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**ICT AND PARTICIPATION  
IN SCHOOL AND OUTSIDE SCHOOL ACTIVITIES  
FOR CHILDREN AND YOUTHS  
WITH PHYSICAL DISABILITIES**

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“Not every child has an equal talent or an equal ability or equal motivation;  
but children have the equal right to develop their talent,  
their ability, and their motivation.” (J F Kennedy)

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# ABSTRACT

The general aim was to investigate the use of Information and Communication Technology (ICT) and participation in computer activities in school and outside school among children and youth with physical disabilities (age 8-19 years), in comparison to children and youth in general. In particular the aim was to gain knowledge about the use of and satisfaction with computer-based assistive technology devices (ATDs) in school and outside school among children with physical disabilities.

**Study I** investigated the use and non-use of ATDs in school by children with physical disabilities and described the children's experiences of using these devices. **Study II** investigated the outside school activity patterns of children with physical disabilities, and specifically their ICT usage compared with non-disabled children. It also aimed to investigate the children's opinions of computer use and the associations between their use of the Internet and their interaction with peers. **Study III** examined the prevalence of children with physical disabilities using a computer-based ATD, and investigated differences in the satisfaction of children and youths with disabilities who used or did not use computer-based ATDs in the application of computers for in school and outside school activities. **Study IV** determined the ICT use in school activities of two groups of children with physical disabilities comprising those who do and those who do not use a computer-based ATD, and compared them with children from the general population. In addition, positive factors associated with in-school computer use were identified for children with physical disabilities.

The findings in **Study I** showed it is important that devices are integrated into educational practice and that children must experience the immediate benefits of ATD use for their function in everyday school activities without detrimental effects on their social participation if they are to use the devices provided. The latter was often more important than being able to perform activities independently. **Study II** showed two sets of activity patterns, depending on whether the child was disabled or not and on gender. Proportionally more children with physical disabilities were engaged in ICT-activities, while non-disabled children tended to be engaged in a broader range of activities outside school. The activity pattern was more uniform for boys and girls with disabilities than for their non-disabled peers. Use of the Internet was positively associated with peer interaction outside school. In **Study III** the prevalence of using computer-based ATDs was about 44% among children with physical disabilities, and many were dissatisfied with the service around their ATDs. These children were less satisfied with their computer use in education and outside school activities than the children who did not use an ATD. **Study IV** showed that children with physical disabilities used the computer for less varied educational activities than children in general. Attending mainstream school, the children's age (notably, being 16-18 yrs old), their frequent computer usage, and the teachers' frequent computer usage increased the participation of children with physical disabilities in computer-based activities.

The findings of this thesis have contributed with new knowledge to participation, use of ICT and ATDs of children with physical disabilities in activities in school and outside school. In conclusion, the activity pattern outside school in children with physical disabilities is more varied than earlier research studying ICT-activities has shown. Digital skills (knowledge in using the computer and the Internet) developed outside school engage children with disabilities, giving them increased access to social interactions, and for educational purposes. Therefore, it is discouraging when schools do not provide children with disabilities with opportunities to fully exploit their digital skills in school, when these children participate in a less diverse range of computer activities in comparison with children in general. Children with physical disabilities are not always satisfied with their use of ATDs provided, and the choice to use or not to use an ATD is not only the child's decision. This is an ethical dilemma when children both use ATDs they do not want to use, but also do not use ATDs they want to use. Computer-based ATDs need to be highlighted as an intervention in participation in everyday activities for children with disabilities. However, those children are not satisfied with the use and service of their computer-based ATDs in and outside school. These results can be used as a basis for prioritising and developing support for the optimal use of ICT and ATDs in school and outside school of children with physical disabilities.

Keywords: assistive technology devices, disabled children, education, leisure, occupational therapy, self-help devices

## SAMMANFATTNING PÅ SVENSKA

Informations- och kommunikationsteknologin (IKT) har idag en självklar plats i de flesta barns och ungdomars vardag. Detta doktorandprojekt har därför, utifrån ett barnperspektiv, undersökt om barn och ungdomar med rörelsehinder är delaktiga i datoraktiviteter i skolan och på fritiden i samma omfattning som barn i allmänhet. Ett särskilt fokus har varit att undersöka tillgången till datorhjälpmedel och hur nöjda barnen och ungdomarna var med sin datoranvändning.

I den första studien undersöktes vilka hjälpmedel barn och ungdomar med rörelsehinder hade förskrivna till sig (n=20), vilka av dessa hjälpmedel de använde respektive inte använde i skolan samt deras uppfattning av att använda hjälpmedlen. Det var särskilt betydelsefullt att ta reda på vad som karakteriserade de hjälpmedel som de ville använda och som de tyckte underlättade deras delaktighet i skolan. Det framkom att barnen och ungdomarna hade flera hjälpmedel förskrivna som de inte använde och inte heller ville använda i skolan. Resultatet indikerade att de valde bort hjälpmedel som påverkade deras identitet eller relation med kamrater negativt, framför möjligheten att kunna vara mer självständiga med stöd av hjälpmedlet. Det belyser att hjälpmedel väljs både utifrån ett funktionellt och ett psyko-socialt perspektiv. Denna kunskap behöver exempelvis arbetsterapeuter beakta vid förskrivning av hjälpmedel till barn och ungdomar med rörelsehinder.

I studie två fokuserades på barnens och ungdomarnas aktivitetsmönster, deras tillgång till IKT och hur de använde IKT på fritiden. Dessutom undersöktes deras synpunkter på dator och Internetanvändning samt sambandet mellan online-kommunikation via Internet och att träffa kamrater på fritiden. Studiegrupperna var pojkar och flickor med (n=215) och utan rörelsehinder (n=1379). Resultatet visade att aktivitetsmönstret på fritiden såg olika ut beroende på om barnen hade ett rörelsehinder eller inte och av kön. Fler pojkar och flickor med rörelsehinder ägnade sig åt IKT-aktiviteter på fritiden, dessutom var deras aktivitetsmönster var mer jämlikt, i jämförelse med pojkars och flickors i allmänhet. Barn och ungdomar utan rörelsehinder hade dock en bredare aktivitetsrepertoar på fritiden än barn med rörelsehinder. Att använda Internet som ett socialt media hade ett positivt samband med att träffa kamrater på fritiden. Slutsatsen är att IKT-aktiviteter har en bred variation vilket innebär att de kan passa för många och så även för barn och ungdomar med

rörelsehinder. Dessutom kan goda digitala kunskaper ge förutsättningar för utveckling och lärande i skolan, och i samhället i stort.

I studie tre undersöktes prevalensen av barn och ungdomar med rörelsehinder (n=287) som använde ett datorhjälpmedel (dator, styrsätt och speciell programvara). Fokus var också på skillnader i användning och nöjdhet med dator i skolan och på fritiden bland de som använde respektive inte använde ett datorhjälpmedel. Resultatet visade att 44% av barnen och ungdomarna använde ett datorhjälpmedel i skolan. Generellt var dessa barn mindre nöjda med sin datoranvändning och flera ville använda dator oftare och till fler aktiviteter, både på fritiden och i skolan, än de som inte använde ett hjälpmedel. Barnen som använde ett datorhjälpmedel var dessutom missnöjda med servicen kring sina hjälpmedel. Flera av hjälpmedlen, såsom styrsätt och speciell programvara, använde barnen och ungdomarna dessutom mer på fritiden än i skolan. Slutsatsen är att barn med rörelsehinder som använder ett datorhjälpmedel är mer nöjda med sin datoranvändning på fritiden än i skolan. Samordningen kring förskrivning av datorhjälpmedel till hemmet och skolan behöver därför ses över. Hemmet skulle kanske också i högre utsträckning kunna fungera som en arena för träning med dator och datorhjälpmedel, för att barnen och ungdomarna ska få möjlighet att vara delaktiga i de datoraktiviteter de har behov av, önskar eller förväntas göra både i skolan och på fritiden.

I den sista studien i avhandlingen undersöktes och jämfördes användning av IKT i skolan bland barn och ungdomar med rörelsehinder (n=287), de som använde och de som inte använde ett datorhjälpmedel, och en grupp barn och ungdomar utan rörelsehinder (n=940). Dessutom identifierades faktorer associerade med delaktighet i varierade datoraktiviteter i skolan för barn och ungdomar med rörelsehinder. Resultatet visade att barn och ungdomar med rörelsehinder deltog i ett mindre varierat utbud av datoraktiviteter i skolan än de utan rörelsehinder. Att gå i vanlig grundskola, vara i åldern 16-18 år, att själv använda dator samt ha en lärare som ofta använde dator i undervisningen visade sig vara faktorer som hade ett samband med delaktighet i datoraktiviteter i skolan för barn och ungdomar med rörelsehinder. Slutsatsen är att barn och ungdomar med rörelsehinder har en begränsad delaktighet i datoraktiviteter i skolan jämfört med barn och ungdomar utan rörelsehinder. Därför bör en individuell plan, med kontinuerlig uppföljning, upprättas där målet är att varje barn och ungdom med rörelsehinder ska ha möjlighet att använda dator och datorhjälpmedel i skolan för att kunna tillgodogöra sig undervisningen, i samma omfattning som klasskamraterna.

## LIST OF PUBLICATIONS

This thesis is based on the following publications, referred to in the text by their roman numerals:

- I. Hemmingsson, H., Lidström, H., & Nygård, L. (2008). Use of Assistive Technology Devices in mainstream schools; students' perspective. *American Journal of Occupational Therapy*, 63 (4), 463-472.
  
- II. Lidström, H., Ahlsten, G., & Hemmingsson, H. (2011). The influence of ICT on the activity patterns of children with physical disabilities outside school. *Child: care, health and development*, 37 (3), 313-321.
  
- III. Lidström, H., Almqvist, L., & Hemmingsson, H. Computer-based assistive technology device for use by children with physical disabilities: A cross-sectional study. Submitted.
  
- IV. Lidström, H., Granlund, M., & Hemmingsson, H. Use of ICT in school: A comparison between students with and without physical disabilities. Submitted.

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## LIST OF ABBREVIATIONS

ANOVA	Analysis of variance
ATD	Assistive Technology Device
HC	Habilitation centre
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health: Children & Youth version
ICT	Information and Communication Technology
MoHO	Model of Human Occupation
OT	Occupational Therapy/Occupational Therapist
WHO	World Health Organization



# INTRODUCTION

## CHILDREN WITH PHYSICAL DISABILITIES – a part of the digital generation

The increased use of information and communication technology (ICT) i.e., "technology for collecting, storing, processing, recovering and communication of data, text, images and talk" (Statistics Sweden, 2009, p. 104) has shaped the "digital generation". Children and young adults embrace new information technologies in large numbers more than any other age group, and use computers and the Internet widely for many of their daily activities (NTIA, 2002). High access to computers and the Internet are explanations as to why Swedes are among the most connected people in the world (ITU:2008). Today, parents of young children are habituated Internet users and their children grow up with computers and the Internet as an integral part of their home just like television. Already half of all four year olds in Sweden use the Internet (Findahl, 2009) and this trend is likely to increase. This means that Swedish children and youths have good opportunities to use computers at home, e.g., to play games, in school work and to reach the whole world via the Internet and links to trade, communication and culture. Additionally, social media (i.e., instant messaging, communities, chat groups, blogs) is the sector of application which is the growing fastest on the Internet (Nordicom, 2009; Notley, 2009).

