandfonline.com/doi/full/10.1080/11038128.2020.1770330

ABBREVIATIONS

CRPD	Convention on the Rights for People with Disabilities
DSM	Diagnostic and Statistical Manual of Mental Disorders
EU	European Union
ICF	International Classification of Functioning; Disability and Health
ID	Intellectual Disabilities
UN	United Nations
WHO	World Health Organization

PREFACE

During the early 1990s, I worked as a caregiver for adults with severe intellectual disabilities (ID) in a large nursing home in Sweden. In 1993, about 2500 people with ID in Sweden were still living in institutional care (Grunewald, 2008; SOU, 2008:77). Over the course of a few years, the last residents of the nursing home moved into new, community-based group homes in accordance with the Act concerning Support and Service for Persons with Certain Functional Impairments (SFS, 1993:387). It is an entitlement act that came into effect in 1994 and is still valid today. I was not aware of it at the time, but I was involved in a historical occurrence, namely the right to participation in society for people with ID on equal terms with others, in accordance with the Act. My working experiences with the implementation of the Act when the residents were moving into the group homes, together with my later experiences, as an occupational therapist working with persons with ID, has given me a paradigm, or worldview, that every individual has the right to engagement and participation in occupations in their daily life. In addition, I have a recognition of the individual as being in constant interaction with the surrounding environment. This makes the complexity of society and its impact upon occupations an epistemological notion for me. This complexity may be greater for people who experience restrictions on their participation and find themselves marginalised in society, for example due to ID. Hence, we need to make substantial efforts to understand, investigate and describe this.

The meaning of participation changes with time, context, and the development of society (Kjellberg, 2002). Those early years of working as a caregiver guided this thesis, together with my knowledge as an occupational therapist, focusing on everyone's right to be active and participate in society. This is especially true of the efforts made to adapt the data collection methods to enable adolescents and young adults with ID to themselves describe their digital participation in everyday life. However, the participation described in this thesis, refers to the wider context of the digitalisation of society, and how, and if, digital participation is prevalent among adolescents and young adults with ID.

/Krissa

INTRODUCTION

The internet is used worldwide, and has become an increasingly important resource for performing activities in daily life, democracy, community-living and participation (Carretero Gomez, Vuorikari, & Punie, 2017; Findahl & Davidsson, 2015). This is especially true in northern Europe, specifically Sweden, which makes up the global environmental study context of this thesis. Sweden ranks high on internet accessibility and users (Statista, 2020). However, access to and use of the internet can be more difficult for some than for others, for example people who have an intellectual and/or cognitive deficit. Adolescents and young adults with intellectual disabilities (ID) may experience deficits in both intellectual and adaptive functioning (American Psychiatric Association, 2013) and it is not unusual for people with ID to find themselves excluded from ordinary leisure activities, higher education and the labour market (Arvidsson, 2013; Arvidsson, 2016). This marginalisation of people with ID can be understood by applying different perspectives (Ineland, Molin, & Sauer, 2019). In this thesis, the environmental demands and facilitators on the individual are considered, but also personal abilities and the dynamic interaction between the individual and their environment in line with an occupational perspective (Taylor & Kielhofner, 2017; Wilcock & Hocking, 2015). From an occupational perspective, not being able to perform activities, e.g. internet activities, in one's everyday settings is identified as a risk to health, personal development and participation, both in everyday life and in society (Wilcock & Hocking, 2015).

Previous research has revealed a digital divide for people with ID, with less access to the internet than other people (Chadwick, Wesson, & Fullwood, 2013), but the digital technology is changing at high speed and it has been shown that adapted computers and social media interfaces can offer opportunities for people with ID (Davies et al., 2015; Hoppestad, 2013). Despite this vast development, there is a lack of studies on internet use among adolescents and young adults with ID in their everyday lives, especially involving valid statistics where the young people with ID themselves provide the data. General population-based surveys on internet use among adolescents have not been adapted to enable participation by adolescents with ID (Swedish Media Council, 2015). Therefore, the knowledge gap about actual access to and use of the internet, as well as digital participation in everyday life, among adolescents and young adults with ID is large. The studies in this thesis were designed and implemented to help fill this gap.

Epilogue to the Introduction: The finalisation of the writing of this thesis was achieved in spring 2020 during the coronavirus pandemic (https://www.who.int/). Within only a few months, the internet has become the foundation upon which we rely for carrying out any activities in our lives. In light of this, the question of digital participation for all is more important than ever. The knowledge this thesis generates on access to and use of the internet, participation in internet activities, and the opportunities and risks of the internet for young people with ID can serve as one of the important contributions needed to rapidly enable digital participation for all.

BACKGROUND

The digitalised society and digital participation

The digitalisation of society refers to the ever-increasing use of digital technologies, primarily the internet, in all everyday activities and settings where people live their lives. Worldwide, 59% of the population are internet users, while 75% of adolescents and young adults (15—24 years) are using the internet, although there are large differences across the world (Statista, 2020; UNICEF, 2017). In Northern Europe and Sweden, where this thesis is being conducted, 95% of the population are internet users (Internetstiftelsen, 2019; Statista, 2020), rising to 99% among adolescents (Swedish Media Council, 2019). The number of internet users in Sweden has been increasing every year during the last 25 years, with 2% using it in 1995, rising to 90% using it in 2014 when this thesis project started, (Internetstiftelsen, 2014). Nonetheless, when combining non-users of the internet today with rare users, it was shown in the most recent annual report on how Swedes use the internet, that 1.1 million Swedes, approximately 10%, of the population rarely or never use the internet, and they are found even among 12—25-year olds, (n=26 000) (Internetstiftelsen, 2019). Having a lower education level and lower income are apparent traits for these none users or rare users, and in 2018 it was revealed, that rare users feel that they are not participating in digital society, just like non-users (Internetstiftelsen, 2018).

In the Swedish governmental strategy for sustainable digitalisation digital participation can be understood as the ability and possibility to participate in the digitalised society for all (Swedish government, 2017/18:47). To achieve this, the ability to develop and use one's digital competencies is highlighted as being of utmost importance. Digital competencies are described as having a set of digital skills, including technical skills, the ability to find and evaluate information, and having knowledge of digital development (Government, 2017). Digital competencies are also acknowledged by the European Union (EU), as comprising: information and data literacy, communicating and collaborating with others using the internet, creating digital content, internet safety and problem solving (Carretero Gomez et al., 2017). Digital competencies are identified as necessary in order to gain access to the labour market, higher education and to take part in the services of society (Carretero Gomez et al., 2017; Swedish government,

2017/18:47). Children and adolescents often develop digital competencies when they go online, using the internet for individual, educational and societal purposes (Livingstone, Kardefelt Winther, & Saeed, 2019). However, it has been stressed that using the internet incorporates both opportunities and risks, which have been researched among children and adolescents in general (Livingstone, Cagiltay, & Ólafsson, 2015; Swedish Media Council, 2017b; UNICEF, 2017).

Today, participating in contemporary society and everyday life inevitably involves using the internet, meaning that digital participation is of utmost importance for individuals as well as companies, the public service sector, the health care system and governments. Yet, the most recent report showed that digital services are used to different extents in the general population, with 50% not using e-health services, i.e. digital healthcare services (Internetstiftelsen, 2019).

Digital participation and digital competencies need to be studied in more detail, especially in relation to marginalised groups (Ólafsson, Livingstone, & Haddon, 2014). This is accomplished in this thesis in relation to adolescents and young adults with intellectual disabilities (ID).

Adolescents and young adults with intellectual disabilities

People with ID have limited abilities to interpret and understand their everyday contexts and achieve personal independence in their everyday life due to intellectual and cognitive deficits (American Psychiatric Association, 2013; Kylén, 1986). In Sweden, the Diagnostic Statistical Manual of Mental Disorders, DSM-5, is used for diagnosing intellectual disability, and it is categorised as a neurodevelopmental disorder (American Psychiatric Association, 2013). It appears during the early developmental years, before 16—18 years, and causes deficits in both intellectual and adaptive functioning. Intellectual functioning is determined through IQ (<70) and the deficits caused are in areas such as abstract reasoning, problem-solving and learning from previous experiences (American Psychiatric Association, 2013). However, the importance of adaptive functioning has been highlighted to a greater extent in recent years (Tassé, Luckasson, & Schalock, 2016). Adaptive functioning can be explained as the ability to manage everyday life in different environmental settings, such as school or community. This ability differs with different levels of severity of ID, referred to as mild, moderate, severe, or profound ID (American Psychiatric Association,

2013). Difficulties are more evident for people with moderate than mild ID, and even more so for people with severe/profound than moderate ID. The difficulties can be summarised as appearing in the three everyday life domains: conceptual, social and practical (American Psychiatric Association, 2013). In the conceptual domain, difficulties with learning, and understanding concepts, letters and numbers are prevalent. Academic skills, reading and writing can be complex challenges. In the social domain, communicating and interacting with others can be difficult. In the practical domain, difficulties with living everyday life and performing daily activities are found. For people with mild ID, this could be in banking or estimating the time needed for different tasks. For people with moderate ID, even more difficulties emerge for example deciding on clothes in relation to the weather, understanding time and using spoken language. People with severe/profound ID have difficulties in understanding the time of day, and verbal communication, and need support with personal care (American Psychiatric Association, 2013). Additional disabilities, such as physical conditions are often prevalent (Reichenberg & Riedy, 2014) and can contribute further to the complexities of living everyday life.

In regard to general public health and well-being among people with ID, little is known because they are generally not represented in the national population-based surveys conducted by governmental agencies such as the Public Health Agency of Sweden (Ineland, 2013). This is due to their intellectual functioning and difficulties in the conceptual domain, with such skills as reading the questions in surveys. Through a literature review, it is known that people with disabilities in general in Sweden experience poorer health and unequal living conditions, including higher unemployment, lower income, and fewer social contacts (Umb-Carlsson, 2008). Although their life expectancy has increased, and adults today with mild ID have the same life expectancy as other adults, this study showed an increased vulnerability to both physical and mental health issues (Umb-Carlsson, 2008). Higher rates of obesity and diabetes have been reported among adults with ID in Sweden, compared with the general population. It is suggested that this is due to unhealthy lifestyle choices starting early during childhood or adolescence due to lack of knowledge of their effects, attributed to the intellectual disability and inadequate support, for example, to encourage physical activity (Flygare Wallen, Ljunggren, Carlsson, Pettersson, & Wändell, 2018). Mental health problems are more common for adolescents and adults with ID than in the population in general, including depression and anxiety (Mineur, Bergh, & Tideman, 2009; Umb-Carlsson, 2008). One

reason suggested for this is that, with greater demands from society on independence and self-determination, significant cognitive abilities are much needed today, and those who lack them become more vulnerable (Nylander, Fernell, & Björkman, 2014).

Due to the difficulties with adaptive functioning of people with intellectual disability, according to DSM-5, support is needed for most people with ID throughout the lifespan. The type and amount of support differs depending on severity level of the ID and should be adapted to individual needs according to the Act in Sweden concerning Support and Service for Persons with Certain Functional Impairments (SFS, 1993:387). In 2019, 75 000 people in total were receiving support due to the Act, and of these 89% were people with ID (National board on health and welfare, 2020). Persons supporting people with ID are generally parents, and staff at, for example, special after-school clubs or group homes for adults with ID. Children and adolescents with ID are in compulsory special school and upper secondary special school with adapted curriculums (National Agency for Education, 2018). After graduating school, work at daily activity centres can be applied for by young adults with ID, according to the Act (SFS, 1993:387). In 2019, 38 300 people, which constitutes 32% of all services granted, had this service, making it the most common service provided (National board on helth and welfare, 2020). However, after upper secondary special school, about 25% of young adults with ID find themselves a job in the ordinary job market, most with some form of wage subsidy. Very few go on to higher education and the progression of as many as 25% is not known (Arvidsson, 2016). The service of living in group homes or support homes, had been granted by 29 610 people with ID in 2019 (National board on helth and welfare, 2020).

The estimation of the total prevalence of people with ID in Sweden is about 0.5—1% of the population, partly based on the numbers of services granted according to the Act (SFS, 1993:387), i.e. after-school clubs, daily activity centres, group homes. This is in line with estimations of the prevalence globally (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Since there are no registers in Sweden of people with ID, the exact numbers are not known (Arvidsson, 2016). Statistics for the number of pupils in special schools show that about 1% of the total number of pupils were in compulsory special schools and upper secondary special schools in 2016, when the data collection for this thesis took place. This amounts to approximately 15 000 pupils between the ages of 13 and -20 years (National Agency for Education, 2016). To be enrolled in special school in Sweden the diagnosis

'intellectual disability' is needed. School enrolment for adolescents with ID is four years of upper secondary special school, which is a year longer than for adolescents in general (National Agency for Education, 2018). Hence, adolescents with ID have a longer time at school in order to learn more because the cognitive development takes longer when you have ID, according to DSM-5 (American Psychiatric Association, 2013) and the model of the intellect, developed by Kylén (1986) and widely used in Swedish context. With experience and environmental support, learning does occur throughout the lifespan and experience-based development of functioning can occur (Kylén, 1986). Therefore, it is possible to stay longer in special school in Sweden before transitioning to adult life, and for example work.