ICT has also a documented potential to enhance learning and is known to be of value as an educational tool, for example in activities such as word-processing, e-mailing, making presentations and knowledge acquisition on the Internet (Fredriksson, Gajek, & Jedeskog, 2009; Hakkarainen et al., 2000; Ilomäki & Rantanen, 2007; Watson, 2001).

From an equality perspective is it important that the opportunities ICT offers at home, in education and in the society in general may be available to all children and youths whether they have a physical disability or not. Swedish and international school regulations and "Conventions on the rights of the children" (SFS 2010:801; UNESCO, 1994; United Nations, 1989, 2008) are some documents that stress disabled children's inclusion in everyday activities in different contexts, e.g. the provision of opportunities to use assistive technology devices (ATDs). Moreover, it is

documented that the mainstream developments in ICT have influenced the development of ATDs (wheelchairs, communication aids, interactive whiteboards) in general and computer-based ATDs (computers, computer input interfaces and special educational software) in particular (Koos van Woerden, 2006). Although it is suggested that ATD and ICT use can enhance participation in everyday activities (Copley & Ziviani, 2004; Craddock, 2006; Hasselbring & Glaser, 2000; Skär, 2002; Todis & Walker, 1993), a number of hindrances that affect the opportunities for children with disabilities in their use of ATDs are identified (Copley & Ziviani, 2004; Craddock, 2006; Derer, Polsgrove, & Rieth, 1996; Egilson, 2005). Despite that, ATDs are intended to enable children with physical disabilities to participate more fully in everyday activities (Copley & Ziviani, 2004; Lidström & Borgestig, 2008; Skär, 2002; Swinth, 2001) and this can have positive effects on the child's independence and autonomy development and thus provide increased opportunities to work in adult life.

In order to promote children with physical disabilities' participation in and parity with their peers in the digital generation, further knowledge is needed regarding children with disabilities' access to ICT and ATDs, in particular computer-based ATD, the influence of ICT-activities in the activity pattern in and outside school, participation in computer educational activities, as well as their satisfaction with use of computer and computer-based ATD in school and outside school activities.

### *Physical disabilities*

The term, children/youths/students with physical disabilities, is used throughout this thesis with reference to the group studied. Children with physical disabilities is a heterogeneous group and it is difficult to describe these children' and youths' abilities, among other things because of the differences, but also because of the inadequate amount of documentation (Vanderwood, McGrew, & Ysseldyke, 1998). Physical disabilities is a generic term for different diagnoses, in this research children with motor limitations, and need not be limited solely to motion or movement patterns, but may also include control of motor activity (Bille & Olow, 1999; Möller & Nyman, 2003). The most prevalent diagnoses among children with physical disabilities are cerebral palsy (about 40%), spina bifida and neuromuscular disorder (10 % respectively) (Nylèn, 2004). The diagnostic category does not significantly

affect the intensity and diversity of participation in everyday activities (Almqvist & Granlund, 2005; Eriksson & Granlund, 2004a; Law et al., 2004; WHO, 2008). The proportion of boys with disabilities is slightly higher than that of girls, because certain diseases and injuries are more common among boys, including certain muscle diseases and injuries due to accidents (Hasselbring & Glaser, 2000; Paulsson & Fasth, 1999).

The cause is either an injury or a disease, which is congenital or has occurred at a later stage in life and has resulted in a state of motor limitation (Bille & Olow, 1999; Nylèn, 2004). A diagnosis of motor limitation is often accompanied by disturbances of cognition, communication, perception, and/or visual and hearing disorder that impact on their performance to successfully complete everyday activities (Möller & Nyman, 2003). For example, in the group of children with cerebral palsy there is, due to the heterogeneity, substantial variability in functioning in mobility, self-care, and social function (Østansjø, Brogren Carlberg, & Vøllestad, 2005).

There are no accurate statistics in Sweden on the number of children and youths with physical disabilities. However, of the country's entire population the group 2-17 year olds is approximately 20% of the population, i.e., about 1.9 million children. Of these, an estimated 225 000 children and adolescents have a chronic illness or mild to severe disabilities. Of these, in turn, it is expected that around 7000 children and youths have physical disabilities (SIAT, 2002). The study area in Studies II-IV comprised four counties in the central health care region in Sweden, with a total population of 1.3 million inhabitants. The statistics based on this population and on the available statistics for children with physical disabilities (SIAT, 2002) revealed that the sample (Studies II-IV) represented approximately 10% of the eligible participants in Sweden.

During the academic year 2009/2010 there was 892 000 children in mainstream schools, 13 000 in special education schools, 395 000 in upper secondary schools and 9500 in special education upper secondary schools in Sweden (Skolverket, 2011). Primarily children with intellectual disabilities, i.e., diagnosis such as Down syndrome, autism attended special education schools but there were also children with other diagnoses who had learning difficulties and severe motor limitations. The school's mission is to provide equivalent education to all students. United Nations school regulations and regulations in Sweden stress participation in educational activities as a right from an equality perspective (SFS 2010:801; UNESCO, 1994; United Nations, 1989), "All children and youths, regardless of gender, geographic residence and social

and economic conditions, have equal access to education in the public school system for children and youth. The education shall be provided within each type to be equivalent, wherever in the country they live"(SFS 2010:801, chap. 1, 2 § ). This means that all students are expected to participate in the same activities in school, whether the student has a disability or not and/or is in need of a computer-based ATD (Brodin & Lindstrand, 2003; Simeonsson, Carlson, Huntington, & Sturtz McMillen, 2001).

All participants in this study were enrolled in habilitation centres (HCs). Habilitation services in Sweden are aimed at children and youths with disabilities, their families and the network of people around the children (Granat, Lagander, & Börjesson, 2002). Occupational therapists are the group at the habilitation centred who often prescribe ATDs, as one strategy to enable children with physical disabilities to participate more fully in various activities (Carpe, Harder, Tam, & Reid, 2010; Case-Smith & O'Brien, 2010; Copley & Ziviani, 2004; Roger & Ziviani, 2009).

## THEORETICAL FRAMEWORK

### International Classification of Functioning, Disability and Health

The World Health Organization's (WHO's) International Classification of Functioning, Disability and Health, children's and youths' version (ICF-CY) (2008) was designed to be a unified and neutral descriptive framework to understand health in relation to functioning and disability for children and youths. The Model of Functioning and Disability (WHO, 2001) takes a biopsychosocial approach. This is done in order to avoid the fallacies of dichotomous perspectives from the medical model or the social model (Leonardi, Bickenbach, Ustun, Kostanjsek, & Chatterji, 2006). In ICF the term "functioning" refers to body function, activity, and participation, while "disability" is a state of decreased functioning associated with disease, disorder, injury, or other health conditions, classified as an impairment, activity limitation, or participation restriction. Disability is defined within the context of health and a function of features of the environment in which people live.

The two terms, context and environment have often been used interchangeably, but it is important to distinguish between them (AOTA, 2008) because in ICF, contextual factors include two components: the environment and personal factors respectively (WHO, 2001). Personal factors are to date not classified

in the ICF, but form the background of the child's life and living, e.g. gender, age, education, and are not included in health conditions. The environmental factors refer to the physical, social and attitudinal environment in which children live and conduct their lives. These include factors involving both immediate (e.g., assistive technology devices) and more distant environments (e.g., social attitudes, system, and policies) that might have an impact on a person's functioning. Environmental factors are said to have an impact (i.e., facilitating or hindering) on all components of functioning and disability (WHO, 2008). In this thesis, examples of environmental factors studied, which may have an impact on children's participation in ICT-activities can be; accessibility to ICT in school and at home, personal assistance, teachers' use of computers in teaching, attending regular school or special school. In addition, in this research even the Internet-based environment is included, with e.g. social network sites, communities for interest and virtual reality environments (Notley, 2009).

### Children's activity and participation

For children and youths with disabilities, participation in everyday activities is defined as "the context in which they learn skills, do tasks and activities, develop friends, and find satisfaction" (Law, 2002, p. 1). Participation is therefore essential for children's and youths' development, health and well-being (Bourke-Taylor, Law, Howie, & Pallant, 2009; King et al., 2003; King et al., 2010; King, Petrenchik, & Hurley, 2009; Law, 2002; Law, Petrenchik, Ziviani, & King, 2006; Majnemer et al., 2008). In ICF-CY, participation is consistent with "an individual's involvement in a life situation" and the concept activity is defined as "the execution of specific tasks or actions by an individual" (WHO, 2008).

The ICF has been discussed in general, because activity and participation seen to be separate terms, but are listed jointly in the classification (Brandt, Samuelsson, Töytäri, & Salminen, 2011). There is also criticism that the children's subjective experiences of involvement, that include the personal (i.e., role, satisfaction) are not clear in the ICF-definition (Hemmingsson & Jonsson, 2005). King et al. (2009, p. 126) point out the child's own experiences of participation when she describes the importance of participation in outside school activities in children as follows; participation "offers children opportunities that go beyond competence development – by allowing them to experience a sense of belonging to a group or community, and to develop a sense of who they are as individuals". It is particularly important to capture the children's subjective experience of using ICT in school and

outside school activities, because it is important for an occupational understanding of participation (Hemmingsson & Jonsson, 2005). The children's subjective aspects of participation are included in this thesis by investigating the children's own experiences and satisfaction with ATD and ICT use. For example, questions about the children's satisfaction with the service around their computer-based ATD, if playing computer games and browsing the Internet are fun etc., serve as indicators of their subjectively perceived participation.

To describe the essence of children's participation in school and outside school activities in this thesis, the concept of 'doing' according to the Model of Human Occupation (MoHO) (Kielhofner, 2008) was used. In occupational therapy, participation falls into a continuum of "doing" at the levels of participation, performance, and skill. The concept occupation refers to the doing of play, activities in daily living or productivity (e.g. education) within a context. In MoHO occupation is defined as comprising three broad areas of doing: activities of daily living, play, and productivity. Activity is instead what we actual do. Occupation "becomes more complex with the inclusion of meaning or purpose" in comparison to activities (Case-Smith & O'Brien, 2010, p. 24). Despite the fact that humans' experience is not included in "doing of activities" according to Christiansen and Baum (2005), the concept activity is preferable to occupation, because, in this thesis children's meaning and purpose in doing the activities are not investigated. Nevertheless, it is important for participation to question "what does the child want to do?", "how do most children behave?", and "what activities have high social and educational priority?" (McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006) and opportunities to make own decisions (Hemmingsson, 2002; McConachie, et al., 2006). Therefore the child's satisfaction in their use of computer-based ATDs in school and outside school activities and children's experience of functional and psychosocial aspects when using an ATD in education are some areas investigated in this research.

It is also necessary in this thesis to clarify the concept *social participation* in relation to children with disabilities. Earlier research has described both performance (doing) and social aspects as important for participation (Asbjørnslett & Hemmingsson, 2008; Heah, Case, McGuire, & Law, 2007; Hemmingsson & Borell, 2002; Hemmingsson & Jonsson, 2005). Social interpersonal interaction and relationships in the domain "Activities and Participation" is an important aspect of health, as it is a component in



the classification scheme regarding ICF-CY (WHO, 2008). However, this aspect is related to social participation, which is not included in ICF.

Participation in this thesis is defined as involvement in school and outside school activities, and is divided into participation in activities (the opportunity to do the same things as other children) and social participation (the opportunity for interaction and a sense of belonging to the group). Social interpersonal interaction may be basic and complex with strangers, friends, relatives etc. in a contextually and socially appropriate manner (WHO, 2001, p. 159). This definition is useful in order to understand and investigate the role of ICT in social participation in children with physical disabilities. Another more specific definition, based on a literature review of social participation of children with special needs in regular education, is the definition by Koster, Nakken, Pijl and van Houten (2009). Social participation is operationalised as “the presence of positive social contact/interaction between these children and their classmates; acceptance of them by their classmates; social relationships/friendships between them and their classmates and the students’ perception they are accepted by their classmates” (p. 135). This definition provides three themes useful in this thesis to increase understanding of children's experiences of using ATDs in school (acceptance by classmates), and meeting friends (friendship/ relationships) and not least use of computers and the Internet as a social media (contacts/interactions).

### Digital skills

The MoHO (Kielhofner, 2008) suggests, that a person's performance unfolds through dynamic and continuous interaction between the person, the task and the environment. This means that the child's physical, emotional, cognitive abilities, and motivation and ability, and the child’s activity pattern, as well as changes in the environment, e.g. in terms of access to an ATD, all affect performance. To enable or enhance a child’s participation, for example, in a computer activity in school, interventions may focus on accomplishing changes in any or several of these components; the person, the task or the environment. To understand the relationship between doing and performance, in ICT-activities, it is important to also have a definition of skills. Skills are defined as “observable, goal-directed actions that a person uses while performing tasks (Kielhofner, 2008). Further, skills are also a function of the interaction between personal characteristics and the environment. In this thesis the objective view of performance is not examined therefore it is preferable

to use the concept doing, i.e., which ICT-activities the child usually does outside school. Hence, an environmental adaptation, such as a computer-based ATD can give opportunities in doing an ICT activity, where a child can developed skills, for example digital skills. Digital skills is defined as knowledge in using the computer and the Internet (Kuhlemeier & Hemker, 2007; Sølvsberg, 2002). Digital skills are of course also dependent on the child's motor, process and communication and interaction skills (Kielhofner, 2008). The computer knowledge is generated by frequent use of computer and software i.e., not something you can only read about, you also have to perform a variety of computer activities to acquire digital skills. From this perspective “skills are embedded in performance, and performance is embedded within participation” (Kielhofner, 2008, p. 104). This means for children who use ATDs that they need to have the "right" devices to develop and improve their digital skills by gaining experience and training in a variety of different activities at school and outside school. Thus, to encourage children with physical disabilities to participate in school and outside school activities it might be important to accumulate new knowledge about how the ATDs provided suit the children’s needs and satisfaction from the perspective of the child. In thesis the objective view of performance is not examined therefore is the concept doing preferable to use, i.e., which ICT-activities the child use to do outside school.

## USE OF TECHNOLOGY – BY CHILDREN WITH PHYSICAL DISABILITIES

### Assistive technology devices (ATD)

Assistive technology device is an important concept in this thesis and is defined as “*any product, instrument, equipment, or technology adapted or specially, whether acquired commercially, modified or customized, that is used to maintain, increase, or improve the functional capabilities of individuals with disabilities*” (ISO 9999:2007). This means that products for children with disabilities include many types of ATDs; such as wheelchairs, orthotics, special chairs, special watches, rollers, and door openers, as well as computers and computer-based ATD. Based on the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations, 2008) everyone has the right to receive assistive devices for greater independence in daily life.

Assistive technology device services refers to “*any service that directly assists a child with a disability in the selection, acquisition, or use of an assistive technology device*” (IDEA, 2004). The prescription of ATDs, e.g., computer-based ATDs is governed by laws, ordinances and regulations which, among other things, regulate who is eligible for an ATD and who has the right to prescribe the ATD that is eligible (Blomqvist, 2008). The prescriber is also responsible for customising the device to meet the child's specific needs, teaching and training the child and other persons in the child's environment to use the ATD in adequate activities, and repairing broken equipment.

In this thesis different ways of organising the products/ATDs in types are identified. One is from a financial perspective where products/ATDs are grouped based on who is responsible for the cost of the device, the family, county or the school (Blomqvist, 2008). Another is based on the child's function and what impairment the ATD is proposed to compensate for and assist (Fuhrer, Jutai, Scherer, & Deruyter, 2003; Scherer, 2002). Tech is another way to subdivide (Dell, Newton, & Petroff, 2008) i.e., how the device is constituted, from low tech to high tech. In the classroom, typical low tech ATDs include diaries, special schedules, heavy rulers and pencils. ICT is an example of high tech ATDs, often more expensive and requiring more training, because they are more complicated to operate (Isabelle et al., 2002).

### Information and Communication Technology (ICT)

The term ICT is usually understood as computers and the Internet (Brodin & Lindstrand, 2003; Ilomäki & Rantanen, 2007; Watson, 2001), but ICT can also include e.g. video conference systems and screen readers (Abbott, Austin, Mulkeen, & Metcalfe, 2004; Hasselbring & Glaser, 2000). In this thesis the broader definition of ICT is used in Study I-II (e.g., daisy-, DVD-, game- and video player, as well as communication devices and TV) but in Studies III-IV only the Internet, computers and computers with special computer applications (such as computer input interface, special software) were included in the definition.

Computers and their operating systems and programs, described as being Universally designed (Hasselbring & Glaser, 2000; Mummery, 2004; Rose, Hasselbring, Stahl, & Zabala, 2005), are progressing towards being usable by a diverse group of people, with and without disabilities. In contrast, computer-based ATD is specifically designed to assist an individual, e.g. with disability, to enable participation in activities (Rose, et al., 2005). However, the development of ICT is a

very straightforward feature of computer-based ATD (Koos van Woerden, 2006; Man & Wong, 2007; Rose, et al., 2005) and Rose et al. (2005) argue that there are no sharp distinctions between computers as conventional technology with universal design and computer-based ATDs. There is a lack of knowledge about the impact of the dual role of ICT for students with physical disabilities in which the computer acts as both conventional technology and as an ATD. It is fundamentally important to gain more knowledge about how these approaches can enhance and even support one another for the further benefit of children with disabilities (Rose, et al., 2005). For example, do children with physical disabilities have the same access to computers and computer-based ATDs at home as in education settings? This is an interesting question when the goal is to enable children with disabilities to participate more fully in various activities both at home and in educational settings. Therefore, it is important to investigate ATDs, in particular the beneficial effects of ICT for participation in school and outside school activities for children with physical disabilities from the child's perspective.

## Education and ICT

Inclusion in mainstream schools for children with physical disabilities has been advocated for years (UNESCO, 1994). Inclusion in general education is an approach to educating children with special needs most or all of the time with non-disabled children (Moen, Nilssen, & Weidermann, 2007). Nevertheless, several studies have revealed that children with physical disabilities often have both limited accessibility to the school environment and restricted participation in activities in education (Eriksson, Welander, & Granlund, 2007; Hemmingsson & Borell, 2002; Pivik, McComas, & LaFlamme, 2002). Both these limitations may have consequences for the learning opportunities of children with physical disabilities. Therefore, the learning environment and teaching methods need to be adapted, based on the children's individual prerequisites and needs (Gülbahar, 2007; Hasselbring & Glaser, 2000; Simeonsson, Carlsson, Huntington, McMillen, & Brent, 1999; Watson, 2001). An example of such adaptations is to use ICT as an educational tool and a computer-based ATD.

Extensive efforts have been made to increase the inclusion of computer use in both primary and secondary schools for non-disabled children (Carpe, et al., 2010). Söderlund (2000) has in his thesis studied the development of ICT; in this case computers and the Internet at school. The ICT wave started with political decisions in

the 90's, when both the United States and the European Commission in Europe made financial commitments at the beginning of 1990. In Sweden, the introduction of ICT in schools within this time span implied great financial efforts and it primarily involved teachers; e.g. in-service training for 60 000 teachers in teams. Nowadays, almost all youths aged 12-19 years have access to computers and the Internet in school (92-99%) (Findahl, 2009).

The main reasons for introducing computers in Swedish schools were initially; democracy, working life and learning, i.e., all students, irrespective of where they live in the country, and to which social class they belong, have a right to become computer literate in Swedish schools. The ability to search for information and to communicate on the Internet is regarded to be just as fundamental as the ability to read, to write and to do arithmetic (Riis & Jedeskog, 1998). Therefore, our point of departure is that all children, with and without disabilities, need access to ICT and opportunities to participate in computer activities in school.

However, for children with physical disabilities, ICT might even be of importance as an effective ATD. One example is computer-based ATDs, that are specifically designed to assist and enable an individual's participation in diverse activities in educational settings, such as writing and communication (Derer, et al., 1996; Gillette, 2006; Rose, et al., 2005; Todis & Walker, 1993). Unfortunately, many studies show that the computer use in school is far from optimal for children with disabilities (Carpe, et al., 2010; Copley & Ziviani, 2004; Craddock, 2006), and the implementation of ICT has taken too long (Brodin & Renblad, 2009). It has previously been noted that the development of ICT is moving quickly and the use of computers and the Internet is increasing in the society and in school. It can therefore be assumed that a change for the better has taken place over time. Nevertheless, it is important to be aware that children who use computers both as ATDs and as a tool in education, to cope with everyday life, i.e., to reach educational goals (Besio & Salminen, 2004; Copley & Ziviani, 2004; Lidström & Borgestig, 2008; Rose, et al., 2005; Todis & Walker, 1993), may need to use them more frequently and in more activities at school than those who do not use computer-based ATDs. But do children with physical disabilities take advantage of ICT's unique capabilities, as a compensatory tool and do they have the same activity pattern in educational computer activities in school as children in general? These are some of the questions investigated in this research.

## Outside school activities and ICT

Activities in which children participate outside of the traditional school day are, in this thesis, defined as outside school activities. Outside school activities include leisure activities, e.g. “activities that offer different kinds of experiences of play” (Poulsen & Ziviani, 2006, p. 284), homework and household tasks. This is because leisure is something one chooses to do (Christiansen, et al., 2005; Poulsen & Ziviani, 2006), and homework and household tasks may be something one has to do and may be perceived as work by children. The boundaries between work and leisure can overlap. An example of an activity which may overlap is *Searching for information* on the Internet as a school task at home.

Children with physical disabilities have documented restricted participation in both outside school and in school activities compared to children without disabilities (Brown & Gordon, 1987; Imms, Reilly, Carlin, & Dodd, 2008; Law et al., 2006; Majnemer, et al., 2008). A literature review by Imms (2007) showed that physical access, transportation difficulties and social exclusion were common barriers for children with cerebral palsy wishing to participate in outside school activities. The same result appears in a systematic review by Shikako-Thomas and colleagues (2008) who found that the activities of children with physical disabilities were more passive, home-based, and lacked variety. Age, gender, activity limitations, family preferences and coping, motivation, and environmental resources and support were all factors that influenced their participation in outside school activities.