Adolescents and young adults with ID and participation in society

The right to independence of people with life-long disabilities, for example intellectual disabilities, and participation in all areas in their everyday life and society is expressed in the Convention on the Rights of Persons with Disabilities, CRPD (UN, 2006). Likewise, the right to participation on equal terms with others along with self-determination in everyday life for persons with ID are stated in Swedish law in the Act concerning Support and Service for Persons with Certain Functional Impairments (SFS, 1993:387), and encompass children and adolescents together with their families, as well as adults. In the Act it is specifically stated that when a child/adolescent receive the support and services, they should be involved and their self-determination is highlighted; however this has been difficult to put into practice (Swedish Agency for Participation, 2020). Restrictions on participation among adolescents with life-long developmental disabilities, for example ID, have been found in everyday life. Some restrictions faced by them are affected by environmental factors that are similar to those for adolescents without disabilities, for example peer-relations, however in school the effect of disabilities are especially evident (Anaby et al., 2014; Lygnegård, 2018). A recent report shows that adults with ID do not perceive themselves as having equal rights in society and state that expectations of others on themselves as citizens with ID to be active members of society are low (Swedish Agency for Participation, 2020). Digitalisation is briefly mentioned in the report, as one possible hindrance in society. At the same time, it is declared that one way of making society accessible for all is through the development of digital technologies, but that there is a risk of exclusion for some (Swedish Agency for Participation, 2020).

It is stated that Sweden should have a sustainable information society for all, and it has been declared that one of the targets when implementing disabilities policies is to increase the accessibility and usability of the public web (Swedish Agency for Participation, 2019). Therefore, the use of the internet among persons with ID needs to be studied further. When searching the Swedish Media Council, which conducts research and investigations regarding the use of the internet among children and adolescents in Sweden, no available data on people with ID could be found in 2014, when this thesis project started. However, the CRPD defines access to internet as a human right (UN, 2006). The importance of access to the internet for personal independence is especially true among the adolescents and young adults of today, who are considered to belong to the digital generation for whom digital life is intertwined with everyday life (Dunkels, 2008; Livingstone, Mascheroni, & Staksrud, 2017).

An occupational perspective on internet use and digital participation

This thesis applies an occupational perspective, which is broadly defined as observing and being aware of the complex processes of human doings in everyday life (Njelesani, Tang, Jonsson, & Polatajko, 2014). Human doings occur and have relevance at both individual and societal levels, and are important for health and wellbeing (Njelesani et al., 2014; Wilcock & Hocking, 2015). Furthermore, the activities people do in everyday life involve interactions with environmental factors that have an influence as either hindering or facilitating them (Taylor & Kielhofner, 2017). In addition, the human doings contribute to being, belonging and becoming in everyday life and society through engagement in occupations from an occupational perspective (Njelesani et al., 2014; Wilcock & Hocking, 2015). The use of internet is stated to influence occupational engagement and the things that people do in everyday life today (Larsson-Lund, 2018; Larsson-Lund & Nyman, 2019).

Environmental contexts of everyday life

Everyday life consists of the ordinary occupations that take up a person's time in everyday settings, recognising the complex interactions between the person, the environment and the occupation (Christiansen & Townsend, 2011; Law, 2002; Njelesani et al., 2014). Everyday life is lived in a temporal, physical and sociocultural context in which people conduct

their occupations and daily activities (Taylor & Kielhofner, 2017). The environmental contexts can be described in terms of three dimensions; the occupations themselves, the physical dimension, consisting of spaces and objects, and the social dimension of the people with whom we interact. The environment can both hinder and facilitate activities and the environmental contexts have an impact upon the motivation, organisation and performance of occupations (Taylor & Kielhofner, 2017). The occupational, physical and social dimensions are encountered in our closest, most immediate settings at home or at school, in the local context, such as in our neighbourhood, and in global contexts, for example in society in general (Taylor & Kielhofner, 2017). Quality aspects are also considered in the environmental dimensions and involve the understanding that, beyond certain components, the environmental dimensions should uphold qualities; for example, spaces in the physical environment should be accessible and safe and objects available. In the social environment, the quality of interactions is highlighted, and in the occupational dimension the supports available are addressed (Taylor & Kielhofner, 2017). The complex interactions between the individual and their physical and social environments were found for adolescents with ID in upper secondary special school, when examining participation in the everyday settings of these adolescents (Molin, 2004).

Participation, activity, and health

Prerequisites for participation by adolescents with ID in upper secondary special school can be both internal, relating to involvement and engagement in participation together with the ability to participate, and external, experiencing accessibility to participate (Molin, 2004). Further, this was related to forms of participation, such as involvement in doing activities, but also formal and informal belonging in everyday settings (Molin, 2004). Engagement and involvement in activities are related to the International Classification of Functioning, disability and health (ICF) (WHO, 2001) and the definition of participation in the classification. ICF (WHO, 2001) is a broad framework that takes a biopsychosocial perspective on health. It frames functioning and disability with contextual factors, which interact with and affect health conditions. Functioning and disability incorporate both body structures and functions, and activity and participation, while contextual factors are environmental and personal. Activity is explained as the *execution of a task* or activity performed by an individual and participation as; *involvement in a life situation* (WHO, 2001), and these descriptions are used in this thesis. Involvement is explained as including different aspects of participation, for example being engaged in, taking part in, and having access to the resources necessary for participation (WHO, 2001).

These aspects are used in this thesis and contribute to the understanding of the concept of digital participation, for example taking part in internet activities and having access to devices to go online with. If the activity and participation of an individual are affected, this can be expressed as restrictions in execution and involvement. The contextual factors in ICF are defined as environmental and personal, with the latter not classified but concerning demographics such as age, sex, and ethnicity. Environmental factors are described as including aspects that are involved in both immediate environments (e.g., smartphones, the internet) and more distant environments (e.g., policies and services that regulate the digital environment) that might have an impact on a person's functioning.

The description given in the ICF (WHO, 2001) of the individuals' activity and participation, and the contextual factors for health, is in line with an understanding of the environment as interacting with the individual who is doing the activities and occupations from an occupational perspective (Hemmingsson & Jonsson, 2005; Njelesani et al., 2014; Taylor & Kielhofner, 2017; Wilcock & Hocking, 2015). However, the ICF has been criticised for failing to recognise the subjective importance of meaning for participation, because participation is operationalised as observed performance in the ICF (Hemmingsson & Jonsson, 2005). Not having the opportunity to intentionally perform activities in one's everyday life is identified as a risk to health, personal development and participation (Taylor & Kielhofner, 2017; WHO, 2001; Wilcock & Hocking, 2015). Furthermore, occupational therapy models have been criticised for misusing the concept of participation interchangeably with occupation, when these concepts should rather be used together, and in conjunction with engagement (Larsson-Lund & Nyman, 2017; Taylor & Kielhofner, 2017). An occupational perspective on the internet highlights the environmental aspects of understanding access to and use of the internet in relation to the individual and his/her engagement in internet activities.

Internet use and digital participation in everyday life

The immediate, local and global environments in which we live can all be considered digitalised today. The internet is part of the everyday environment surrounding us and people are in constant interaction with this environment when performing activities in their different everyday settings (Taylor & Kielhofner, 2017). The study contexts in this thesis are the everyday environmental settings of school/work, home, and free time/leisure time, where the adolescents or young adults with ID live their lives, perform

activities and use the internet. An environmental prerequisite for performing activities is access, or accessibility, which comprises components of both the person and their physical access to the environment, for example access to the internet (Iwarsson & Stahl, 2003). Use, or usability, of the environment involves an activity component in relation to both the person and the physical environment, and is more complex than mere access, for example, performing internet activities (Iwarsson & Stahl, 2003). Digital participation in this thesis is identified as the ability and opportunity for everyone to participate in the digitalised society (Swedish government, 2017; Swedish Agency for Participation, 2017; UN, 2006), and the internet activities being performed in everyday life are indicated as one of the components that make up the digitalised society.

Internet access and use among adolescents and young adults with ID

Based on the occupational perspective, the abilities, and possibilities of digital participation in this thesis are understood as having both access to and being able to use the internet. Therefore, internet access in this thesis is defined as having access to online connections and internet-enabled devices such as smartphones, tablets or computers, either having one of one's own or sharing a device with others (Findahl & Davidsson, 2015; Swedish Media Council, 2015, 2017b). In addition, the concept of internet use in this thesis is defined as performing internet activities. Such activities include searching for and retrieving information; entertainment activities such as listening to music, watching moving pictures (TV series, film clips) and playing games; shopping online; and maintaining social contacts and communicating with others (Findahl & Davidsson, 2015; Swedish Media Council, 2015, 2017b). Using the internet is also about the time spent on different internet activities in relation to other activities, together with the opportunities and risks involved in using the internet (Swedish Media Council, 2017a).

A literature review of inequalities and opportunities focusing on the internet showed that persons with ID of different ages are less likely to access and use the internet than the general population and that the internet seems to be yet another part of life from which people with ID are excluded (Chadwick, Wesson, & Fullwood, 2013). However, there is a lack of large-scale studies on internet use among people with ID (Chadwick et al., 2013;

Chiner, Gómez-Puerta, & Cardona-Moltó, 2017), and those that do exist focus on people with disabilities in general (Dobransky & Hargittai, 2006; Johansson, Gulliksen, & Gustavsson, 2020; Vicente & López, 2010). Studies regarding how the internet is used among people with ID and in what settings have been requested (Normand & Sallafranque-St-Louis, 2016). The few cross-sectional studies on access and use of the internet by people with ID are by-proxy studies (Palmer, Wehmeyer, Davies, & Stock, 2012). If surveys are used, they are filled in by someone else through an interview situation with the person with ID, (Chiner, Gómez-Puerta, & Cardona-Moltó, 2017; Jenaro et al., 2017), so there is a lack of cross-sectional studies in which the individuals with ID themselves have been the answering participants. However, the results from the few studies that do exist show that there is a digital divide in access to devices to go online with (Chiner et al., 2017; Palmer et al., 2012). Although the access to these devices has increased in recent years for people with ID, specifically to smartphones (Jenaro et al., 2017). One recurring reason for not having access to devices is their cost, and this is also seen in more recent studies (Chadwick et al., 2013; Lussier-Desrochers et al., 2017). This indicates that demographic data other than having ID may cause a lack of access to devices; for example, low income, which has been shown in other studies on internet use, together with being considered to belong to a vulnerable group (Helsper & Reisdorf, 2017). There have been requests to include people with both mild and moderate ID when studying access to and use of the internet, as some studies have shown that internet technology is applicable for young people with moderate and severe ID, and are influencing their everyday lives (Hoppestad, 2013; Kennedy, Evans, & Thomas, 2011; Söderström, Østby, Bakken, & Ellingsen, 2019).

Studies of internet use among adolescents and young adults with ID demonstrate that it is mostly used for entertainment activities, such as watching film-clips and playing online games (Chiner et al., 2017; Jenaro et al., 2017). A literature review of internet use through social media among adolescents with ID showed that social media is used but with difficulties, for example due to a lack of accessible devices and limited literacy skills (Caton & Chapman, 2016). Studies have shown that literacy skills are considered to be a very important digital competence when using the internet (Wu, Chen, Yeh, Wang, & Chang, 2014), and among people with ID this is strongly affected by their cognitive deficits. One reason for lower internet access and use that has been found in studies is cognitive deficits (Chadwick et al., 2013; Lussier-Desrochers et al., 2017; Sorbring, Molin, &

Löfgren-Mårtenson, 2017; Wu et al., 2014). It was even suggested that people with ID are excluded from using the internet in their daily lives. Reasons found for this were such as their cognitive deficits, technical abilities, affordability, and lack of support. Even though some studies have used environmental adaptations of devices and interfaces to overcome cognitive deficits (Cihak, McMahon, Smith, Wright, & Gibbons, 2015; Davies et al., 2015; Raghavendra, Hutchinson, Grace, Wood, & Newman, 2018), use of the internet in the everyday settings where it is used daily needs to be further examined (Normand & Sallafranque-St-Louis, 2016).

Another reported barrier to internet use and social media was safeguarding by others due to safety issues (Caton & Chapman, 2016). Qualitative studies show that access to and use of the internet by adolescents and young adults with ID can be restricted by caregivers such as parents, teachers or staff at group homes and that their attitudes are of great importance(Molin, Sorbring, & Löfgren-Mårtenson, 2015; Ramsten, Martin, Dag, & Marmstål Hammar, 2019; Sorbring et al., 2017). These studies also show that their support is needed to facilitate internet use by the target group. However, differences in attitudes among parents and teachers were found (Löfgren-Mårtenson, Molin, & Sorbring, 2018; Molin et al., 2015). Furthermore, discrepancies between caregivers and young people with ID have been found in relation to internet use and access to it (Chiner et al., 2017). More knowledge is needed on the support to ensure safe internet use that enables adolescents and young adults with ID to take advantage of its opportunities (Sallafranque-St-Louis & Normand, 2017). However, the potential risks of internet use need to be researched and support needs to be scrutinised because internet safety is very closely guarded by others and this may limit the autonomy of people with ID. Early on Seale (2007) raised the question of whether creating content on the internet through homepage authorship by people with ID is interdependent with or dependent on the parent supporting the authorship. Further research is needed on how the internet is used, along with its opportunities and risks, before conclusions are drawn on what preventative work might be needed (Normand & Sallafranque-St-Louis, 2016).

In summary most studies report a need for more research that include young people with IDs' own perspectives on their internet use in the different settings where they live their lives and use the internet (Borgström, Daneback, & Molin, 2019; Caton & Chapman, 2016; Lussier-Desrochers et al., 2017) .

Rationale

The advances in internet technologies are affecting human doings and participation, both in everyday life and in society. The research on internet use and digital participation among persons with ID has so far been limited, but lack of access to the internet constitutes a risk of restricted participation (Lussier-Desrochers et al., 2017). Further, in-depth knowledge about how the internet is used by people with ID in the contexts of everyday settings has been requested, together with knowledge about the risks and opportunities associated with the internet for this target group. Specifically, the lack of studies including adolescents and young adults with moderate or mild ID and internet use, has been highlighted. Environmental aspects, such as physical access to the internet, but also aspects in the social environment, for example parents' perceptions of their adolescents' internet use, are likely to contribute to (hindering or facilitating) the young person's internet use. Therefore, it is important to investigate parents' perceptions of the opportunities and risks faced by their adolescent when using the internet. Knowledge about difficulties and challenges in the digital environment needs to be emphasised among adolescents and young adults with ID, and specifically in comparison with young people in general, which is important from a human rights perspective. Research in general on the internet-generation of adolescents born since 1995 further emphasises the importance of focusing on both the opportunities and risks associated with the internet (Livingstone et al, 2017).