Being such a common and promising tool for development, it is also essential to examine ICT from a gender perspective. Previous research found gender differences where boys were more often interested in ICT, used computers more frequently i.e. computer games (Dix, 2005; Kautiainen, Koivusilta, Lintonen, Virtanen, & Rimpelä, 2005; Kuhlemeier & Hemker, 2007), and had more positive beliefs about their digital skills (i.e., skills associated with using the computer and the Internet) (Kuhlemeier & Hemker, 2007; Sølvsberg, 2002; Whitley, 1997). Girls’ Internet skills were less developed than boys’ (Kuhlemeier & Hemker, 2007). However, today and in the future, digital skills are needed to participate in common outside school activities performed by boys and girls, in education as well as other areas of society (Ilomäki & Rantanen, 2007).

The increasing use of ICT in outside school activities may be a particularly promising area for children with disabilities, when children with physical disabilities favour participating in informal activities such as ICT-activities (e.g., *Watching TV*,

*Using computers, Listening to music*) (Imms, et al., 2008; Law, King, et al., 2006; Majnemer, et al., 2008). However, far too little attention has been paid to how the increased use of ICT has also affected the activity patterns of children and youth with disabilities outside school, when digital skills might bring about increased opportunities in working and social life in adulthood.

#### Use of ATD and ICT – by children with physical disabilities

The use of some type of an ATD is common in children with physical disabilities (Johnson, Dudgeon, Kuehn, & Walker, 2007; Skär, 2002; Østansjø, et al., 2005) and previous research has shown that ATDs can have significant beneficial effects for children with multiple disabilities (Copley & Ziviani, 2004; Derer, et al., 1996; Skär, 2002). For example when a child has an activity limitation in writing, computer and computer-based ATDs can enable participation and completion of tasks requiring hand function (Handley-More, Delitz, Billingsley, & Coggins, 2003; Priest & May, 2001). Nevertheless, access to an ATD is no guarantee for promoted participation in everyday activities in children with physical disabilities (Scherer, 2002). There could be many reasons why children adopt, do not use and do not want to use their ATDs. The sparse research regarding perceptions held by children and youths reported different experiences of use of ATD (Skär, 2002). For example, children may experience positive feelings when they describe their ATD almost as an integrated part of themselves, something that helps them to get around, to play with others and to give them a feeling of independence (Skär, 2002). In contrast, Craddock (2006) describes that one reason why the ATDs were not used by students in postsecondary education was that the ATD threatened the person's sense of "fitting in" because it attracted unwanted attention from peers.

If the child's needs and expectations are fulfilled, it is more likely that the child will be satisfied and want to use his/her ATD (Scherer, 2002). Several authors have described the nonuse of ATD (Goodman, Tiene, & Luft, 2002; Philips & Zhao, 1993; Wessels, Dijicks, Soede, Gelderblom, & De Witte, 2003) which may indicate dissatisfaction among the children who use ATDs and computer-based ATDs. Consequently, more research is needed in this area from the child's perspective. Of course, there are several reasons why the ATD is not used; it might be perceived as a waste of resources and not viable from a cost perspective (Scherer, 2002), but above all it may result in the children's activity problems persisting. Other reasons besides children's subjective experiences to nonuse of an ATD may be environmental factors.

Earlier research found for example that the service may be inadequate (Hoppestad, 2007), a lack of appropriate staff training and support, negative staff attitudes to using an ATD, a lack of cooperation between teacher and therapist and arrangement in school activities may not be satisfactory (Carey & Sale, 1994; Copley & Ziviani, 2004; Derer, et al., 1996; Hemmingsson, Gustavsson, & Townsend, 2007). Furthermore, there may be inadequacies regarding the person-centered approach (Hoppestad, 2007). Despite recognition that the extent of children's use of ATD and ICT is strongly influenced by the children's everyday environments, relatively little research has focused on identifying and describing differences in environmental barriers to participation in ICT-activities for children with disabilities in school and outside school.



# RESEARCH AIMS

## GENERAL RESEARCH AIM

The general aim was to investigate the use of ICT and participation in computer activities in school and outside school among children and youth with physical disabilities, in comparison to children and youth in general. In particular the aim was to develop knowledge about the use of and satisfaction with computer-based ATD in school and outside school among children with physical disabilities. The results can be used as a basis for prioritising and developing support for the optimal use of ICT and assistive technology devices in and outside school of children with physical disabilities.

## Specific aims

- To investigate the use and nonuse of ATDs in school by students with physical disabilities and to describe students' experiences of using these devices. In particular, this investigation included the characteristics of the ATDs students want to use because these devices might be those that support participation in school. (Study I)
- To investigate the outside school activity patterns of children with physical disabilities, and specifically their ICT usage compared with that of non-disabled children. In addition, the aim was to investigate the children's opinions of computer use and the associations between their use of the Internet and their interaction with peers. (Study II)
- To investigate the prevalence of children with physical disabilities who used a computer-based ATD, and to investigate differences in the satisfaction of children and youths with physical disabilities who used or did not use computer-based ATDs with the application of computers for in school and outside school activities. (Study III)
- To determine the ICT use in school activities of two groups of students with physical disabilities comprised of those who do and those who do not use a computer-based ATD and to make a comparison with students from the general population. In addition, positive factors associated with in-school computer use are identified for students with physical disabilities. (Study IV)

# METHODS

## DESIGN

Different methodological approaches were used in the studies in order to develop knowledge about the use of ICT and satisfaction with computer-based ATD in school and outside school among children with physical disabilities. All the studies were based on children and youths as informants, through interviews, observations (Study I) and self-report questions (Studies II-IV). For an overview of focus, design, participants, methods of data collection and analysis, see Table I.

Table I. Overview of the four studies included in the thesis: Focus, design, participants, methods of data collection and analysis.

	<b>Study I</b>	<b>Study II</b>	<b>Study III</b>	<b>Study IV</b>
<b>Focus</b>	Investigating use and nonuse of ATDs <sup>1</sup> in school and to describe students' experiences of using these devices	Investigating outside school activity patterns, specifically the ICT <sup>2</sup> usage. In addition, investigating the children's opinions on computer use and the associations between their use of the Internet and interaction with peers	Investigating prevalence of children with disabilities who used a computer-based ATD <sup>1</sup> , and differences in satisfaction with and use of computer in school and outside school activities of children who used and did not use computer-based ATD <sup>1</sup>	Investigating use of computer in school among students with physical disabilities who used and did not use a computer-based ATD <sup>1</sup>
<b>Design</b>	Mixed method nested strategy, predominantly with a qualitative approach	Cross-sectional study with group comparison between children with physical disabilities and non-disabled children outside school	Cross-sectional study with comparison between children who used and did not use a computer-based ATD <sup>1</sup>	Cross-sectional study with comparison between students with physical disabilities and students from general population
<b>Participants</b>	20 students with physical disabilities in age of 8-19 years	215 children/youths with physical disabilities in age of 10-16 years	287 children/youths with physical disabilities in age of 10-18 years	
<b>Reference group</b>	-	1379 children without disabilities	-	940 children without disabilities
<b>Methods of data collection</b>	Field observations and Interviews with students and occupational therapists	Postal or web based questions		
<b>Data analysis methods</b>	Comparative analyses Descriptive statistics	Descriptive statistics Chi-square test Student's <i>t</i> -test Logistic ANOVA <sup>3</sup>	Descriptive statistics Chi-square test Spearman rho One-way ANOVA <sup>3</sup>	Descriptive statistics Chi-square test Kruskal-Wallis test Logistic regression

<sup>1</sup> Assistive technology device

<sup>2</sup> Information and Communication Technology

<sup>3</sup> Analyse of variance

In Study I the aim was to investigate the use and non-use of ATDs in school by children with physical disabilities and to describe the children's experiences of using these devices in school. A mixed method nested strategy that adopted a predominantly qualitative approach was used. This mixed method approach involves collecting and analysing both qualitative and quantitative data in a single study (Creswell, 2002; Polit & Beck, 2006). Thus, in Study I observation and interviews with children were the main focus and quantitative data (i.e., number and types of devices) were only used as a starting point to better understand the children's perspectives on using ATDs in school.

Studies II-IV concerned children's satisfaction with and use of ICT in school and outside school and had a cross-sectional design (Polit & Beck, 2006). These studies were based on the results from Study I, where it for example, emerged that ICT and computer-based ATD was one of the devices that the children wanted to use more often in school. In addition, the literature about how children with physical disabilities use ICT in everyday activities is sparse, and previous studies usually comprised of just a few children (Egilson, 2005; Fasting & Halaas Lyster, 2005; Gillette, 2006; Todis & Walker, 1993) and did not have a reference group of children from the general population (Craddock, 2006; Priest & May, 2001). Therefore, Studies II-IV had a cross-sectional design (Polit & Beck, 2006) focused on the use of ICT in school and outside school among a larger group of children with physical disabilities. In addition, the results in Studies II and IV were compared with those of two reference groups of children without disabilities. In Study IV children's satisfaction with and use of computers was compared in two contexts; in school and outside school, and between children with physical disabilities who used and did not use a computer-based ATD.

In the next section, participants, data collection and data analysis in Study I will be presented. Thereafter follows a description of the participants (see Table II), instrumentation, and data analysis in Studies II-IV.

Table II. A  $X^2$  analysis was performed to describe the demographic variables in two of the groups of participants: those who used a computer-based assistive technology device (ATD)<sup>1</sup> in school and those who did not.

Characteristic	STUDY I	STUDY II	STUDY III and STUDY IV
	<i>n</i>	<i>n (%)</i>	<i>n (%)</i>
<i>Children with physical disabilities</i>	20	215	287
<i>Gender</i>			
Boys	9	118 (54.9)	154 (53.7)
Girls	11	97 (45.1)	133 (46.3)
<i>Age</i>			
10 - 12 years	12	96 (44.7)	105 (36.6)
13 - 15 years	5	119 (55.3)	138 (48.1)
16 - 18 years	3	-	44 (15.3)
<i>Diagnosis</i>			
Cerebral Palsy and related disorders <sup>2</sup>	5	83 (38,6)	106 (36.9)
Spina Bifida	5	19 (8.8)	28 (9.8)
Neuromuscular disorder	6	19 (8.8)	26 (9.1)
Acquired brain injury and/or epilepsy	2	11 (5.1)	16 (5.6)
Diseases affecting the skeleton and joints <sup>3</sup>	-	18 (8.4)	25 (8.7)
Other diagnoses <sup>4</sup>	2	65 (30.2)	86 (30.0)
<i>Mobility</i>			
Walks without an aid	7	146 (67.9)	188 (66.2) <sup>6</sup>
Uses a mobility aid <sup>5</sup>	13	69 (32.1)	96 (33.8) <sup>6</sup>
<i>Access to computer</i>			
in school <sup>7</sup>	20	205 (95,3)	270 (94.1)
at home <sup>7</sup>	-	212 (98,6)	281 (97,9)

<sup>1</sup> Assistive technology device

<sup>2</sup> Includes diagnoses such as cerebral palsy, Erbs pares, ataxia.

<sup>3</sup> Includes diagnoses such as osteogenesis imperfecta and rheumatoid arthritis.

<sup>4</sup> Includes diagnoses such as Ehlers-Danlos syndrome and Charge syndrome.

<sup>5</sup> Of these 96 children, 68 children used a wheelchair

<sup>6</sup> Information missing

<sup>7</sup> Includes computers that have been provided by the health care system or the school

NS= not statistically significant

## STUDY I

### Participants

The selection of participants in Study I was conducted by occupational therapists (OT) based at habilitation centres (HCs) in both urban and rural areas in central

Sweden who were asked to identify potential participants among children in their caseload. The criteria for inclusion in Study I were children who 1) had physical disabilities with motor limitations, 2) attended mainstream schools, and 3) had received an ATD in school from the therapist within the past three to six months, and 4) that the children, their teacher and their therapists all agreed to participate in the study. Children with intellectual disabilities were not included. Twenty-two children who met the criteria were invited to participate and twenty agreed (see Table II). Students from different years and schools and with different levels of disabilities were included to obtain a varied picture. The OTs contacted the children and their parents and provided them with verbal and written information about the study. If the children accepted the invitation, the school's headmaster and the children's class teacher received written information about the study and were asked for permission to conduct observations in class.

## Data collection

### *Procedure*

In Study I field observations and interviews with therapists and children with physical disabilities were used for data collection. The first step of data collection was to collect background information about the child through interviews with the therapists ( $n=17$ ) who had identified presumptive participants (Kvale, 1997). The therapists were asked for demographic data (e.g., age, gender, diagnosis) of the participating children and the number and type of ATD the children had received in school. The therapists used the children's case records to provide supplementary information. All interviews were audio-taped and transcribed verbatim. A list of ATDs used in school was drawn up for each child, based on the therapist's information.

The second step in the data collection was an observation in school of the 20 children included, followed by an interview with each child to investigate her/his use and experience of using ATDs in school.

### *Field observations*

A one-day observation in school of the 20 children was conducted for each participating child. The observations and interviews were done with a time lapse of three to six months after the provision of ATDs, to enable the child to have sufficient time to integrate the use of recently provided ATDs in the school environment. The

observations were planned and discussed in cooperation with each child, his/her parents and teacher to ensure that this fitted in with each participating child and her/his classmates' schedules and requirements.

The observation was conducted to ensure contextualised information concerning the children's ATDs and their use and integration in the school situation. Observations were also conducted to facilitate the subsequent interview with the child by making it possible to ask questions based on observations of actual actions (Curtin, 2000).

The observer followed each child in all activities during one day in school, including breaks, and acted as a partial onlooker during the observation, i.e., did not participate in activities or interrupt social interactions in class (Patton, 2002). The observational focus was set on the children's use of ATDs and detailed field notes were taken that comprised both descriptive and reflective material (i.e., relating to settings and conversation) (Bogdan & Biklen, 2007). The field notes were then transcribed by the observer.

#### *Interviews with children*

After observation, data collection was supplemented by a semi-structured interview with each child (Kvale, 1997). Previously collected information on her/his case gathered from the therapist interview, the established list of ATDs, and observations made in class were used to adjust the interview guide individually for each child. Questions concerned the children's use and experiences of using ATDs in school, and why they used/did not use certain devices. The interviews lasting between 45 and 90 minutes were conducted on a one-to-one basis and audio-recorded. The interview procedure was designed to allow children over a wide age range, and with different cognitive abilities and communication difficulties to respond and express their views. Therefore, the method Talking Mats (a low-tech communication framework which uses a mat with picture symbols) (Bornman & Murphy, 2006) was used as the communication device for two children with communication difficulties. All interviews were audio-taped and transcribed verbatim.

#### **Data analysis**

As Study I used a mixed method strategy (Creswell, 2002), both content analysis (Graneheim & Lundman, 2004) and descriptive statistical analysis (Polit & Beck,

2006) were used. The analysis of field notes and interviews in Study I was divided into two phases.

#### *Descriptive statistics*

In the first phase a list of types and numbers of ATDs obtained during the interviews with the OTs and the descriptive statistics was compared with the field notes and children's statements about their ATD use in school, and with their preferences for use. Then a list of ATDs used in school was drawn up for all participating children; all ATDs which the children had received, both specifically for use in school (e.g. computer-based ATD, pencils and rulers), and those they used in school but had received before starting school (e.g. mobility or communication aids) were included. The ATDs were tallied and the different types were identified, including dichotomous data on whether the children used or wanted to use these devices or not. All the different ATDs on the list were then categorised into groups; for example, computers, joysticks, DVD-players, or voice synthesis were all categorised into the group ICT for writing and reading. When an inconsistency appeared in the data regarding whether or not a child used an ATD in school, the children's statements and the field observation were considered to be superior to information provided by the OTs. Then the analysis searched for patterns concerning the types of ATDs the children had received in school and which of these they claimed they used, did not use, and did or did not want to use. The first phase provided background information for the subsequent examination of the children's experiences of using ATDs in school.

#### *Qualitative content analysis*

In the second phase a qualitative content analysis method (Graneheim & Lundman, 2004) was chosen in Study I, to explore the children's experiences of using ATDs in school. Here, all accumulated data from the children's interviews and the field notes were used. First, the interviews and field notes were read through several times for each child, and all data were divided in two domains; a) data about children's use or non-use of ATDs and perceptions of their ATDs, and b) the children's narratives about everything else except ATD, the latter were not included in the analysis. The data in domain a) was then systematically coded in a line-by-line process (Graneheim & Lundman, 2004). The primary focus was the children's perceptions of the ATDs provided and their experiences of using them in school.

Up to this stage, field notes and interviews were analysed separately for each child. The data were analysed independently by the first and the second author (before these individual analyses were discussed) in an attempt to compensate for single-researcher bias. Then, codes for each child were compared to identify similarities and differences between children, and grouped together into themes on a more general level (Bogdan & Biklen, 2007). During this step we found that the children explained why they wanted to use some ATDs while they rejected others, and some children were able to describe the underlying reasons for this. They also expressed feelings towards ATDs and clarified when and how ATDs enabled activities in school, which helped us to identify new content areas (Graneheim & Lundman, 2004). During the analysis, all emerging themes were constantly compared to data obtained from interviews and to the observation data to ensure that they were based on the data.

In the final step, relationships between themes were investigated to identify characteristics of the ATDs children used and appreciated. These characteristics were carefully checked against all existing data. To investigate the credibility of the analysis, peer examinations were conducted (Krefting, 1991) continuously throughout the research process. To increase the validity further, quotations were used in the results (Lundman & Hällgren Graneheim, 2008).

## STUDIES II-IV

### Participants and criteria for collection

Sweden is divided into 21 counties, with one main habilitation centre (HC) in each. In this thesis seven main HCs, encompassing both urban and rural areas in central Sweden, were invited to join the study; four centres agreed to participate. These HCs identified 475 potential participants from their medical records. This eligible sample was estimated to represent approximately 10% of children with physical disabilities in Sweden, based on the population in the actual counties and available statistics on children with physical disabilities (SIAT, 2002). The inclusion criteria were: children and youth of between 10 and 18 years of age with a primary diagnosis of physical disabilities (cerebral palsy, neuromuscular disorder, spinal cord injury, spina bifida, acquired brain injury, juvenile arthritis etc.). Children with intellectual disabilities as a primary diagnosis were excluded.

Based on the estimated number of potential participants from two HCs, the statistician consulted arrived at a response rate of between 150 and 400 children. The



precision of the estimate was that the proportion is +/- 8% if 150 children respond and +/- 5% if 400 respond. Figure I presents a summary of the participants in Studies II-IV from the eligible study population ( $n=475$ ), the participating children in Study II ( $n=215$ ) and in Studies III and IV ( $n=287$ ).

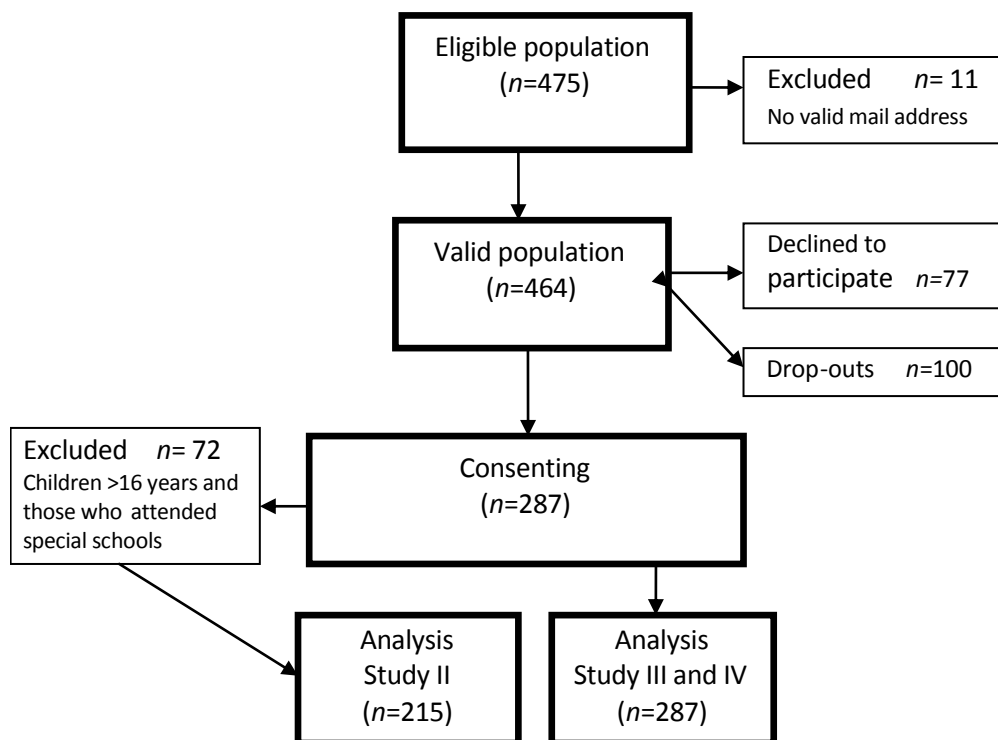


Figure I. Summary of participants in Studies II -IV

A total of 287 completed the survey, 77 declined to participate and 100 dropped-out, comprising a response rate of 62%. Analyses for response bias indicated no significant differences between respondents and non-respondents regarding their diagnosis, sex, age or place of habitation ( $p<0.05$ ). Table II p 18 shows an overview of the characteristics of the children with physical disabilities included in Studies II-IV.

The design of Studies II-IV was cross-sectional with group comparisons. As can be seen in Table II, two separate reference groups were used to compare collected data of children with physical disabilities with data of children from the general population in Study II and IV. Further, in order to match the children in the reference group in Study II, the age span differs from Studies III-IV. The inclusion criteria for age in

Study II were therefore, children between 10 and 16 years. In Studies III-IV children and youth between 10 and 18 years of age were included.

In Study II the reference group was obtained from an annual national survey “Kids and Media, 2006” (Mediarådet, 2006) conducted by the Swedish Media Council and involved a random sample of non-disabled children (9-16 years) taken from The Swedish Tax Agency. The survey included 1379 children and youth comprising 688 boys and 691 girls, with an age-split of 9-12 years ( $n=702$ ) and 13-16 years ( $n=677$ ); the response rate was 70%. One item that was estimated to be of importance (concerning kinds of activities outside school) was not found in the 2006 survey but was included in the survey the year before. Therefore, data from 693 boys and 732 girls from the survey “Kids and Media, 2005” (Mediarådet, 2005) were analysed with respect to this specific item.