Having cognitive limitations often means being excluded from national surveys due to questions not being adapted to the needs of participants with ID. This has resulted in a lack of comparative studies, for example, on internet use by the target group, which is why adapting survey questions for inclusion was important in this thesis project. Furthermore, adolescents and young adults with ID themselves are still missing as participants from studies on internet use.

AIMS

The overall aim of this thesis was to explore and describe internet access and use, and digital participation in everyday life among adolescents and young adults with intellectual disabilities.

The specific aims of the studies

Study I: To explore and describe access to the internet and how it is used among adolescents and young adults with mild and moderate intellectual disabilities in their everyday settings.

Study II: To investigate digital participation of adolescents with intellectual disabilities by comparing aspects of internet use among adolescents with and without intellectual disabilities. Specifically, addressing and comparing whether there are differences in: (a) access to internet-enabled devices, (b) performing internet activities, (c) difficulties using the internet and (d) risk and risk management when using the internet.

Study III: To investigate opportunities and risks of internet use as perceived by the parents of adolescents with intellectual disability in comparison with a national reference group of parents of adolescents.

METHODS

This thesis is based on three studies using both qualitative and quantitative methodological data collection that were adapted for the target group of adolescents and young adults with ID. An overview of the methods used in the three studies is presented in Table 1.

Table 1. Overview of the design, participants, data collection and analysis in studies I-III.

Studies	Design	Participants	Data collection	Analysis
I	Inductive, using observations, and follow-up interviews	15 adolescents and young adults with ID, aged 13—24 years from seven municipalities	Direct observations in everyday settings with conversations, photographs, and follow-up interviews, during 2015—2016	Qualitative content analysis
II	Cross-sectional and comparative	114 adolescents with ID, aged 13—20, in compulsory and upper secondary special schools in four municipalities. Comparative national data, n=1161	Cognitively adapted national survey into an easy-read version, available on paper and through the web, distributed in the years 2016—2017	Cronbach's alpha test. Descriptive statistics and comparative analyses with chi-square test or Fisher's exact test
III	Cross-sectional and comparative	99 parents of the sample of adolescents in study II. Comparative national data, n=828	National survey, postal. Data collected -in the years 2016-2017	Cronbach's alpha test. Descriptive statistics and comparative analysis using Fisher's exact test. Logistic regression and Bonferroni corrections

Design

Overall, this thesis applied both qualitative and quantitative methodological approaches. In study I, an inductive design was used and qualitative data was collected using direct observations and conversations in everyday settings with adolescents and young adults with ID (n=15), taking field notes and photographs as well as conducting follow-up interviews with the adolescents and young adults with ID. The design of studies II and III was

quantitative, cross-sectional and comparative. The quantitative data on internet access, use, opportunities and risks during leisure time was collected from adolescents with ID (n=114) in study II, and from their caregivers/parents (n=99) in study III using population-based national surveys from the governmental agency The Swedish Media Council. In study II, the national survey "Kids and Media" (Swedish Media Council, 2017b) was cognitively adapted into an easy-read version, both in paper and web-based, to enable the adolescents with ID to answer the survey themselves. For study III, the national survey "Parents and Media"(Swedish Media Council, 2017a) was used. These surveys, which were controlled for measurement technology on aspects such as questions and response alternatives, were used because comparative data from the Swedish Media Council could be obtained from an age-appropriate reference group of adolescents without ID, and a reference group of parents of adolescents without ID.

Preunderstanding of the author

When entering this thesis project, the author had many years of experience as an occupational therapist and, before that, a caregiver working with adults with mild, moderate and severe ID, in community-based settings of daily activity centres and group homes. This preunderstanding was an asset in designing the studies, gaining access to the everyday settings (study I) and when contacting special schools for participation in the survey studies (studies II and III). Knowledge of the area and previous work experience could be communicated to the contact persons in these settings, which was positive and gave the access to meet possible participants. The preunderstanding of the author included knowledge about the cognitive implications in everyday life for people with ID, picture-support and knowing some sign-language. These experiences were of assistance during the contact with participants in study I and when developing the easy-read survey (study II) and pilot testing the surveys (study II and III). However, the author did lack experience of special schools, which initially led to the establishment of rapport taking somewhat longer at special schools. In addition, a lack of experience of using the internet for social media and gaming was initially a factor. However, open-ended questions were perhaps easier to formulate due to this (study I). Reflexivity of the preunderstanding (Patton, 2015), and the lack of it has been constantly present during the work with this thesis and challenged in discussions with supervisors and at higher seminars.

Overall participant recruitment process

Participants in this thesis are adolescents and young adults with ID aged 13—24, (study I), adolescents with ID aged 13—20 (study II), and parents of adolescents with ID (study III). The recruitment process was community based, including special schools and daily activity centres (study I) and special schools (studies II and III) in overall eight different municipalities in four of Sweden's 25 provinces. The daily activity centres are work settings, where people with ID are entitled to work, if they are over 18, according to Swedish legislation (SFS, 1993:387). Web pages of the municipalities were used to identify the managers at the office of social affairs who were in charge of the daily activity centres (study I). The special schools in each municipality that were listed in 2016 at the National Agency for Education (2016) were identified, and based on this information the municipalities' web-pages of the special schools were used to find updated contact information for principals (studies I-III).

Study I

Participants and recruitment

In the qualitative study (study I), both special schools and activity centres were included, and a purposeful sampling (Patton, 2015) was used to include participants of different ages with both mild and moderate ID. The principals of nine special schools and the managers of four offices of social affairs in eight municipalities from a total of three provinces were contacted, and all but one agreed to identify contact persons to recruit participants with ID. Initially, 17 contact persons were identified, but three declined to participate, all from schools, due to a heavy workload. In addition, two were unable to identify participants fitting the inclusion criteria who were willing to participate. This left 12 contact persons who recruited participants from six municipalities during a one-year period from spring 2015 to spring 2016, in accordance with the inclusion criteria. The inclusion criteria were young people with mild or moderate ID, aged 13—25 years who were using the internet to some extent according to the knowledge of the contact person, and who were willing to be observed and interviewed about this in their different everyday settings.

In total, the participants were 15 adolescents and young adults with mild (n=6) and moderate (n=9) ID recruited from compulsory (n=3) and upper

secondary special schools (n=7) and activity centres (n=5). In Sweden, adolescents with mild, moderate and severe ID are enrolled in different types of curriculum in special schools, with the enrolment verifying the severity of ID (National Agency for Education, 2018). At the activity centres, staff who were health professionals verified the severity level of ID of participants. The participants were aged 13—24 years (m=18.5), eleven were female and four male, 13 lived in their parental homes and two lived in group homes. All communicated verbally, although with difficulties articulating, and some (n=5) used sign language in combination with verbal speech.

Data collection methods

Observations with conversations and follow-up interviews, supported by photographs taken during observations, were used to collect the data. For each participant (n=15), data were collected on two or three observation occasions per participant and during one follow-up interview, which took place at the end of the final observation occasion. In total, 32 observation occasions, 2—6 hours per participant (m=3.45), added up to a total of 56 hours of observation time. This included the time for the follow-up interview, which varied between 10 and 30 minutes. A variety of technologies was used to collect the data, in line with Patton (2015). Handwritten field notes were taken describing the observation setting and occurrences during observations in chronological order. Each page in the notebook had a margin for the observer to write down immediate brief reflections. This was done as a step in the reflexivity process, reflecting about oneself and what you bring into the observation (Patton, 2015). Digital audio recordings were made during both the observations and the follow-up interviews. Photographs were taken of the internet-enabled devices that participants used in the settings, adding up to a total of 269 photos, ranging from 4—52 per participant (m=18). The photographs were used both when documenting the collected data, and during the follow-up interviews as a cognitive adaptation to enable participants with both mild and moderate ID to participate. The photographs facilitated recall of the earlier observation occasion, even when the participants had difficulties with abstract thinking or recollecting previous events (Folkestad & Folkestad, 2000).

The focus during observations was on the participants' access to and use of the internet in the everyday settings. The observer's role was initially part spectator-observer when starting the first observation and evolved into part participant-observer with involvement with the participants through conversation, in line with Patton (2015). Conversations concerned how they accessed and used the internet in the setting, asking questions like:

"Can you show me more of what you do [on the internet]?" or "Can you show me how you did that?" The observer's role was overt, with full disclosure to everyone in the settings. The focus of the follow-up interviews was on clarifying events of accessing and using the internet during the earlier observations. Based on events from the earlier observations, two recurrent questions were asked of each participant: "You showed me [your tablet/smartphone/a social media app etc]: i) how are things going with it?" and ii) "How come/why?" Participants also used their devices and apps during the follow-up interview as support to help them answer. Probing questions were used, formulated with easy wordings and in either-or formats, which can increase trustworthiness because acquiescence, the likelihood of saying "yes" to questions, diminishes (Finlay & Lyons, 2001).

Transcriptions were made by the author of this thesis shortly after the observations. The transcripts included the handwritten field notes and the audio-recordings of both the observations and follow-up interviews, focusing on internet access and use.

Procedure

The contact persons, chosen and named by the school principals or office managers, identified participants based on the inclusion criteria. Then, with guidance from the author of this thesis, the contact persons distributed information letters to parents and adolescents, in easy-read format and with picture support if needed and collected the consent forms. They arranged the first meeting with the participant in the school or work setting. The first observation took place in one of these settings and the second took place in the home settings of the participant or during their free time at school or work, as not everyone was willing to be observed in their home environment. The second observation was arranged by the author of this thesis with the participants themselves and in many cases including contacts with someone in their home environment: parents or staff at the group homes. The second observation was conducted within a fortnight of the first for all participants. Two participants were observed on three occasions. At the end of the the second, or third, observation the follow-up interview was conducted.

Data analysis

An inductive, data-driven qualitative content analysis was conducted in line with Patton (2015). The unit of analysis was the transcripts of field notes and audio recordings, which added up to 400 pages. The analysis

started with reading through the material with the aim of the study (to explore and describe access to and use of the internet in everyday settings*)* guiding the analysis. Reflections and comments were written in the margins as suggested by Patton (2015). Reflexivity (Patton, 2015) was present during the analysis process, ensuring the material was not interpreted in light of the previous experiences of the author of this thesis but rather staying close to the text of the transcripts. During the second reading, the initial coding process was begun. This was data-driven and derived meaning units that were close to the text, followed by condensation into codes. Table 2 gives an example.

Table 2. Example of the structure of the analysis sheet data and the analysis process from a transcript of a follow-up interview.

Text with underlined meaning units	Code	Grouping of codes	Sub-categories	Categories
"*It would be good if we were <u>allowed</u> to <u>take</u> the <u>iPad home</u>, I think. But <u>we're not</u>. Some are allowed to and take a photo of what they do at weekends and such…. I think that would be good. I think we <u>all should be allowed</u> to do that. I don't remember things otherwise…. Wouldn't that be good?*"	iPads Not allowed to take home Should be allowed	Setting-specific tablets, decided by others	Internet-enabled devices	Access to the internet in different settings

The continuous readings analysed similarities and differences between participants and settings, and codes were grouped into higher-order headings that generated three categories and nine subcategories, as shown in Table 3. In addition, internet connections and the number of internet-enabled devices in each setting were counted and mapped per participant. Rereadings of the transcripts by the whole research group enhanced credibility and dependability, and ensured that the data was stable in the categories (Denzin & Lincoln, 2011). Quotes were chosen that illuminated the categories.

Table 3. Categories and sub-categories of internet access and use found in the everyday settings.

Categories	Subcategories
Access to the internet in different settings	Internet connections Internet-enabled devices
Challenges when using the internet	Reading, writing, and spelling A rapidly changing environment
Strategies to handle the digital environment and take part in internet activities	Getting support from others Word-based strategies Picture-based strategies Voice-based strategies Reducing and personalising devices

Study II

Participants and recruitment

For study II, participants were recruited from special schools, and were adolescents with ID. Two provinces in Sweden were selected, one by convenience sampling, because it would make it possible for the author of this thesis to visit the special schools in one province, and the other because it was more densely populated. In the two provinces, sampling was made in a stepwise manner (Polit & Beck, 2016), starting with four stratified sampled municipalities with few or many special schools, both rural and urban, because internet use may be affected by demographic characteristics. Following this, the total selection of compulsory secondary special schools (n=5) and upper secondary special schools (n=6) in the municipalities were contacted through the principals, and all agreed to the participation of their schools in the studies. A total selection of pupils in the special schools based on the inclusion criteria for the study were included. Inclusion criteria were adolescents with ID in compulsory secondary special school and upper secondary special school, aged 13—20 years. No exclusion criteria were used, enabling the inclusion of all adolescents with mild, moderate, or severe ID, n=318, in the special schools (study II). This was important because digital participation is likely to vary among adolescents with ID.

In total, 114 adolescents with ID participated using the cognitively adapted, easy-read survey based on the national survey "Kids and media" from the Swedish Media Council. The response rate was 36%, which was equivalent to that of the reference group, 38% (n=1161), participating the same year in the survey "Kids and Media" (Swedish Media Council, 2017b). Significantly

more adolescents with ID were male (p=0.005), and older than the reference group (p<0.001), because they are enrolled for a year longer in upper secondary special school (National Agency for Education, 2018) and may be older when starting secondary special school. Based on school enrolment, 66 adolescents with ID had mild ID (59%) and 48 (41%) had moderate ID. Of the adolescents with ID, 75% stated that they had company while answering the survey.