In Study IV, the reference group was obtained from a national survey from The Swedish National Agency for Education entitled “Information Technology in School, 2005” (Skolverket, 2005). In this study 940 children without disabilities participated, 478 boys and 462 girls, with an age-split of 11 years (grade 5) ( $n=292$ ), 15 years (grade 9) ( $n=340$ ) and 17 years (level 2) ( $n=308$ ). The mean age was 14 y 5 mo [SD 2 y 5 mo]. The response rate in the study was not described.

## Data collection and survey instrument

### *Procedure*

The four HCs included drew up a code list of all children with physical disabilities, respectively, including an identification code, the child’s age, gender, primary diagnosis and residential area. The HCs were also asked to identify any ATDs provided, for example mobility devices or computer-based ATDs for the children, but they were unable to provide this information due to the fact that it was too time-consuming. The family/children’s names and addresses were anonymous to the researchers. Information packages were distributed in the spring of 2007 to the 475 eligible participants (see Figure I). The package included: a cover letter explaining the purpose of the study, a questionnaire, and a coded and stamped addressed envelope. To make the information accessible to parents, to children < 15 years, and youths  $\geq 15$  years, the cover letter was written in three different versions respectively. The children’s version was written more briefly with simpler words and the reverse side

was written with symbols to suit those without reading skills. The children were encouraged to respond unaided to the questionnaire, but could get help from an adult if necessary. The surveys were sent out by each centre. One week later a web-based version of the survey was available. Consent was given by directly returning the completed survey in a coded envelope by mail to the first author, to guarantee strict confidence. Additionally, the web-based version was submitted via the Internet to a server to decode the response. All potential participants who had not yet replied received a reminder after an interval of 4–6 weeks, but it was also possible to refuse participation and send back the coded envelope empty.

### *Survey instrument*

The aim of Studies II-IV was derived from the qualitative study, Study I, where results indicated that children with disabilities were restricted in their use of ICT and computer-based ATD in schools. A survey was chosen, with a larger group of children with physical disabilities, to examine this issue. The purpose of the survey was therefore to investigate the satisfaction with and use of ICT and participation in computer activities in school and outside school by children and youth with physical disabilities, in comparison to children and youth in general. To optimise the construct validity of the survey instrument the first step was to establish the aim and the research questions which were to be answered (Domholdt, 2005; Polit & Beck, 2006) in a discussion with scholars from different professions, well-versed in the issues (Landsman, 2006). A conclusion from the discussion was, for example, that children with disabilities should receive equal learning opportunities as they are guaranteed by law as children in general (UNESCO, 1994; United Nations, 1989). Therefore, it was important to compare the results of these children and youth in relation to those children without disabilities. In addition, the findings in Study I and in previous research with small samples (Carpe, et al., 2010; Gillette, 2006) indicated that computer-based ATD has a potential to increase children's independence and participation in computer activities, as well as in general educational activities. Therefore, specific questions about computer-based ATD were needed. In the literature review no single measurement was found that agreed with the purpose of the studies and this resulted in the decision to design the survey used in the data collections in Studies II-IV. However, two national surveys and an assessment battery concerning participation in ICT-activities in and outside school, and autonomy and participation in general school activities used in a Swedish context were found. Questions were chosen

that were consistent with the research aims and to reduce the number of replicated questions the issues were discussed within a group of scholars and with a statistician, consulted for face validity (Terwee et al., 2007).

The final version of the survey consisted of 36 main questions (16 of these had between 4 and 12 sub-questions) in two sections: 1) a questionnaire asking about general demographic information, and including self-reported questions concerning the children's satisfaction with and use of ICT and computer-based ATDs, both in school and outside school, and 2) questions from two assessments concerning children's *Availability and participation in school activities* and their *Autonomy*. Most of the questions were closed-ended which is preferable in terms of respondents who may have difficulty expressing themselves orally and in writing (Krosnick, 1999). The survey is presents as an appendix in Swedish in this thesis.

### *Questionnaire*

In order to examine participation in ICT-activities in school and outside school, in the sense of participation as "involvement in a life situation" as defined in the ICF (WHO, 2001), and describe and draw conclusions about children with physical disabilities' use of computers, in comparison to children from the general population, selected questions from two national surveys were used (Studies II and IV). The surveys were; an annual national survey "Kids and Media" about children's use of ICT outside school, made by The Swedish Ministry of Education and Culture (Mediarådet, 2006) and the national survey "Information Technology at School" about children's use of ICT in school, made by The Swedish National Agency for Education (Skolverket, 2005). An example of the replicated questions was: "What do you usually do outside school", with a dichotomous scale (14 alternatives to tick, e.g., *do sports, take care of animals, watch TV, search on the Internet*). Another question was: "How often do you use a computer in education to e.g. *write... make presentations.... search for information on the Internet?*" with a multiple-choice on a 5 point Likert scale (1=never and 5=often). The aim of the studies was also to investigate children with physical disabilities' access to and use of computer-based ATDs, therefore 3 questions with 25 sub questions were added. Examples of these questions were: "How often do you use a... e.g., *an alternative keyboard, a switch or a joystick* to use the computer in school/outside school?" with a Likert scale (0=never, 1=sometimes and 2=always).

The reliability concerning the items in children's use of ICT in school and outside school was analysed (Krosnick, 1999), with an internal consistency of  $\alpha=0.79$ .

With the purpose to capture the children's subjective experience of using ICT, which is also important for an occupational understanding of participation, (Hemmingsson & Jonsson, 2005) questions with such a focus were replicated. Examples of question statements were "I use the computer enough in school/outside school", "I want to use the computer for more activities in school/outside school" or "It is difficult to use the Internet" (Agree/partly agree/do not agree/don't know). Since the questions concerning children's computer and ICT use in the national surveys were directed to children without disabilities, i.e., without the need of computer-based ATD, it was considered necessary to create supplementary questions about satisfaction with use and the provision of services to the computer-based ATD. Children graded their satisfaction with their computer use in school and outside school, and the delivery of the services provided with their computer-based ATD on a five-step scale, where: 1= not at all satisfied and 5= very satisfied. The demographic information in the questionnaire consisted e.g. of items concerning children's age, gender, school year, need of teacher assistant, need of mobility device, abilities to write with a pencil.

### *Assessments*

Section two in the survey measured the children's participation in general school activities, their autonomy and interaction with teachers, using a modified version of a self-reported assessment battery, adapted to Swedish contexts. This assessment battery has earlier been used in research on participation in children with disabilities (Almqvist & Granlund, 2005; Eriksson & Granlund, 2004b; Granlund & Björck-Åkesson, 2000) including the *Availability and participation* in school (Simeonsson, et al., 1999), questions from the *ARC self-determination scale* (Autonomy, Self-Regulation, Psychological Empowerment, and Self-Realization) (Wehmeyer & Kelchner, 1995) and *Interaction with students* and *with teachers* (Granlund & Olsson, 1999). An item reduction was done, in consultation with the research group, from the Swedish assessment battery to select items in relation to the general aim of the project. Items concerning *Self-Regulation*, *Psychological Empowerment*, and *Self-Realisation* and *Interaction with students* were therefore excluded.

To measure the degree of *Availability and participation in school activities*, 12 sub-questions out of 27 were replicated from the Swedish assessment battery. The items selected consisted of unstructured and structured school activities in relation to

computer use (such as practicing drawing and painting, computer activity in class, participation in class council). In a first step, the respondents were asked to check if the activity was available, on a scale of 0-3 (0= not available, 1= seldom available, 2= sometimes available, 3= always available), where 0-1= not available, 2-3= available. If the children responded that the activity was available, the extent to which the children participated in the activity were measured on a scale of 0-3 (0= do not participate, 1= seldom participate, 2= participate sometimes, 3 = always participate). To measure the degree of *Autonomy*, 2 items (with 9 sub-questions) such as “choices” (e.g. “what I do during leisure time is my own choice”), “society and leisure” (e.g. “during leisure time I write letters, e-mail or call my relatives and friends”) were included. The scale consisted of four response alternatives (1 = I don’t, even if I have the possibility, 2 = I do sometimes, when I have the possibility, 3 = I do most of the time, if there is a possibility, 4 = I always do, if there is a possibility).

The questions used for measuring how the students perceived their interaction with their teacher (e.g. “I can talk to my teacher whenever I want to” and “I understand what my teachers mean when we talk to each other”) were developed by Granlund and Olsson (1999). The respondents were asked to choose among five response alternatives (1 = seldom, 2 = fairly seldom, 3 = 50 % of the time, 4 = fairly often, 5 = most of the time). These questions were not used in the studies included in this thesis.

The replicated questions from the surveys and the assessments have been used in the same target group, i.e., in children and youth in Swedish contexts, which is important for content validity (Terwee, et al., 2007). In addition, the questions from the assessment have been developed and used earlier in children with disabilities. Nevertheless, this survey, with three-quarters replicated questions and one-quarter new questions about computer-based ATD has not been used before; therefore a pilot test was done. The pilot version of the survey was done with a cognitive pretesting method in four children and youth (aged 10-18), which involved asking the children to “think-aloud” while answering the questions, with the intention of identifying possible confusions and misunderstandings (Someren, Barnard, & Sandberg, 1994; Wilson, 2005). When the children answered the questionnaire an adult was sitting next beside them and the researcher listened to their conversation. In addition, children highlighted the difficult words with a coloured pencil. This pilot test resulted in some language alterations and the removal of two questions from the assessment part. After the children had completed the questionnaire they were asked, to evaluate

the content validity, i.e., how the questions corresponded to the topic (Terwee, et al., 2007). All four children responded that it was about what they usually do on the computer at home and at school.

A test-retest, with an interval of six months, (Krosnick, 1999; Switzer, Wisniewski, Belle, Dew, & Schultz, 1999), was carried out to test the stability over time of items relating to the children's use of ICT in school and items from the second section, comprising 29 children with physical disabilities, with an agreement of 75.4% at group level. Analysis at individual level using Kendall's tau for ordinal scales (Krosnick, 1999; Polit & Beck, 2006) showed a  $\tau = 0.48$ .

### Data analysis

In the following section, the statistical analysis in Studies II-IV will be described. The studies had a cross-sectional design (Polit & Beck, 2006) and a survey was used for data collection. Data from the survey were controlled and then transferred to a spreadsheet. Data from the two reference groups, the surveys "Kids and Media" (Mediarådet, 2005, 2006) and "Information Technology at School" (Skolverket, 2005) were merged into the same spreadsheet. Statistical analyses were then done using STATISTICA software (VERSION 8.0, StatSoft, Inc.).

Initially, a statistician was consulted to discuss analysis methods that could be used, based on design issues and data level. A power analysis was also conducted which indicated that an 80% power was required to detect the difference in a p-value of  $<0.01$  for an eligible sample ( $n=287$ ), with a margin for an unanticipated loss of data. The observations with calculated percentages were based on the number of participants who responded to the relevant item, i.e. missing data was not included in the calculation (Polit & Beck, 2006). Missing values were low ( $<12$  participants) in 94% of the questions.

The analytical process started in all three studies with descriptive analysis (Polit & Beck, 2006) to describe the general characteristics of the participants, e.g. age, diagnoses, gender and number of children who used a computer-based ATD, a mobility device. For between-group analyses cross-tabulation ( $X^2$ ) was used to compare the proportion of boys and girls (Study II), children with and without disabilities (Study IV), and children with disabilities who used and did not use a computer-based ATD (Study III) in items related to demographic information. The statistically significant level was at 0.01 in Study II and 0.05 in Study III and IV, according to the groups' sizes (Petrie & Sabin, 2005).

Most of the data in Studies II-IV were derived in normal and ordinal scales. In addition, for subsequent analyses, the analysis of binary variables was conducted (Studies II-IV). Therefore descriptive statistics and non-parametric analysis have been used with Chi<sup>2</sup>, Spearman rank correlation, logistic ANOVA, Kruskal Wallis test and logistic regression (Petrie & Sabin, 2005; Polit & Beck, 2006). However, parametric analysis i.e., a t-test (Domholdt, 2005) was used in Study II in the hypothesis testing of the mean of the sum of outside school activities and computer and Internet activities boys and girls with and without disabilities usually did.

A one-way analysis of variance, an ANOVA (Study III) (Domholdt, 2005) was also made to compare the mean of satisfaction in computer use among children who used and did not use a computer-based ATD, both in and outside school.

In this thesis, three types of ANOVA were used (Domholdt, 2005; Petrie & Sabin, 2005). To investigate the association between the activities *meet friends* and computer as a social media with activities such as E-mailing and Visiting communities a logistical ANOVA was used in Study II. The Kruskal-Wallis test (a non-parametric ANOVA) was used to compare computer use in some educational activities for the three groups of children (Petrie & Sabin, 2005) (Study IV). Finally, analysis with one-way ANOVA (Study IV) was made to compare satisfaction with computer use between those children with physical disabilities who used and did not use a computer-based ATD.

Further, in Study III all item scores concerning analyses of children's autonomy (9 sub-questions) and participation in general school activities (12 sub-questions) were summarised for each participant and then divided by the number of items respectively. An ANOVA was then made and to evaluate the degree of differences between the groups in the latter analysis, the effect size and eta squared were calculated. According to Cohen's classification, a partial eta squared value of 0.14 or more is defined as large, an effect size between 0.6 and 0.14 is moderate and 0.01-0.06 is small (Levine & Hulett, 2002).

To check the internal consistency reliability, an analysis of the index for perceived autonomy and availability and participation in school activities was made. The Internal consistency for the two indexes (Cronbach alphas) was between  $\alpha = 0.80$  -0.84 (Krosnick, 1999).

A logistic regression, performed in two steps was made in Study IV to investigate which variables were associated with participation in computer activities in school by children with physical disabilities. In the first step a univariate regression



analysis (Alinaghizadeh, 2009) was conducted to examine the association between the dependent variable, the *participation* of children with physical disabilities *in computer activities* and a set of predictor variables. Variables such as *gender*, *class size*, *school type*, and *access to own computer* were tested, and then significant variables with an odds ratio (OR) > 1.5 were added into a multiple regression model. The final model represents those factors that contribute to the production of the best statistical significance (by log likelihood tests) of the model. The odds ratio was given, followed by the appropriate 95% confidence interval (CI) in parentheses.

# FINDINGS

## STUDY I

### Use of ATDs in mainstream schools: students' perspective

The aim of Study I was to investigate the use and nonuse of ATDs in school by students with physical disabilities and to describe students' experiences of using these devices. In particular, this investigation included the characteristics of the ATDs students want to use because these devices might be those that support participation in school.

#### *Use and nonuse of ATD*

In Study I, 20 children with physical disabilities had been provided in school with a total of 125 ATDs in all. A discrepancy was found between the number of ATDs the children had been provided with and the number they actually used in school. The types of devices the children had been provided with e.g. devices for mobility, sitting or standing and ICT for writing and reading, or devices for communication, had an impact on the number they wanted to use, did not want to use and the number they actually used. However it was found that the children wanted to use 89 but used only used 73 of the 125 ATDs provided.

#### *The children's experiences of ATD*

ICT for reading and writing, such as computers, computer-based ATDs and daisy-players, were one type of ATDs the children wanted to use more than they actually did. The children's explanations as to why these ATDs were not used to the extent they wanted were, among others, that the ATDs were not accessible when needed and were not included in the teaching and learning activities, they were broken and the school did not have routines for servicing them.

If the children considered that an ATD was worth using in school they had to experience immediate benefits in their functioning. That is, they had difficulties understanding the long term goals. Examples of ATDs, that immediately facilitated performance in class and made the children more independent, were ICT for reading and writing and devices for communication and mobility. Thus, the children used ATDs that increased their functioning with the objective of decreasing the

performance gap between them and their classmates. The children's understanding of the benefits seemed to be based on their own experiences of facilitated functioning rather than on information provided by others.

Some children also experienced that the use of ATD had a negative impact on their social participation with peers because ATDs were experienced as a possession they had to take care of which could sometimes give rise to conflicts with their peers. The ATDs might also be experienced as a sign of deviance. For example, when the computer-based ATDs were placed in a separate room from that in which the classmates were working, this meant that a child using an ATD felt excluded. The influence the ATDs had on the children's self-images and the reactions of their peers was apparently very important to the children. For that reason, the children tried to avoid ATDs that made them feel different or deviant as well as ATDs that complicated or threatened their social participation with their peers. If an ATD did so, the children might choose to do without it, even if its use would have increased performance opportunities. In conclusion, the children wanted to use ATDs for participation in school activities if the devices were integrated into their educational practice and they experienced immediate support to participation in everyday school activities without a negative impact on their relationship with their peers.

## STUDY II

### The influence of ICT on the outside school activity patterns of children with physical disabilities

The purpose of Study II was to investigate the outside school activity patterns of children with physical disabilities, and specifically their ICT usage compared with that of non-disabled children. In addition, the aim was to investigate the children's opinions of computer use and the associations between their use of the Internet and their interaction with peers.

#### *Activity patterns for children with and without physical disabilities*

One main finding in Study II was that two sets of activity patterns were identified, depending on whether the child was disabled or not, and on the gender of the child. Firstly, outside school activity patterns of children with disabilities were characterised by a higher focus on ICT-activities, while children without disabilities tended to be

engaged in a broader range of outside school activities. Secondly, a more uniform activity pattern was found among boys and girls with disabilities. Gender differences were found in 3 of 14 common outside school activities in children with disabilities, in comparison to 10 of 14 activities in children without disabilities ( $p < 0.01$ ).

#### *Computers and Internet activities*

When examining 10 different computer and Internet activities separately, it was found that a higher proportion of children with physical disabilities did six of these 10 computer activities, in comparison to children without disabilities namely; *visiting communities, doing homework, searching for information, e-mailing and uploading texts and pictures* ( $p < 0.01$ ). This in turn indicates that children with disabilities were frequent computer users outside school and they applied a variety of digital skills.

Concerning gender differences, the same trend as in the outside school activity patterns of boys and girls with disabilities was found in computer and Internet activities. Thus, gender differences were only found in 3 of 10 computer activities among boys and girls with physical disabilities, in comparison to 6 of 10 computer and Internet activities among non-disabled boys and girls  $p < 0.01$ .

#### *Social participation and computer use*

The second main finding in Study II was that a positive association was found between the *meet friends* and use of social media activities, such as *visiting communities* and *e-mailing* among children with disabilities. This result indicated that those children who frequently used the computer as a social media in on-line communication and for playing computer games also did *meet friends* face-to-face, outside school to a higher degree than those who did not use the computer as a social media.

Analysis of the children's views regarding Playing computer games and Using the Internet demonstrated that more than 75% of the children with disabilities considered these activities to be fun and to provide learning experiences and, similarly, 82% of the children with physical disabilities reported that they *use the Internet* as a social activity.

### STUDY III

#### Computer-based ATD for use by children with physical disabilities: a cross-sectional Study

The aim of Study III was to investigate the prevalence of children with physical disabilities who used a computer-based ATD, and to investigate differences in the satisfaction levels among children and youths with physical disabilities who use or do not use computer-based ATDs with regard to the application of computers for in-school and outside school activities.

#### *Used a computer-based ATD*

The prevalence of children with physical disabilities who use computer-based ATD (including computers with special computer applications) was found to be about 44% (n= 127) in the age group 10-18 years. Concerning special computer applications, such as computer input interface and/or educational software, the analysis showed that 94 children had been provided with at least one special computer application; 49 children had a special computer application both in and outside school, 30 only outside school and 11 children only in school. Thus, the children did not have the same type or numbers of computer input interfaces (such as switches, joysticks, alternative keyboards) at home as in school, and ATD was more common in the home than in school.

All the children who used a computer-based ATD responded that they had difficulties writing with a pen or pencil. These children walked to a greater extent with an aid, attended a special school, and received help from an assistant than those children who did not use a computer-based ATD ( $p \leq .001$ ). In addition, they rated significantly lower with respect to autonomy and lower participation in general school activities in comparison with children who did not use a computer-based ATD. These findings indicated that the vast majority of the children seem to use computer-based ATDs as a compensatory tool for limited fine motor skills. Moreover, they had more severe impairment and lower levels of autonomy than children who did not use ATD.

#### *Satisfaction in computer use*

The children who used a computer-based ATD were *less satisfied* with their computer use, both in and outside school in comparison with those who did not use an ATD. In

addition, a higher proportion of the children who used an ATD *wanted to do more activities* with the help of the computer in school and fewer considered they *used the computer often enough* outside school than those who did not use an ATD.

Almost half of all the children who used a computer-based ATD in school were not at all or not very satisfied with the service, and this included areas such as the initial prescription, the repairs and technical services, the provision of information and the training and the follow-up in school. Thus, there seemed to be an association with satisfaction in computer use and the use of computer-based ATDs both in and outside school, and moreover, the children who used a computer-based ATD were also dissatisfied with the associated service delivery which indicates an activity limitation in computer activities in school among this group of children with physical disabilities.

Despite the fact that these children had greater access to computer-based ATD and a higher frequency of computer use at home than in school, findings showed that 63% of the children who used a computer-based ATD considered the computer to be difficult to manage in activities such as *playing computer games* and *using the Internet* outside school, in comparison to 46% of those who did not use an ATD,  $p < 0.01$ . Analysis showed a correlation between those who responded that it was difficult to *play computer games* and/or *use the Internet* and those children who lacked a computer-based ATD when *playing computer games* and *using the Internet*. Consequently, the findings indicated that the computer-based ATDs provided did not fully accommodate the children's needs with respect to activity performance outside school.

## STUDY IV

Use of ICT in school:

A comparison between students with and without physical disabilities

The specific aim of Study IV was to determine the ICT use in school activities of two groups of students with physical disabilities comprised of those who do and those who do not use a computer-based ATD and to make a comparison with students from the general population. In addition, positive factors associated with in-school computer use are identified for students with physical disabilities.

### *Factors positively associated with participation in computer activities*

Four factors were positively associated with “participation in computer activities in school” for children with physical disabilities. The only factor related to the children’s characteristics was their age i.e., *youths of 16-18 years* participated more often in computer activities than younger students. The other three factors which were positively associated were related to the children’s environment; they *attended mainstream schools*, *had a teacher who used the computer in at least two educational activities*, and the children had the possibilities to *use computers frequently* in school.