Data collection method

The national survey "Kids and Media" from the governmental agency the Swedish Media Council that was used to collect the data (Swedish Media Council, 2017b), has been administered biannually since 2005 to survey internet and media use during leisure time among adolescents, aged, 9—18 years, in Sweden. It contains 183 questions in total (48 main questions, most with many sub-questions), with questions on demographics, access to devices to go online with, activities during leisure time and specific internet activities, such as playing online games or using social media, and time spent on the internet. There are also questions about experiences of risks with internet use and personal abilities relevant to using the internet (Swedish Media Council, 2017b). The same survey, with necessary cognitive adaptations made in several steps, was used for adolescents with ID.

The cognitive adaptation process of the survey for the adolescents with ID

The survey "Kids and Media" (Swedish Media Council, 2017b) were cognitively adapted in a six-step process, shown in Table 4 and described in detail below. The adaptation process generated an easy-read, paper-based survey with the option of picture-supported questions and response alternatives in a web-based version that enabled adolescents with ID to answer it themselves. Self-ratings have proven plausible for people with ID (Arvidsson, 2013) and it has been highlighted as crucial to involve adolescents with ID themselves when surveying questions other than basic needs. This is due to differences in ratings found between adolescents and proxy persons (Huus, Granlund, Bornman, & Lygnegård, 2015).

The cognitive adaptations were made by the author of this thesis, with support from senior researchers with previous experience of the target group and in initial cooperation with the Swedish Media Council and a technology company for the web-based version. Pilot testing was done by adolescents

with ID. Furthermore, research literature on collecting data from partici-
pants with ID was used (Finlay & Lyons, 2001; Hartley & MacLean, 2006;
Oschwald et al., 2014). The results of the qualitative study in this thesis on
access to and use of the internet by adolescents and young adults with ID
(study I) also guided the initial redundancy process of questions.

The first of the six adaptive steps was to shorten the survey, as shown in
Table 4, with the initial step of removing questions. The length of the orig-
inal survey of 183 questions was considered too extensive for people with
ID due to possible problems with working memory and endurance, which
may be affected by the level of ID according to DSM-5 (American
Psychiatric Association, 2013). Sections of greater importance were deter-
mined in line with the aim of study II to be access, internet activities and
difficulties in using the internet, together with some concrete questions
about risks. Questions removed from the original survey included specific
questions about internet activities on specific devices e.g. smartphone, and
experiences of specific risks. This was decided in cooperation with the Swe-
dish Media Council, because overall knowledge about adolescents with ID
and internet access and use was needed prior to details about risks. In com-
bination with shortening the survey, abstract concepts were also with-
drawn from the questions, making the survey more comprehensible (Finlay
& Lyons, 2001), leading to questions asking about such details as exact time
statements on internet use/ day being withdrawn. During the initial step of
shortening the survey, reflexivity was used to minimise the number of var-
iables removed based on the author's preunderstanding.

Table 4. The process of cognitively adapting the survey for adolescents with ID.

The stepwise order in the cognitive adaptive process	The cognitive adaptations made to the survey
Shorten the survey and remove abstract concepts	Shortening the survey by withdrawing questions, and removing abstract concepts (Finlay & Lyons, 2001)
Simplify questions	Simplifying questions using easy-to-understand concepts and easy-read text (Finlay & Lyons, 2001)
Fewer alternatives on the response scale	Adapting the response scale to a maximum of a 4-point Likert-type scale with a one-word response/alternative (Hartley & MacLean, 2006)
Audio assistance in the web-based version	Questions and response alternatives were audio-recorded and possible to listen to when answering the survey (Oschwald et al., 2014)
Adding pictures in the web-based version	Two to four pictogram pictures were added per question and one picture per response alternative (www.pictogram.se/) for picture-based support along with the audio assistance
Support to log into the survey	A person (the author of this thesis or occasionally a teacher), provided a tablet and earphones and offered support to log into the survey during school hours

The second step consisted of simplifying the language used (Finlay & Lyons, 2001), in order to make the questions concrete and understandable for people with ID. This meant, for example, that all open-ended questions were removed, such as those on the types of social media used. The third step was shortening the response scale (Hartley & MacLean, 2006) from a maximum of an 8-point Likert-type scale to a maximum of a 4-point scale, as described in Table 4. When shortened and simplified, the easy-read survey consisted of four sections with between 6 and 19 questions in each, adding up to a total of 45 questions, with 3 including sub-questions, see Appendix. The sections were: i) demographics, ii) access to internet-enabled devices, for example computers or smartphones, where the questions were kept to three response alternatives, as in the original survey, iii) internet activities performed, for example watching film clips on YouTube, and iv) difficulties, for example in writing text-based messages, and risks involved in using the internet, for example revealing one's real name. In total, 29 questions in accordance with the aim of study II were used, including questions from all four sections with two to four response alternatives each. The remaining questions are to be used in further studies.

For the subsequent steps, four and five shown in Table 4, the author of this thesis established contact with the technology company and worked closely with them to adapt the survey into the web-based version. In step four, the

audio-recordings were discussed with and made by the technology company for both the questions and the response alternatives. In step five, choosing the pictures used for adaptation of the questions and response alternatives, in accordance with Table 4, was done by the author of this thesis. One example of an adapted question about internet activities with picture-based support is displayed in Figure 1. The original question was *"How often do you search for information on the internet in your leisure time?"* There were five response alternatives on a Likert-type scale: *"Every day"*, *"Several days a week"*, *"Once a week"*, *"Rarely"* or *"Never"*. The cognitively adapted question was: *"Do you search for new knowledge and information on the internet?"* There were four response alternatives on a Likert-type scale: *"Every day"*, *"Every week"*, *"Rarely"* and *"Never"*. The web-based version of the example question with picture-based support is displayed in Figure 1. The final step in the cognitive adaptations was to offer support from a person to log into the web-based study, as shown in Table 4.
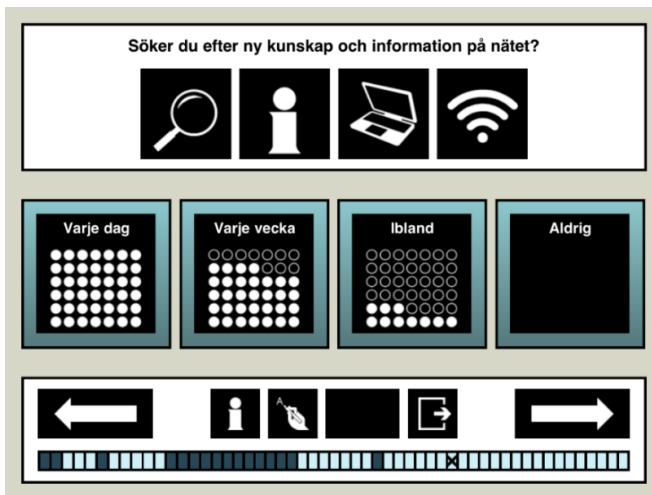

Figure 1. An example of a web-based question [in Swedish] with picture-based support (developed in cooperation with Neonova AB).

Pilot tests of the survey were conducted with adolescents with ID, both the paper-based version after step three, and the web-based version after step six. The author of this thesis conducted all the pilot tests with a total of five adolescents with ID using Think Aloud methodology (Patton, 2015). Fol-

lowing the pilot tests, one question on assistive devices was removed, because it was difficult to differentiate between assistive devices and internet-enabled devices according to all the participants in the pilot tests. Furthermore, two pictures were changed, and the implementation of the suggested sixth step, of a person supporting the adolescents to log into the survey, was highly appreciated. The support person was the author of this thesis, but at two special schools three teachers volunteered as support persons. The author of this thesis gave instructions on how the support was to be given consisting merely of support to log in, and giving the time needed to complete the survey during school hours.

When tested, the easy-read survey had an overall Cronbach's alpha of α=.84, which is an indication of high reliability, because values of 0.7—0.8 generally indicate high reliability and internal consistency (Field, 2018). The subscale internet activities had high reliability, with a Cronbach's α=0.69, as did difficulties and risks, Cronbach's α=0.74. However, access to the internet had somewhat lower reliability, with Cronbach's α =0.55.

Procedure

To aid in the distribution of the surveys, the principals, of the special schools sent address lists for all the pupils (n=318) to the author of this thesis. As the address lists were received, a survey package was sent out, between November 2016 and September 2017, addressed to "The caregiver of [pupils name]". The survey-package consisted of a paper version of the easy-read survey, together with a survey for the parents (study III) and an information letter to the parents about the studies for which the surveys were collecting data. One information letter in easy-read text for the adolescent with ID about study II was also included in the survey package, together with an information letter with pictures about how to access the web-based version of the easy-read survey, and two response envelopes. Two reminders were sent out, two weeks and four weeks after the first survey-package was sent.

Answering the easy-read survey could be done at home on paper or using the web-based version. The latter could also be answered at school, with support if needed; either help from a teacher or from a person in the research team (the author of this thesis) to log into the survey.

Data analysis

The data was analysed using SPSS, version 25 (IBM, 2017.) Initially, all answers were merged into one spreadsheet to include the data from both

groups for each question in the easy-read survey and to collapse response alternatives for comparative analysis. Contingency tables and descriptive statistics with percentages were used. There were no more than nine items of internal missing data in any variable among adolescents with ID. For the statistical analysis in study II, the response scales for seven of the eleven variables on *internet activities* were dichotomised into "Do" (daily/weekly) or "Do not" (rarely/never), due to the remaining four only having the response alternatives "Do" or "Do not" in the data for the reference group. Furthermore, the variables relating to *revealing personal information* were also dichotomised into "Yes", comprising of "Yes" and "Occasionally" and "No". Chi-square tests were used in all the subsequent comparative analyses and, if necessary, Fisher's exact test, due to the variables being categorical with few categories. The statistical significance was set at $p<.05$ (Field, 2018)

Study III

Participants and recruitment

Based on the recruitment for study II, parents/caregivers were identified and recruited simultaneously, n=318, for study III. A total of 99 parents of adolescents with ID participated, giving a response rate of 31%. The comparative data for parents had a response rate of 39% (n=1561); however, for this study, data from n=828 parents fitted the age criteria of adolescents, which was 21% of the total sample. Among the parents of adolescents with ID, significantly more were female (p<0.001) and had a university education (p=0.021) compared to the reference group. Equal percentages of parents in both groups, 84%, state that they themselves spend reasonable time on the internet. The adolescents with ID were significantly older than those in the reference group (p=0.022), with 57% having mild ID and 43% having moderate or severe ID.

Data collection method

The data in study III was collected using the survey "Parents and Media" (Swedish Media Council, 2017a), which is administered biannually to survey parents' perceptions of media and internet use among their adolescent children aged 9-18 years. The same national survey, "Parents and Media", was used for the parents of adolescents with ID and the reference group of parents, with an additional four questions for the parents of adolescents

with ID. These additions were about the parents' demographics and a question about the adolescents' difficulties/disabilities. The latter was added after the survey had been pilot-tested using Think Aloud methodology (Patton, 2015) with the parent to an adolescent with moderate ID, aged 13 years. In total, the survey consisted of 25 questions, where every question had between 3-17 sub-questions. The 25 questions were grouped into three sections about the parents' perceptions of the adolescents': i) internet activities and other leisure activities, ii) opportunities and iii) risks with internet use. Responses were given on a Likert-type scale of between three to seven response alternatives. Questions in accordance with the aim were used, adding up to a total of 15 questions from all the three sections, of which six had sub-questions, and between three and five response alternatives. The specific questions were about the time spent on different activities, the opportunities and risks associated with internet use, including negative consequences, concerns about and incidents of online risks, and the responsibilities of parents.

When tested, the parents' survey had an overall Cronbach's alpha of α=.98, which is an indication of very high reliability, as values of 0.7—0.8 generally indicate high reliability and internal consistency (Field, 2018). The subscale of Opportunities was the only subscale with a somewhat lower Cronbach's alpha, α=0.92.

Procedure

Distribution of the surveys to the parents was conducted in the same way as for study II since they were included in the survey package with the survey for the adolescents. The survey was available in a paper version. The information letter to the parents included information about participation in the parental survey. Informed consent was assumed if they responded to the survey.

Data analysis

The data was analysed using SPSS, version 25 (IBM, 2017.) Initially, all the data from the parental surveys were merged into one spreadsheet for comparative analyses. There were nine items of internal missing data among parents of adolescents with ID, apart from the variables on Opportunities and Risks when playing games in the parental survey, where there were 17 and 19 items of internal missing data respectively.

Among the parental surveys, five were excluded because parents had answered "never do" to all the questions on internet activities performed by

their adolescent, giving n=94 surveys included in the analysis in study III. In this study, the response scales of the variables on *opportunities* (n=4) and *risks with negative consequences of internet use and playing games* (n=6) were trichotomized into "Agree", comprising of "Totally agree" and "Agree to a great extent", and keeping "Partly Agree" and "Disagree". The response alternative "Don't know" was categorised as missing, because it was not found in the 95th percentiles for any variable for the whole sample (Svensson, 2005). The remaining response scales were kept intact. For all the comparative analyses Fisher's exact test was used, with the statistical significance set at *p*<.05, because most questions had at least one response alternative with fewer than 5 expected responses (Field, 2018). Logistic regression was used to control for confounding for parents' sex, parents' educational level and age of the adolescents. Odds ratios and adjusted odds ratio were corrected for multiple comparison using the Bonferroni correction (Field, 2018).

Ethical considerations

In accordance with the Ethical Review Act concerning the ethical review of research involving humans (SFS, 2003:460), ethical approval was applied for and granted by the Regional Ethical Review Board of Linköping for this thesis (141201; Dnr 2014/370-31). The Ethical Review Act specifically highlights the importance of providing *information* to the participants, and them giving *informed consent* for their participation in research, together with *confidentiality* and *protectional* rights of, for example, anonymity. Participants in this thesis had ID (studies I and II) and to ensure that they made an autonomous choice to participate, special attention was paid to this matter. For study I, staff at the schools, activity centres and one after-school club gave the initial information to potential participants, both verbally and by handing out the printed information with consent forms to be handed back to the staff if they agreed to participate. The information given was cognitively adapted, to be understood and decided upon by the adolescents and young adults with ID themselves. This was done through information letters in easy-read text with pictograms (www.pictogram.se) for those who needed them (study I). For participation in the survey-based study (II) information letters were written to parents for consent, and in easy-read text to the adolescents with ID, including photographs on how to access the internet-based survey. When meeting potential participating adolescents with ID as a support person, verbal information was given a second time to assure informed consent. During this process, n=2 declined to participate in the survey. The parents (study III) received an information

letter and a maximum of two reminders about responding to the survey to participate in the study. The procedure of the distribution of the surveys based on the address lists from the special schools were done prior to the General Data Protection Regulation (GDPR) (EU, 2016/679), that came into action during 2018. All personal data has been handled according to the GDPR following its implementation.

For participation in study I the first author offered to visit the special schools and the activity centres to provide further information about the study. This was offered to all schools and activity centres after staff members had handed out the information letters, but before the potential participants had consented to take part in the study, and a visit was made to three special schools and one activity centre. This proved to be an important step because potential participants were able to meet the person who would conduct the observations and the author could give them more concrete information, for example showing them the field note book and how notes would be taken, enabling them to make an independent decision about participation.

There were ethical dilemmas occurring and decisions to make throughout the research. For example, there were pupils who were not interested in participating when data collection was about to start, although consent forms had been signed. In these cases (n=3: n=1 in study I and n=2 in study II) it was important to be flexible and let them make their own decisions not to participate. In digital everyday life, risks were also prevalent for the adolescents and young adults when using the internet, and with their great desire to share their activities on the internet with me in study I, I came across ethical dilemmas of cyber-bullying and contact taken by a stranger on social media where the participant showed me the ongoing conversation. In the ethical approval applications (nr 2014/370-31), these potential hazards had been foreseen and the action that had been decided to take was to empower the participant him/herself to make contact with their parent or a staff member to receive guidance about the situation. This was done with careful follow-up questions from the author of this thesis on the matter during the second observation.

RESULTS

Access to the internet in everyday settings

The results of the qualitative study (study I) showed that the participants (n=15) had access to more internet-enabled devices than they were using. All participants had access to smartphones and nearly all had access to tablets, and some had access to more than one. However, access to internet-enabled devices in the survey-based study (study II), showed that only 67% of the adolescents with ID had access to a smartphone, which was significantly fewer than the 98% of adolescents without ID (p<0.001). However, a smartphone was the device that most adolescents both with and without ID were most likely to own. In addition, a significantly lower number of adolescents with ID had access to most of the surveyed internet-enabled devices, i.e. computer, smart TV and gaming console, compared to the age-appropriate reference group without ID (p<0.001). Tablets, however, were accessed by a significantly higher number of adolescents with ID compared to the reference group (61% vs 48%, p=0.013) (study II).

Few participants in study I were observed using all the internet-enabled devices to which they had access, for example, about $^2/_3$ were observed using their smartphone. Internet-enabled devices that were personal, such as smartphones, often tablets and occasionally adapted laptops with assistive devices, were the most frequently observed devices to be used to access the internet (study I). This was observed both at school, where the schools provided tablets, and during free time or at home. At work, i.e. the daily activity centre, devices were shared with others.

The finding of fewer internet-enabled devices being used than having access to in study I, could be explained by the lack of internet connections on the devices or in the setting (study I). Five participants out of the 15 had internet connections for their devices in all the different settings: school/work, at home and when mobile. Some participants lacked internet-connections on their smartphones due to high costs. All participants had internet connections in their homes. However, access to the internet was observed as limited for the young adults living in group homes, because there was no available Wi-Fi there for them to use in their own apartments. The observations demonstrated that the staff referred arranging for internet connections to the participants' parents or trustees.

Internet activities in everyday life

The participants with ID were using the internet to engage in various activities during leisure time (study II) and in the different everyday settings (study I). Internet activities were performed for entertainment, for example playing games or watching TV series or movies, and many were searching for information. Social networking internet activities were also performed using internet-based communication tools or social media (study I). However, when comparing the eleven internet activities performed during leisure time in everyday life (study II), the internet activity *playing games* was performed by a significantly larger proportion of adolescents with ID compared to the reference group (84% vs 63%, p<0.001). All the other internet activities were performed by a significantly lower proportion of adolescents with ID than in the reference group. However, a high proportion in both groups were conducting internet activities for entertainment, for example *watch film clips (You Tube)*, which was done by 78% of adolescents with ID compared to 97% in the reference group (p<0.001). The largest difference in proportion was displayed between the groups in *searching for information* which was done by only $1/5$ of adolescents with ID compared to more than $4/5$ in the reference group (20% vs 86%, p<0.001). Following this was *having contact with friends on social media,* which was done by 54% of adolescents with ID compared to 93% in the reference group (p<0.001).

The parents' perceptions of their adolescents' internet use (study III) showed significant differences in their perception of the time spent by the adolescents on the surveyed leisure activities. A higher proportion of parents of adolescents with ID perceive that their adolescents never spent time on these activities than the reference group. There were two exceptions out of the nine surveyed leisure activities: *playing online games* and *watching movies/TV*, which showed no significant differences between parents of adolescents with or without ID. The leisure activities demonstrating the largest differences in proportions from the parents' perceptions were *using the smartphone, using social media,* and *meeting friends.* A quarter of the adolescents with ID never spent time *using smartphones* (26%) compared to 0% of adolescents in the reference group of parents. In the reference group, 59% perceived that their adolescent *uses the smartphone* too much compared with 20% of parents of adolescents with ID. Having social contacts through *social media* and *meeting friends* was done significantly less by adolescents with ID compared with the reference group, both from the

perspective of the adolescents themselves and according to the parents' perceptions (studies II and III, respectively).

Challenges to and difficulties with internet use and participation in internet activities

Several challenges to internet use were found in the digital environment for the participants, with one being the rapid changes in it (study I). Examples of this include the continuous updating of software, games or social media that are characteristic of the digital environment today. The ongoing updates made it difficult for the participants to use previous experience when encountering the updated versions. One participant, John, 13 years old with moderate ID, who was playing FIFA on his mum's tablet, expressed it this way: "Really, I think the old version of FIFA was easier. I played it on the TV, on the Play Station. I haven't learnt the new FIFA that well". This updating of the digital environment meant that internet activities had to be re-learnt. Another observed challenge occurred when initially entering the digital environments. Codes were needed to unlock internet-enabled devices, and usernames and passwords were needed for ongoing participation in internet activities, such as logging into social media.

The difficulties encountered when attempting to take part in internet activities were due to the participants' limited abilities regarding reading, writing, and spelling, demonstrated in specific text-based internet activities, for example e-mailing and searching for information on the internet (study I). Kylie, who is 14 years old with mild ID said: "One difficult thing is to find things on the internet if words are long and I need help with spelling". When surveyed in study II, a significantly higher proportion of adolescents with ID had difficulties *sending text-based messages*, *finding information on the internet* and *understand information on the internet* compared to the reference group, with 20—30% of adolescents with ID stating that they never did these things, compared to 1% of the reference group (p<0.001) (study II).

In addition to the above results from studies I and II, a further analysis of these difficulties with internet use was conducted for this thesis. Here, the adolescents' perceptions of their difficulties (*never do, easy, varies, difficult*) in performing text-based internet activities (study II) were analysed in relation to the parents' perceptions of their adolescent's abilities (*never do, good, neither, bad*) (study III). Table 5 shows similar proportions of parents and adolescents in both groups perceiving that the adolescents

never do text-based internet activities. However, parents were more positive about their adolescents' performance than the adolescents themselves. Table 5 shows that about 15% more parents of adolescents with ID reported their adolescent's abilities as *good*, than adolescents stated it was *easy* to perform the three internet activities.

Table 5. Adolescents' difficulties and parents' perceptions of their adolescents' abilities to perform text-based internet activities

Perceptions of difficulties and *abilities* [a] to perform **text-based internet activities** of adolescents and parents	Adolescents with ID (n=114) %	Reference group of adolescents (n=1161) %		*Parents of adolescents with ID (n=96—99)* %	*Reference group of parents (n=828)* %	
Send messages			*			*
Adolescents & *Parents*: Never do	34	1		*35*	*0*	
Adolescents: Easy/Varies/Difficult	34/21/11	83/12/4				
Parents: Good/Neither/Bad				*48/9/8*	*95/4/1*	
Find information			*			*
Adolescents & *Parents*: Never do	24	1		*20*	*1*	
Adolescents: Easy/Varies/Difficult	37/31/8	90/7/2				
Parents: Good/Neither/Bad				*52/13/15*	*93/5/1*	
Understand information			*			*
Adolescents & *Parents*: Never do	21	0.5		*17*	*1*	
Adolescents: Easy/Varies/Difficult	21/34/24	86.5/10/3				
Parents: Good/Neither/Bad				*34/30/19*	*86/11/2*	

[*]p<0.001
[a] written in italics are the parents' perceptions

Opportunities and risks of using the internet

Opportunities were perceived by a significantly higher proportion of parents of adolescents with ID compared to the reference group, with both the internet (p=0.003) and playing games (p=0.005) being *fun and relaxing for their adolescent*. There was also a significant difference in the opposite direction with a lower proportion of parents of adolescents with ID perceiving that the internet *makes their adolescent learn good things* (p=0.006) (study III).

Concerning risks with negative consequences, a lower proportion of parents of adolescents with ID perceived negative consequences to internet use

and playing games compared to the reference group, with significant differences for both internet use and playing games in *making the adolescent learn bad things* (p=0.001, p=0.010) and *stealing time away from more important activities* (p=0.003, p<0.001) (study III).

Regarding concerns about, and incidents of, online risks, a lower proportion of parents of adolescents with ID had concerns for their adolescents compared with the reference group (study III). For example, a significantly lower proportion of parents of adolescents with ID had concerns about their adolescents being bullied online compared to the reference group (46% vs 63%, p=0.003) (study III). In study II however, a significantly higher proportion of adolescents with ID compared to the reference group stated that they had been bullied on the internet (23% vs 11% p<0.001). The findings of study III showed that a lower proportion of parents in both groups perceived that incidents had occurred, in relation to their concerns. One significant difference was found, with a higher proportion of parents of adolescents with ID (20%) compared to the reference group (11%) stating that their adolescent had *spent so much time on the internet or playing games that the adolescent became socially isolated* (p=0.023) (study III).

Basically, all the parents in both groups perceived themselves as having the primary responsibility to support their adolescents' internet use (study III). Fewer perceived that they received the information and guidance they needed to enable safe internet use for their adolescents, with a significantly lower proportion (37%) of parents of adolescents with ID compared to 51% of parents in the reference group reporting that they did so (p=0.001) (study III).

No confounding was found in opportunities and risks connected with internet use and playing games when controlling for the demographic variables of parents' sex or educational level, or the adolescents' age group. This indicates that the independent variable of having an adolescent with ID answered for the significant differences found (study III).

Strategies to access and use the internet for digital participation

Overall, study I revealed five types of strategy used by the participants with both mild and moderate ID to overcome the challenges and difficulties of handling the digital environment and taking part in internet activities.

These were: *getting support from others,* r*educing and personalising devices,* and *using word-, picture-,* and *voice-based strategies* respectively. The strategy that was most often used, in all the different everyday settings and by adolescents and young adults with both mild and moderate ID, was *getting support from others* to access and use the internet. 'Others' included staff and peers but were most often parents. *Reducing and personalising devices* meant that they preferred to use personal internet-enabled devices were. These were taken between the different everyday settings, e.g. work and home, but not by all participants. Furthermore, not all the devices to which they had access in the different settings were used. Simon, who is 19 years old with moderate ID, changed from a laptop to his own smartphone when he wanted to show a new film clip on You Tube. When asked why he did not use the laptop, he said: "Nah. It's no good. And it's Emma's too [his younger sister]." The personalised devices often had touchscreens organised by the person her-/himself on the start screens, and a few devices were adapted to include assistive devices. *Word-based strategies* were used to enable access to both the devices and content on the internet, for example, notes with codes to unlock devices that were kept close to the devices. Handwritten notes with passwords or correctly spelled search-words were used, as well as written directions on how to reach higher levels when playing games. *Picture-based strategies* were used by participants with difficulties in reading who, for example, searched pictures and videos in the search engines and clicked on them to find what they were looking for. Furthermore, the preferred use of application icons, apps, when starting an internet activity is an example of using a picture-based strategy. Examples of *voice-based strategies* include equipment on the devices such as microphones and voice-controlled programs, although few participants were observed to use them. One reason for not using them was having difficulties with articulating and thereby struggling to get the strategy to work.

DISCUSSION

A lag in digital participation in everyday life

The main findings of this thesis show a lag in internet access and use, and in digital participation in everyday life, among adolescents and young adults with ID. This is demonstrated through lower access to most internet-enabled devices, except tablets, and a lower proportion of adolescents with ID engaging in the surveyed internet activities compared to the reference group, except for playing games (study II and III). This is in line with earlier studies that describe inequalities, including lower access to the internet, for people with ID (Chadwick et al., 2013; Tanis et al., 2012) and specifically low access to devices (Palmer et al., 2012) . This is important because having access has been highlighted as one of the most important aspects of achieving digital participation (Lussier-Desrochers et al., 2017). In a recent literature review on young people with ID and their use of the internet and social media (Borgström et al., 2019), a prevalent digital divide was referred to; however, this was mainly caused by other identified barriers, such as low levels of literacy or lack of adequate support. Based on the included studies it was suggested that young people with ID, aged 11-30 years, had overcome the barrier of access to internet-enabled devices (Borgström et al., 2019). This contrasts with the findings of this thesis, where access to internet-enabled devices, for example smartphones, was not achieved to the same extent as for a reference group of adolescents (study II). This result is, however, in line with Johansson et al. (2020), who report on the presence of a digital divide among adults with disabilities, especially related to cognitive understanding and language difficulties, as people with those difficulties report less access to the internet and greater difficulties in using it than adults with other disabilities. Another factor associated with lower access and lower internet use was the participant having attended a special school (Johansson et al., 2020).

The lag in digital participation found to be prevalent in this thesis reveals itself in the occupational engagement in internet activities. As was found in study III, the parents of adolescents with ID perceive that the time spent in internet activities was lower for adolescents with ID compared with a refence group of parents. This is in line with the one comparative study including people with ID that was found, which showed that adults with ID use the internet less frequently than a comparison group, but play online

games more frequently, especially on their smartphones, than the comparison group (Jenaro et al., 2017). The findings that adolescents with ID use the internet to a high extent for entertainment activities, such as playing games (studies II and III) has been reported elsewhere (Chiner et al., 2017; Ramsten, Martin, Dag, & Hammar, 2018).

The results for adolescents and young adults with ID taking part in internet activities using several strategies (study I), indicate that adolescents and young adults with both mild and moderate ID do perform internet activities (study I), although not to the same extent as adolescents in general (studies II and III). Performing internet activities may be a means to achieve digital participation in everyday life, in line with an occupational perspective (Njelesani et al., 2014) involving the understanding that, while engaged in an activity, experiences can be gained and skills developed, if support to enable this is offered (Larsson-Lund, 2018; Larsson-Lund & Nyman, 2019). Internet use must involve a successful interaction between the person (adolescent and young adults with ID), the environment (access to devices and connections) and the activity (performing internet activities). This indicates that participation in internet activities can be both a means and an end to digital participation, in line with Imms et al. (2017), who describe opportunities for engagement in activities as important both at a personal level and an environmental level for the development of young people with lifelong disabilities, e.g. ID, and for their well-being. Enabling participation in internet activities is also important according to research on adolescents in general and the internet use of today, where a need to engage with the internet to be able to live in the world of today as been described, rather than only using the internet for their own pleasure or social contacts (Livingstone et al., 2017).

The prevalent lag in digital participation in everyday life for the target group will be discussed further below in relation to: i) the impact of the (digital) environment and personal digital competencies, ii) opportunities and risks of using the internet, and iii) digital participation and participatory citizenship in a digitalised society.

Impact of the (digital) environment and digital competencies

Environmental (digital) dimensions

The results demonstrate that adolescents with ID experience difficulties using the internet due to both personal abilities (studies I and II) and environmental challenges (studies I, II, III) and that the latter can differ in different everyday settings (study I). This is in line with research on participation by adolescents and young adults with ID in special school, identified as being both internal, relating to engagement together with the ability to participate, and external, relating to the experience of having the accessibility to participate (Molin, 2004). Environmental digital challenges found were both physical, for example, lacking sustainable internet connections in some everyday settings (study I) or stemmed from the social environment, such as needing support from others to access and use the internet (study I). The environmental challenge of sustainable internet connections has been found in previous research, revealing a need to highlight the complexity of access to the internet in terms of both devices and internet connections, due to factors such as high costs (Johansson et al., 2020; Lussier-Desrochers et al., 2017). Costs can be particularly crucial for young people with ID due to their lower income (Borgström et al., 2019). The results also revealed access to more internet-enabled devices than were used (study I), indicating that too many digital objects in the physical environment can limit access and internet use, as well as too few. This can be explained using the concept of quality aspects considered in the environmental dimensions, according to Taylor and Kielhofner (2017). For example, it is necessary to consider the quality of the cognitive accessibility of spaces and the availability of devices adapted for the person in the physical environment, not just increasing the access to devices. Only a few participants had assistive adaptations on their devices (study I). Differences have previously been found between caregivers' perceptions of access to devices and those of the person with ID themselves, with the caregiver perceiving significantly higher access to computers for the person with ID than the person with ID themselves did (Chiner et al., 2017). One reason for this may be that the individuals with ID include the possibility of using the internet-enabled devices within the concept of access, and because of difficulties with that aspect report lower access to the devices.

Environmental challenges were found for the adolescents and young adults with ID in the occupational environment, with digital challenges to using internet-enabled devices due to codes, passwords and usernames (study I), and using the internet due to the web being inaccessible for people who have text-based difficulties (study II). This may be a hinder within the environment, which affects many aspects of everyday life because internet accessibility is declared important not only for leisure activities, but also for work and education (Eurostats., 2018; UNICEF, 2017). In line with the development of the digitalised society, it could be important from an occupational perspective to highlight the impact of the digital environment as an overarching context that influences the occupational environment, in the same way as cultural, political and economic influences need to be highlighted, according to Taylor and Kielhofner (2017).

Still, the finding that more than half of the participants, 65% of adolescents with ID, have access to devices (study II), indicates that digital objects in the physical environment offer opportunities facilitating internet use, although only a few had adapted devices. The parents constituted parts of the social environment that facilitated internet use, as more parents of adolescents with ID expressed opportunities with the internet, compared to a reference group of parents (study III). These findings indicate that the environmental impact incorporates both opportunities and demands that may facilitate or hinder a person in doing their digital occupations in everyday life (Taylor & Kielhofner, 2017).

Digital competencies

The results of this thesis emphasises that significantly more adolescents with ID than adolescents in the reference group experience difficulties using the internet for text-based internet activities (study II), indicating that their personal levels of literacy are not compatible with the demands of the digital environment for adolescents and young adults with ID. This is demonstrated in the fact that only 20% search for information on the internet compared to 86% in the reference group (study II). This indicates that the digital competency of *information and data literacy*, expressed as one of five important digital competencies necessary to achieve digital participation (Carretero Gomez et al., 2017), is not developed among the target group of this thesis. Individual cognitive deficits affect their literacy skills, and this has proven difficult to overcome when using the internet for adolescents with ID (Borgström et al., 2019; Lussier-Desrochers et al., 2017).

In addition to this, the further analysis of the result in this thesis showed discrepancies between the perceptions of parents and their adolescents with ID about text-based digital competencies (Table 4). Parents seemed to perceive them to be more developed in their adolescents with ID than the adolescents themselves experienced when participating in internet activities (Table 4). This indicates the risk of a lack of suitable support being given for text-based internet use, which would negatively affect the enablement of digital participation for adolescents with ID. Discrepancies have been found to hinder digital participation if targeted support is not given and if the persons providing support have insufficient knowledge of internet technology themselves (Buchholz, Ferm, & Holmgren, 2018; Molin, Sorbring, & Löfgren-Mårtenson, 2019; Ramsten et al., 2019).

Problem-solving is another digital competence that does not seem to be attained for the adolescents with ID. This was shown through the demand from the digital environment to keep up with rapid changes due to updates and, if someone failed, risked coming to a halt in their use of the internet (study I). Handling rapid changes can be a challenge for people with ID due to the difficulties with problem-solving that come with the deficits in intellectual and adaptive functioning (American Psychiatric Association, 2013).

The digital competencies *Internet safety*, meaning for example keeping personal data to oneself (Carretero Gomez et al., 2017) was investigated among adolescents with ID (study II) and their parents (study III). The results show that adolescents with ID show an awareness of risks, and do not reveal personal information to the same extent as a reference group when using the internet (study II). This awareness of online risks among adolescents with ID has been found in earlier studies (Molin, Sorbring, & Löfgren Mårtensson, 2017). However, adolescents with ID had less access to devices such as smartphones (study II), and only half of them spent time using social media (study III), which indicates an ambiguous result with the lower proportions of adolescents with ID revealing personal information online perhaps being due to having less access.

Opportunities and Risks

The results revealed that one of the most frequently used strategies of taking part in internet activities was getting support from others, mostly parents (study I), and this called for surveying and comparing perceptions among parents of the opportunities and risks associated with internet use for their adolescents (study III). Attitudes are expressed as an environmental factor in ICF (WHO, 2001) and the attitudes of others may affect the

opportunities for digital participation for adolescents and young adults with ID. The results demonstrated that, overall, parents of adolescents with ID perceived lower risks and had fewer concerns compared to a reference group of parents. Parents are often the ones providing support, and the results demonstrating that parents of adolescents with ID are more positive about internet use compared to a reference group of parents is an important finding. It is also counterintuitive and does not match previous research, where it has been suggested that factors such as poor insight and difficulty with problem-solving skills put people with ID at greater risk when using the internet (Chadwick, 2019). However, recent studies have revealed that parents state that the opportunities outweigh the risks with the internet (Molin et al., 2019). The results from study III may be related to the parents' perceptions of their adolescent never using smartphones or social media compared with the reference group. This has been highlighted in previous research, i.e. that not having access to internet-enabled devices or digitally participating make the prevalence of risk experiences low according to parents, and difficult to foresee (Chadwick, 2019). Parents of adolescents in general have been shown to have more concerns about online safety related to more time being spent on the internet by the adolescent (Sorbring, 2014). However, adolescents and young adults with ID have the right to take risks and enabling them to do so may be important for increasing their independence, in line with developments during the adolescent period in general (Seale, 2007). Contemporary research suggests building the possible use of a positive risk-taking approach (Borgström et al., 2019; Molin et al., 2019; Seale & Chadwick, 2017) for both parents and staff to overcome the digital lag among adolescents and young adults with ID. This can be developed by focusing on both the opportunities of the internet that were found and managing the risks rather than avoiding them. The results indicate that avoiding risks is done for many adolescents with ID, with about 50% lower use of social media, compared to the reference group. Lacking access to adapted personal devices that is possible for them to handle, and that they are allowed to use, may result in both overprotection by parents and a lack of the support needed by people with ID when searching the internet for new knowledge and information, as suggested in recent research (Salmerón, Fajardo, & Gómez-Puerta, 2019). Furthermore, it may lead to relevant online risks not being experienced. This may have an impact upon the independence of young people with ID, who are rather in need of support in decision-making about how to handle possible risks using the internet (Chadwick & Fullwood, 2018; Chadwick, 2019). Building on this, development of the digital competency of problem-solving (Carretero Gomez et al., 2017) could be encouraged among the target

group, in order to resolve problem situations in digital environments. It can be questioned whether this opportunity is given to adolescents and young adults with ID to the same extent as adolescents and young adults in general, even though parents' perceptions of the risks associated with the internet are lower and more opportunities are foreseen with internet use (study III).

The opportunity of using the internet to learn new things was perceived by fewer parents of adolescents with ID than in the reference group, which may indicate that parents see greater possibilities of the internet than they are yet experiencing for their adolescents (study III). This is in line with other studies which have reported parents describing themselves as being at the forefront of the internet use of their adolescents with ID, compared to other persons giving them support, for example teachers (Löfgren-Mårtenson et al., 2018; Molin et al., 2015; Sorbring et al., 2017) .

Digital participation and participatory citizenship

The everyday settings in which data was collected for this thesis: home, school, work, free time (study I) and leisure time (studies II and III), make up the immediate contexts for the participants. According to Taylor and Kielhofner (2017), these immediate contexts interact further with the higher levels of environmental contexts, both local and global. This indicates that the results found in this study of internet use and digital participation by adolescents and young adults with ID in their immediate everyday lives affect and are affected by aspects of the local and global contexts. The global society, which is increasingly digital today, places demands on the individual to participate digitally in their everyday lives on an immediate and local level. By being a participating individual on the immediate level, one may engage in occupations that affect both the local and global contexts.

The studies in this thesis gave contradictory results for the internet activity *searching for information*, an activity that is important in immediate, local and global contexts. In study I, many participants were observed searching for information using different strategies, such as pictures. However, searching for information revealed one of the largest significant differences between the groups of adolescents, with 80% of adolescents with ID never doing it compared to 14% in the reference group (study II). Finding and

understanding information could be seen as a first step towards participation for people with ID in occupations, including independence to make one's own decisions, based on being well-informed (Goodman, Hurst, & Locke, 2008).

As society uses the internet more and more, the accessibility of digital information for all will also be crucial in order to gain the right to engage in meaningful occupations for the concern of health and well-being of the individual and that of their society (Hammell, 2008, 2015b; UN, 2006). This casts light on the right to occupation that is ensured by access to and use of the internet, regardless of differences or individual impairments. For example, in cognitive rehabilitation after stroke the internet and the use of internet-enabled devices was found to be not only useful but required in order to manage and recreate everyday lives (Gustavsson, Ytterberg, Nabsen Marwaa, Tham, & Guidetti, 2018). The focus on occupational rights, extends to that of social justice, to move beyond the individual approach and assess and adapt people's contexts to allow for doing occupations rather than enhancing the abilities of the individual client (Hammell, 2015a; Nilsson & Townsend, 2014). This is in line with the results of this thesis on internet use, involving aspects of access and the digital environment in conjunction with developing appropriate support to enable digital participation.

The importance of digital participation from an occupational perspective can be understood from Wilcock and Hocking's (2015) definitions of dimensions of occupation and its importance for health and wellbeing, using their concepts of *doing, being, belonging* and *becoming. Doing internet activities* is a necessity for development and well-being in the digitalised everyday life and society of today. Using strategies to overcome difficulties with digital competencies and environmental demands means that adolescents and young adults with ID are performing internet activities to some extent and may in their own time reflect on themselves as *being internet users*, or *not being internet users,* like other adolescents and young adults in society. Through engaging in internet activities adolescents and young adults with ID can develop in the different transitional periods of life through digital participation. This means that opportunities may occur for *belonging to the internet-generation* of adolescents born since 1995 (Livingstone et al., 2017) equally with other adolescents and young adults. However*, belonging to a digitalised society* and not being occupationally deprived of any necessary activities, does not yet seem to have been achieved by adolescents with ID. The digital lag is still prevalent. This

means that adolescents and young adults with ID have not yet *become digital participatory citizens* on equal terms with others in conjunction with acts and laws (SFS, 1993:387; UN, 2006). The findings of this thesis further conclude that an essential prerequisite that needs to be added from an occupational perspective for participation, is access. Having access to the digital environment in everyday life is required for human doings, as has been highlighted by others (Swedish Agency for Participation, 2017).

Bringing participatory citizenship into focus as an outcome would mean an increased emphasis on the environmental demands of the local and global environmental dimensions, rather than focusing on personal factors and deficits (Fransen, Pollard, Kantartzis, & Viana-Moldes, 2015). This is in line with an occupational perspective and the social disability model, which acknowledges the importance of the occupation taking place in an environmental context that influences it, even more so than individual impairments (Hocking, 2020; Oliver, 2013). Furthermore, the social disability model has suggested the need to include a more apparent rights perspective (Berghs, Atkin, Hatton, & Thomas, 2019). The same applies for occupational rights debates, having attracted critics of occupational therapy, but for being too individually focused with little reference to human rights, and occupational rights and equality of opportunity (Hammell, 2015a). Nevertheless, it has been suggested by Imms et al. (2017) that participation restrictions can be solved only by addressing both environmental demands at the level of society, and personal disabilities at the level of body structure and functions of the ICF . This is in line with the results of this thesis. It is essential to have knowledge of the personal disabilities, and to acknowledge them to be aware of the digital competencies or lack thereof. Furthermore, the environmental demands that arise, can be possible to overcome using universal design, together with appropriate individual adaptations of the digital environment. Bringing these together can enable digital participation in everyday life, by enhancing both the abilities and possibilities to be participatory citizens in the digitalised society.

METHODOLOGICAL CONSIDERATIONS

At the launch of this thesis project in 2014, there had been very few studies conducted on internet use among people with ID. The starting point was therefore qualitative data collection with purposeful sampling to gain an information-rich set of data (Patton, 2015). This knowledge was essential for the implementation of the cognitive adaptations of the easy-read survey (study II); for example, when selecting the questions in the first step of adaptations of the national survey that enabled comparative analysis.

However, there are methodological limitations that need to be considered. When conducting research that include people with ID, adaptations of data collection methods are needed, as their cognitive limitations need to be overcome to enable participation. This requires extra notions to be added to the quality criteria of the research (Sigstad, 2014). Quality principles are trustworthiness for qualitative studies (Denzin & Lincoln, 2018; Patton, 2015) and validity and reliability for quantitative studies (Polit & Beck, 2016). It is also important to consider aspects of generalisation of the findings of quantitative studies, in order not to over- or underestimate the generalisability of the findings (Polit & Beck, 2016).

Study I

For the qualitative study, the preunderstanding and previous experience of the author of this thesis were important for gaining access to the natural everyday settings. This preunderstanding required constant reflexivity when conducting observational studies in naturalistic settings. This means reflecting about oneself, and what you bring into the observation and analysis process (Patton, 2015). The preunderstanding of the author of this thesis may have led to follow-up questions that were not asked, because the answers seemed obvious to the author, and therefore information might have been missed. However, the lack of preunderstanding regarding the internet probably led the author to ask more probing questions. How to express these probing questions was thoroughly considered because people with ID may answer in acquiescence (Finlay & Lyons, 2001). Although the reflexivity was a continuous process, with support from the research group, the preunderstanding may have affected what was written in the field notes during observations, especially early in the data-collection process. It may

also have influenced what was emphasised in the analysis process. However, having field notes, audio-recordings and photographs taken during the observations became a way of triangulating the data (Patton, 2015) and increasing its dependability (Denzin & Lincoln, 2018). Furthermore, during the follow-up interviews, open questions related to the aim of the study and the findings during observations were asked. These related to the photographs that were taken. This probably increased the credibility of the findings (Denzin & Lincoln, 2018). In addition, the inductive content analysis (Patton, 2015) was useful when analysing the data, because it should be driven by the aim of the study and stay close to the transcribed text during the analysis process. This supported the author in avoiding getting caught in the preunderstanding.

The purposeful sampling technique (Patton, 2015) with the inclusion criterion of using the internet to some extent, led to participants with ID who in different ways were experienced internet users. This needs to be kept in mind when transferring the results to other settings or the population at large. This was a conscious choice of sampling technique in relation to the aim of the study.

Study II

By cognitively adapting the national survey "Kids and Media" (Swedish Media Council, 2017b) into an easy-read paper and web-based version via several steps, the participation of adolescents with ID was enabled and comparison possible with an age-appropriate reference group of adolescents. The original survey had been tested for measurement technology, for example, for understanding the wordings of questions, but not for psychometric properties, which can be considered a limitation. However, it has been used biannually since 2005 and the questions have been revised following reliability and to increase the response rate. Furthermore, the cognitively adapted easy-read survey, which was answered by the adolescents with ID, gave a high overall internal consistency score of α=.84, on Cronbach's alpha.

The adaptation of the survey into the easy-read version, involved excluding questions from the original survey, and this may be considered a limitation, questioning the validity and whether the same underlying concepts are being measured (Polit & Beck, 2016). However, the thorough comparisons made were on a question-by-question basis and the questions were chosen in cooperation with experts from the Swedish Media Council together with the research team, as well as researchers and practitioners in occupational

therapy to ensure the validity related to the aim. It cannot be denied that changing questions to be more concrete may mean that some dimensions were excluded. However, the adaptation of the survey with support from references (Finlay & Lyons, 2001; Hartley & MacLean, 2006; Oschwald et al., 2014) and the pilot testing with representatives from the target group were efforts that was possible to make in order to use the survey in line with the aim of the study (II), even though some dimensions had to be deleted from the original survey.

In relation to the adaptations made, 75% of the adolescents with ID reported that they answered the survey together with someone. This may be considered a limitation, because it is not known how much this other person was involved in answering the questions. It may be that some only supported the logging in to the survey, as the author of this thesis did as a support person, but some may have been more involved in responding to the questions.

The sampling procedure was thoroughly discussed with a statistician because there are no available registers of adolescents with ID in Sweden. The strategic sampling technique (Polit & Beck, 2016) was considered relevant to strategically sample municipalities that differ in size and number of special schools. From the special schools, a selection was made of the total population of pupils, which included pupils of different severity levels of ID. However, it is likely that most participants have mild or moderate ID, because even pictures may be too abstract for adolescents with severe ID (American Psychiatric Association, 2013).

Study III

The original survey "Parents and Media"(Swedish Media Council, 2017a), which was used for both parental groups, with four additional questions for parents of adolescents with ID, had not been tested for psychometric measures, which is a limitation. However, the questions have been adjusted since the first survey in 2010, in line with measurement technology. The reliability of the survey answered by the parents of adolescents with ID was tested and high internal consistency was reached of α=.98, which is perhaps too high. Indicating that some questions were repetitive (Field, 2018). This may be a limitation, and may have contributed to the somewhat low response rate among the parents of adolescents with ID.

What may have contributed further to the low response rate is that the survey package that was sent out addressed to the parents of adolescents with

ID contained both the survey for the parent and the paper version of the survey for the adolescent, with two information letters. This may have put many constraints on the parents and may be one reason for the high number of parents with higher education participating in the parental survey, because a lot of information was included in the survey package. This may affect the results.

PRACTICAL IMPLICATIONS

The findings of this thesis have described access to and use of the internet among adolescents and young adults with ID in their everyday lives, and a lag in digital participation by the target group has been found. Descriptive knowledge about occupations in everyday life is of enormous importance because it gives a broad picture of people's activities in different contexts and is the foundation upon which all practice is built (Pierce, 2012).

Governmental agencies engaged in population-based studies should find the cognitive adaptations in the easy-read survey of great importance and very useful. This survey proves that people with ID, or other cognitive limitations, can participate in large-scale survey studies when adaptations are made of them.

For adolescents and young adults with ID, overcoming the prevalent lag of digital participation can be important as they seek to become participatory citizens in the digitalised society of today on equal terms with others. Based on the findings of this thesis, increased access can be achieved, through fewer but more adequate personally adapted internet-enabled devices with sustainable internet connections. Furthermore, use of the internet and participation in internet activities can be facilitated through word- picture- and voice-based strategies, combined with support from others.

Parents often provide this support, and the results demonstrating that parents of adolescents with ID are more positive towards internet use than a reference group of parents, is an important finding upon which to build the possible use of a positive risk-taking approach. This approach can be developed to manage the risks rather than avoiding them by restraining access to internet-enabled devices or internet activities. An example would be using guidance in independent choices and problem-solving aspects.

Occupational therapists or teachers, together with other staff, such as staff in community-based services, could provide the support needed when the young individual with ID uses the internet in cooperation with their parents. In addition, internet-based interventions could be provided to enable the development of digital competencies among adolescents and young adults with ID, once the demands of the digital environment are facilitated.

For professionals who work with people with ID, for example, in occupational therapy, psychology, social work, caring, nursing and medicine, it is important to acknowledge the lag in digital participation, and the effects this may have on participation in areas such as health care or social services for adolescents and young adults with ID. Compensating for the personal intellectual disabilities of the target group with digital adaptations in the physical and digital environment, along with further adaptations in policies and regulations, may be needed.

Theoretical implications for occupational therapy could include the need to more evidently emphasise digital environmental dimensions in the future, as there seems to be little recognition of this in current theoretical frameworks.

FUTURE STUDIES

In future studies that focus on enabling digital participation for adolescents and young adults with ID in everyday life, wider societal contexts, both local and global, would preferably be included. Based on the involvement of adolescents with ID, who pilot-tested the easy-read survey in this thesis, future studies would be likely to benefit from greater involvement by the target group in the whole research process. This could be achieved using a participatory design, planning the research design with the intended target group, which has proven plausible with young people with ID (Beighton et al., 2019; St John, Mihaila, Dorrance, DaWalt, & Ausderau, 2018) and is done with adolescents in general in internet-based life-style interventions (Müssener, Bendtsen, Bendtsen, & Löf, 2020).

The results of the studies in this thesis indicate that adaptations of the digital environment are needed. In order to comprehend the usability of the internet for adolescents and young adults with different levels of ID, universal design aspects could be included (Swedish Agency for Participation, 2017). The studies could be implemented in an interdisciplinary manner, focusing on adaptations of internet-enabled devices, user interfaces, and web accessibility, with simpler web-sites, navigation using pictures or voice-based support, and including the digital competencies of adolescents and young adults with ID and the support they need.

Designing longitudinal studies to investigate digital participation as a process for adolescents with ID when transitioning into adulthood and beyond, in the digitalised society, would be of significant value. It could be important in these studies to include support from others, which was shown to be important in this thesis, and what will happen when adolescents with ID who use the internet to a high extent today move into group homes.

CONCLUSIONS

The overall conclusion of this thesis is that a lag is prevalent in the digital participation of adolescents and young adults with ID in everyday life in comparison with a reference group. This lag is due to environmental challenges, such as lower access to personal internet-enabled devices, and to less developed personal digital competencies, such as problem-solving and information and data literacy, among adolescents and young adults with ID. This means that the demands of the digital environment, i.e. the environmental opportunities to participate digitally, are not in line with the personal abilities to do so of adolescents and young adults with ID. The impact of the environment interacts with the difficulties in developing digital competencies due to limited cognitive abilities. This result highlights the need for environmental support for adolescents and young adults with ID in the digital, physical, and social environment. In relation to social environment, the findings show that the parents of adolescents with ID are more positive about their adolescents' use of the internet than a reference group of parents, seeing fewer negative consequences and having fewer concerns about online risks for their adolescents. These findings provide deeper knowledge about digital participation and both call for and give examples of steps to reach participatory citizenship for adolescents and young adults with ID. From an occupational perspective, this is important for health and well-being in a digitalised society.

The collection of data from adolescents and young adults with ID themselves, using observations, follow-up interviews and a cognitively adapted national survey into an easy-read version, with picture support for those who needed it, show that inclusion in large-scale research is possible for this target group. It is recommended that this methodological knowledge be used in future studies to increase the involvement of people with ID in research on matters concerning their own everyday lives.

By describing the unequal access and use of the internet, recognising both the opportunities and risks involved, and the perceptions of people providing the support needed, the knowledge gathered in this thesis can contribute to the digital participation of a group of people who are often marginalised from society. With increased environmental support the possible use of a positive risk-taking approach by professionals and people supporting adolescents and young adults with ID to use the internet and participate digitally is suggested.

LÄTTLÄST SAMMANFATTNING

Hur unga med IF använder internet

Den här kunskapen om unga och internet

kommer från ny forskning.

I forskningen har ungdomar och föräldrar deltagit.

De har visat och berättat hur de använder internet.

Ungdomarna som deltog var mellan 13 och 25 år gamla.

I den här texten kallas de för unga med IF.

IF betyder intellektuell funktionsnedsättning

eller utvecklingsstörning.

De flesta spelar spel på internet

Unga med IF använder internet ganska mycket

i sin vardag.

Det vanligaste sättet att använda internet

är att spela spel.

Unga med IF spelar mer än andra ungdomar.

De flesta unga med IF använder mest
smartphone eller surfplattor.

En del tar hjälp av olika stöd på internet,
till exempel bildstöd eller att få text uppläst.

Många unga tycker ändå att tekniken är svår

Många unga med IF tycker samtidigt att det är svårt
att använda internet och olika sorters teknik.
Till exempel är unga med IF ofta inte med
på sociala medier, som Instagram.

Unga med IF använder inte smartphone eller dator
lika mycket som unga utan funktionsnedsättning.

Unga med IF är sammanlagt kortare tid på internet
än andra.
Och det är vanligt att de måste fråga någon annan
om hjälp med tekniken.

Föräldrarna tycker att spel och internet är bra

Många föräldrar till unga med IF tycker det är bra
att deras barn använder internet.
De tänker att unga med IF lär sig mycket
av att spela spel.

Föräldrarna är inte så oroliga för att det
kan finnas risker med internet.
De är mycket mindre oroliga jämfört med
föräldrar som har barn utan IF.

Unga med IF kan få mer tillgång till internet och bli mer delaktiga

Det finns möjligheter att skapa nya stöd
som gör det enklare att använda internet.
Det är bra att många föräldrar tycker att
internet är bra för unga med IF.
Då kan nya stöd utvecklas i samarbete mellan
unga med IF, deras föräldrar och personal.

I samhället idag är det viktigt
att kunna använda internet i vardagen.
Om unga med IF får mer tillgång till internet,
kan de bli mer delaktiga i hela samhället.

Mer om forskningen

Jag som har forskat och skrivit den här boken
heter Kristin Alfredsson Ågren.
Jag jobbar på Linköpings universitet.

Kristin Alfredsson Ågren

Förut fanns inte så mycket kunskap om
hur unga med IF använder internet.
Därför valde jag att forska om det.

När vi får ny kunskap, så kan människor
komma på nya lösningar.

Så här gick forskningen till:
Jag tittade på när 15 unga med IF
använde internet i skolan, på jobbet och hemma.
Jag intervjuade dem också om internet.

Sedan skickade jag enkäter med frågor
till unga elever på 11 olika särskolor i Sverige.

Jag skickade enkäter till mer än 300
unga med IF och deras föräldrar.

Frågorna handlade om hur de unga
använde internet på fritiden.

Frågorna handlade också om vad föräldrarna tyckte
om internet.

De unga som deltog hade olika grader av IF.

I den här boken har jag sammanfattat
resultatet av alla svar.

I min forskning hade jag två handledare.
Tack till er, Helena och Anette.

SAMMANFATTNING MED BILDSTÖD

Hur unga med IF använder internet
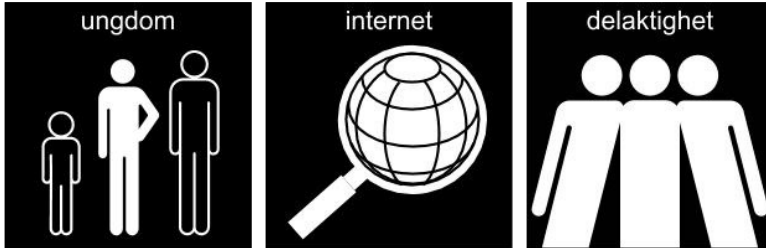
Ungdomar med intellektuell funktionsnedsättning

använder internet ganska mycket.
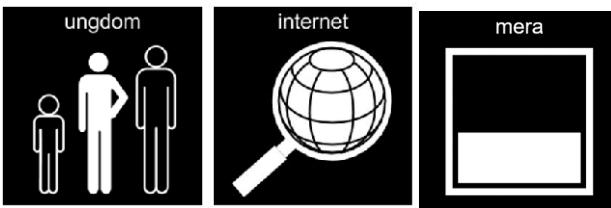
Många av dem spelar spel på internet.

Det vanligaste sättet att använda internet
är på mobil eller surfplatta.
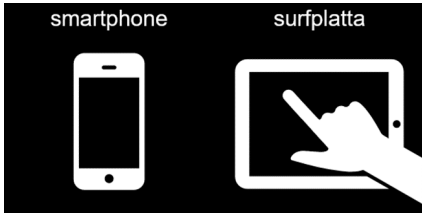
Men många tycker fortfarande att det är svårt
att använda internet för att till exempel
leta efter ny information.
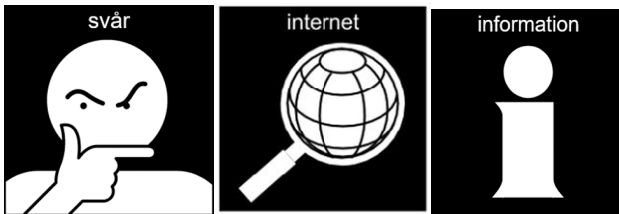
Unga med IF kan få mer stöd
och bli mer delaktiga

Det behövs stöd.

Ungdomar, föräldrar och personal kan tillsammans

skapa stöd som gör det enklare att använda internet.
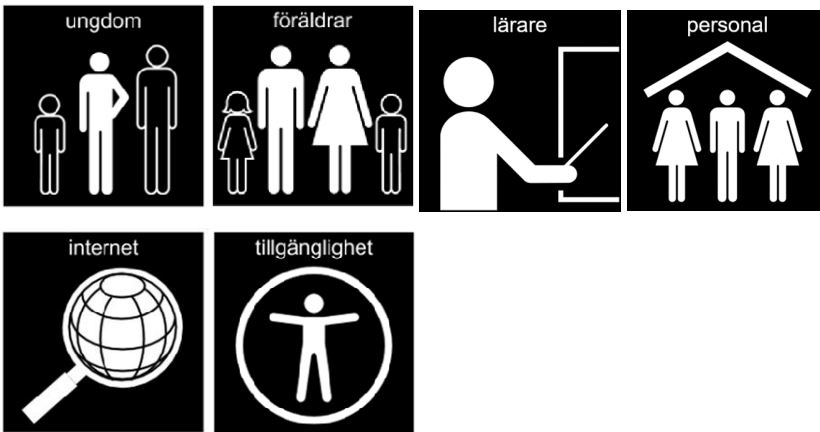
Då kan ungdomar

med intellektuell funktionsnedsättning

bli mer delaktiga i samhället.
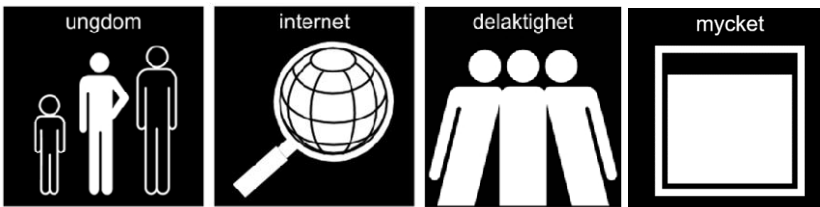
ACKNOWLEDGEMENTS

It feels so good to finally get to write the acknowledgements! What a privilege to be able to say THANK YOU in an open way to so many people.

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APPENDIX

The easy-read survey (Study II):

LINKÖPINGS UNIVERSITET   Statens medieråd   Kod:_____

November 2016

Frågor om internet till dig som är ungdom i särskolan
Det är flera delar med frågor.
Du ska välja mellan olika svar.
Välj det svar som passar för dig.
Sätt kryss i rutan före det svaret.
Det finns inget rätt eller fel, och du kan hoppa över en fråga.
Det är viktigt att du svarar det <u>du</u> tycker.

Frågor om dig	
1. Är du pojke eller flicka?	☐ Pojke ☐ Flicka
2. Hur många år är du?	☐13 -14 ☐15-16 ☐17-18 ☐19-20
3. Bor du med både mamma och pappa?	☐ Ja ☐ Ibland mamma, ibland pappa ☐ Nej, bara en ☐ Bor själv
4. Har du syskon?	☐Ja ☐Nej
5. Vilket språk pratar ni hemma hos dig?	☐ Svenska ☐ Annat språk ☐ Både svenska och annat språk
Frågor om du har mobil, surfplatta eller dator hemma eller inte	

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6. Har du en egen mobil med appar?	☐ Ja, en egen ☐ Nej, delar med andra ☐ Har ingen
7. Har du en egen knappmobil?	☐ Ja, en egen ☐ Nej, delar med andra ☐ Har ingen
8. Har du en egen platta, exempelvis Ipad?	☐ Ja, en egen ☐ Nej, delar med andra ☐ Har ingen
9. Har du en egen dator?	☐ Ja, en egen ☐ Nej, delar med andra ☐ Har ingen
10. Har du en egen TV?	☐ Ja, en egen ☐ Nej, delar med andra ☐ Har ingen
11. Har du eget Xbox, Playstation eller Wii?	☐ Ja, ett eget ☐ Nej, delar med andra ☐ Har ingen
12. Hur fungerar det för dig att använda mobil?	

	☐ Lätt
	☐ Ganska lätt
	☐ Ganska svårt
Om du har svarat Använder inte svarar du också på fråga 12 a,b,c nedan. Annars svarar du på fråga 13.	☐ Svårt
	☐ Använder inte
12 a Vill du använda mobil?	
	☐ Ja
	☐ Nej
	☐ Vet inte
12 b Kan du använda mobil?	
	☐ Ja
	☐ Nej
	☐ Vet inte
12 c Får du använda mobil?	
	☐ Ja
	☐ Nej
	☐ Vet inte
13. Hur fungerar det för dig att använda platta exempelvis Ipad?	☐ Lätt
	☐ Ganska lätt
	☐ Ganska svårt
	☐ Svårt
	☐ Använder inte
Om du har svarat Använder inte svarar du också på fråga 13 a,b,c nedan. Annars svarar du på fråga 14.	
13 a Vill du använda platta?	☐ Ja
	☐ Nej
	☐ Vet inte
13 b Kan du använda platta?	
	☐ Ja

13 c Får du använda platta?	☐ Nej ☐ Vet inte ☐ Ja ☐ Nej ☐ Vet inte
14. Hur fungerar det för dig att använda da-tor? Om du har svarat Använder inte svarar du också på fråga 14 a,b,c nedan. Annars går du till fråga 15.	☐ Lätt ☐ Ganska lätt ☐ Ganska svårt ☐ Svårt ☐ Använder inte
14 a Vill du använda dator?	☐ Ja ☐ Nej ☐ Vet inte
14 b Kan du använda dator?	☐ Ja ☐ Nej ☐ Vet inte
14 c Får du använda dator?	☐ Ja ☐ Nej ☐ Vet inte

Frågor om du använder internet eller gör andra saker hemma.	
15. Brukar du sporta och träna?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig
16. Brukar du läsa böcker och tidningar?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig
17. Brukar du titta på film eller TV-program?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig
18. Brukar du titta på Tv-nyheter eller läsa nyhetstidningar?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig
19. Brukar du träffa kompisar hemma eller ute?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig
20. Brukar du använda mobilen?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig

21. Tittar du på TV-program eller film på nätet exempelvis SVT Play?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig
22. Tittar du på filmklipp exempelvis på YouTube?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig
23. Gör du egna bilder/filmer med mobilen, plattan, datorn?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig
24. Köper du saker på nätet med mobil, platta, dator?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig
25. Tittar du på porr på nätet på mobilen, plattan, datorn?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig
26. Lyssnar du på musik på nätet på mobil, platta, dator?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig
27. Spelar du spel på mobil, platta, dator?	☐Varje dag ☐Varje vecka

	☐Ibland ☐Aldrig
28. Spelar du om riktiga pengar på nätet?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig
29. Söker du efter ny kunskap och information på nätet?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig
30. Har du kontakt med kompisar via nätet till exempel Snapchat, Instagram, KiK, Facebook?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig
31. Ringer du videosamtal på nätet exempelvis Skype eller Facetime?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig
32. Använder du karta och GPS i mobilen via nätet?	☐Varje dag ☐Varje vecka ☐Ibland ☐Aldrig
33. Hur mycket tycker du att du använder nätet på mobilen, plattan, datorn?	☐ För mycket ☐ Lagom ☐ För lite

Frågor om vad du tycker om internet och det du gör där	
34. Har någon varit dum mot dig på mobilen eller via nätet?	☐ Ja ☐ Ibland ☐ Nej
35. Pratar du med någon vuxen om saker du sett på mobilen eller nätet?	☐ Varje dag ☐ Varje vecka ☐ Ibland ☐ Aldrig
36. Pratar du med någon vuxen om datorspel du har spelat?	☐ Varje dag ☐ Varje vecka ☐ Ibland ☐ Aldrig
37. Vem bestämmer vad du får göra på mobilen, plattan, datorn?	☐ Jag själv ☐ Jag och förälder/vuxna ☐ Förälder/vuxna
38. Visar du bild på dig själv på nätet på mobilen, plattan, datorn?	☐ Alltid ☐ Ibland ☐ Aldrig
39. Skriver du ut ditt riktiga namn på nätet på mobilen, plattan, datorn?	☐ Alltid ☐ Ibland ☐ Aldrig
40. Visar du vilken skola du går i på nätet på mobilen, plattan, datorn?	☐ Alltid ☐ Ibland ☐ Aldrig

41. Hur är det för dig att skicka meddelanden exempelvis sms, mail?	☐ Enkelt ☐ Olika ☐ Svårt ☐ Gör aldrig
42. Hur är det för dig att hitta information på nätet på mobilen, plattan, datorn?	☐ Enkelt ☐ Olika ☐ Svårt ☐ Gör aldrig
43. Hur är det för dig att förstå information på nätet?	☐ Enkelt ☐ Olika ☐ Svårt ☐ Gör aldrig
44. Behöver du hjälp av någon för att gå ut på nätet?	☐ Ja ☐ Ibland ☐ Nej
45. Hur har du fyllt i frågorna?	☐ Ensam ☐ Tillsammans med någon
Tack för att du har svarat på frågorna!	

Papers

The papers associated with this thesis have been removed for copyright reasons. For more details about these see:

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