### *ICT in educational activities*

The use of ICT (ICT; computers and the Internet) in school was compared between; a) children with physical disabilities who used computer-based ATD ( $n=127$ ), b) children with physical disabilities who did not use an ATD in school ( $n=160$ ) and c) children without disabilities ( $n=940$ ). An assumption was that children who used a computer-based ATD, such as an alternate keyboard, joystick or switches use computers more frequently and in more activities in school than children who did not use ATDs. This assumption was based on the fact that these children used the computer both as an educational tool and as a compensatory tool, in activities such as reading and writing in order to compensate for e.g. motor and/or cognitive impairments. In accordance with this assumption, the findings in Study IV showed that the majority of daily computer users were children with physical disabilities who used a computer-based ATD.

Another assumption was that there is no difference in computer use among children with disabilities who do not use an ATD and children without disabilities. Nevertheless, the findings indicated that children with physical disabilities, and relevant both for those children who used and those who did not use a computer-based ATD, had restricted participation in several general educational computer activities (such as *searching the Internet*, *e-mailing* their teacher). The only exception was the activity *practice exercises* (using the computer as an alternative tool in learning, e.g. in mathematics and spelling), this activity was more common among children with disabilities. As a result, regardless of whether they use a computer-based ATD or not, students with a physical disability have less variety in computer-based educational activities, in comparison to students from the general population.

## GENERAL DISCUSSION

This thesis presents new knowledge about the use of ICT and participation in school and outside school activities for children with physical disabilities, in comparison to children and youth in general. The results can be used as a basis for prioritizing and developing support for the optimal use of ICT and ATD in school and outside school of children with physical disabilities.

The main findings from these investigations will be discussed under the following themes: 1) Use and non use - a child's dilemma, 2) Prevalence and satisfaction with use of computer-based ATDs, 3) New perspective on ICT-activities, 4) Environments provide different opportunities for developing and using digital skills, 5) Social participation in the digital generation.

### Use and non-use - a child's dilemma

In this thesis, children with physical disabilities describe their experiences of use and non use of computer-based ATD in school and outside school (Study I, III-IV). This issue will be discussed in light of a client-centered approach in occupational therapy (Law, Baptist, & Mills, 1995). Study I shows that use of an ATD in school has no value for a child with a disability if he/she does not feel they experience immediate benefits for their functioning in everyday school activities, without detrimental effects on their social participation if they are to use the devices provided. This means that to adopt or abandon an ATD is a dilemma that the child faces. Overall the research in this thesis indicates that the child was not given opportunities to influence whether or when they could use the ATDs provided. To give the child these opportunities to make their own decisions in personal matters can be seen as a part of the concept participation (Hemmingsson, 2002; Hemmingsson & Jonsson, 2005; McConachie, et al., 2006).

To allow children to participate in decisions that concerns personal matters in choosing, e.g. in which activities they want to participate and if they should perform the activity with or without the use of an ATD could promote children's autonomy and independence (Söder, 1989). There are several documents, including the Children's Convention (United Nations, 1989), that describe children's right to be



listened to and to be given influence over their own choices, while parents still have a responsibility to promote the best for the child. Thus, using a client-centred approach is complicated with children as the client can be both the child and her/his parents. In fact, a family-centred approach is used at most habilitation centres in Sweden (Granat, et al., 2002). Regarding school, the client can also be the teacher and the teacher's assistant.

Clients with different interests can be an explanation for why the child's willingness to use or not use a tool is not always followed. Based on the results that children are not satisfied with their use of ATDs provided, the results indicate that the choice to use or not to use an ATD is not only the child's decision (Study I, III). A paper by Brodin and Renblad (2009) with the title "How many positive results on inclusion do we need to make changes?" signals a kind of resignation in this area. Have professionals, parents, teachers resigned regarding the optimal use of ATDs and ICT in school, regardless of the child's view of their use? Or does the child's views disappear because there are too many actors involved in ATD delivery and inclusion in educational settings with cooperation difficulties (Hemmingsson, et al., 2007)? In Study I the results show that children even use ATDs they do not want to use. You may ask how one can avoid FORCING children to use ATDs "for their own good"? This issue is discussed earlier as an ethical dilemma in the delivery of ATDs (Swinth, 2001) but collaborative decision making with the child and the family can foster an intentional relationship that leads to an increased child participation (Case-Smith & O'Brien, 2010).

However, what about children's rights when the reverse is true, i.e., when children do not have the opportunity to use the ATDs that they WANT to use (Study I, III)? As far as we know, no one has earlier discussed the usage of ATDs in the sense of a lack of access to an ATD being an ethical dilemma. This is a complex issue since there are laws and regulations that define the right of access to the devices the child needs (SFS 1982:763; United Nations, 2008) but also to self-determination when it comes to matters affecting the child (United Nations, 1989). Further research should be done to investigate the children's role in the provision of ATD, when ATD is an intervention to increase children's participation in everyday activities. The finding that children evaluated ATDs as much from a psychosocial perspective as from a functional one (Study I), has support in earlier research (Gillette, 2006; Skär, 2002), and this is important to consider in this context. The experience of how an ATD affects the user's relationship with peers and the sense of group identity is

subjective and can never be judged by anyone other than the person using the device (Hocking, 1999; Scherer, 2002; Seymore, 2005). An implication of this is therefore to always ask the child about the psychosocial experience of using an ATD. Above all, this is appropriate for ATDs to be used in an environment in which there is a risk that the child may feel uncomfortable with his/her ATD. It is important that ATDs are provided for those children who need and will use them.

### Prevalence and satisfaction with use of computer-based ATDs

This research found that the prevalence of using computer-based ATD in school was 44%. The results indicate that fine motor limitations are common in children with physical disabilities, and this was supported in a study by Imms (2008) in which 40% of the children with a cerebral palsy diagnosis have fine motor limitations. The fine motor limitations are one explanation for the prevalence of children who use a computer-based ATD (Handley-More, et al., 2003; Murchland & Parkyn, 2010). Furthermore, the results in the survey studies show that computer-based ATDs are more common than mobility aids for children with physical disabilities (44 % vs 34 %). This result is supported by earlier research amongst children with physical disabilities (Johnson, et al., 2007). Based on these results it is thus established that computer-based ATDs are common aids in schools for children with disabilities. In comparison with mobility aids (Law, King, et al., 2006; Østansjø, et al., 2005) computer-based ATDs are rarely documented in research, and few studies have focused on the use of ATDs from the perspective of the child. Given the high incidence of ATDs, it is disappointing that children who use a computer-based ATD are less satisfied with their computer use at school than those who do not use an ATD (Study III). The children's dissatisfaction with the use of computers in schools is among other things that they want to use the computer more often and for more activities (Study I, IV). This is consistent with the finding that participation in computer activities in school is limited for children who use a computer-based ATD, compared with children without physical disabilities (Study IV). One reason why they are unsatisfied with their computer use may also be that just under half of the children are not at all satisfied with the delivery, service, information, and follow-up of their ATDs (Study III). This dissatisfaction with the use of ATDs also applies to some extent to outside school, when the children describe their willingness to use more ATDs (Study III).

The ATDs can also have a negative impact on social inclusion and they are not always available, they can for example be broken or be in another room (Study I). It was also found in Study I that satisfaction with the ATD was characterised by the ATDs being integrated into the teaching and learning and the students' experience that the ATD enable functioning in everyday school activities without threatening or complicating their social participation with peers.

In conclusion, the results show that computer-based ATDs are common. It can therefore be interpreted as a neglected area when many children are not satisfied with their use of computers and computer-based ATDs at school and outside school and it has been sparsely studied. Furthermore, almost half are dissatisfied with the service of their computer-based ATDs that they are offered (Study I, III, IV), a result that is consistent with previous research of small groups of children with physical disabilities (Murchland & Parkyn, 2010). These studies indicate a need for intervention research in this field to study the implication of specific plans for each child with continuous monitoring of the ATD for its integration into the teaching and so that the children will have access to the ATDs they believe they need for both outside and in school.

According to Sherer (2002) children's satisfaction with an aid is an important measure if the children feel that they have use of the aid in the activities they want to do, and functions as information as to whether the professionals have managed to meet the child's needs and expectations. Since children grow and develop, and their participation in activities and social participation, often changes in a transition between different environments many times as they grow, they need new or up-dates of their ATDs provided (Skär, 2002). The conclusion is that repeated follow-ups are important for children with physical disabilities (Priest & May, 2001; Skär, 2002). The absence of repeated follow-ups with the assessment of the children's satisfaction with their computer use, may explain why children are dissatisfied with the service and use in Study I and III. That is, they do not perceive any benefit from their ATDs in participation in everyday activities.

To measure the child's needs and satisfaction with their ATD use requires a reliable measuring instrument that is adapted to Swedish conditions and to children. Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) (Demers, Weiss-Lambrou, & Ska, 2001) and the Psychosocial Impact of Assistive

Devices Scale (PIADS) (Jutai & Day, 2002) are two examples of measuring instruments, validated for Swedish conditions that among other things measures satisfaction and use of ATDs in adults. There is a need for further research with regard to validating any possible existing instruments or developing new ones for children, which include measuring the children's satisfaction with access to and use of ATDs for participation in activities, and social participation.

### New perspective on ICT-activities

ICT is a multidimensional tool used in different activities and contexts by boys and girls with and without disabilities as show in the results from this research (Studies I-IV). Children without disabilities' use of ICT as a multidimensional tool in school and outside school has been studied in previous research (Ilomäki & Rantanen, 2007), however research into children with physical disabilities is sparse. Often only computers as computer-based ATD are included (Carey & Sale, 1994; Handley-More, et al., 2003; Salminen, 2008). Furthermore, in an occupational therapy assessment used in current research, The Children's Assessment of Participation and Enjoyment (CAPE), children s participation in computer use is classified as a recreational activity (like *watching TV*) (King, et al., 2010), passive and isolated (Shikako-Thomas, et al., 2008). New knowledge is provided in this thesis indicating that the activity pattern in children with physical disabilities is more varied than earlier research studying ICT-activities has shown from a broader perspective.

The results of Study II show that children with physical disabilities have greater focus on computer activities outside school than children without physical disabilities. This result contradicts to some extent previous research that has found that children with and without physical disabilities have been involved in computer activities to the same extent (Maher, Williams, Olds, & Lane, 2007). One explanation may be that previous research has focused mainly on how often children *used computers* or *played computer games* (Law, King, et al., 2006; Maher, et al., 2007; Majnemer, et al., 2008). In this study, that question was put differently in so much as the computer's possible areas of application have been divided into several sub-activities, such as *browsing the Internet, e-mailing, doing homework* and *working with images / texts* (Study II). This in turn made it possible to study with more precision the similarities and differences in activity patterns between children with and without physical

disabilities and between girls and boys. An example of this is when the differences between boys' and girls' computer use is studied in Study II and IV. Previous research has revealed disturbing differences between the sexes regarding the use of computers, where the boys used computers more than girls (Li & Kirkup, 2007). Disturbing because digital skills are skills that are useful in education, work and as a member of the society, namely that: "A lack of skill in using the computer and the Internet is likely to put a student in a competitive disadvantaged position" (Kuhlemeier & Hemker, 2007). With respect to children with physical disabilities Study II shows that the computer-based activity patterns were more similar for boys and girls with physical disabilities than for children without disabilities. Furthermore, it shows no gender differences in the computer activities in school of girls and boys with physical disabilities (Study IV). This is a positive result from an equality point of view, which would not have been apparent if only activities such as *playing computer games* had been investigated. To confirm these results, more research is needed which studies of ICT from a broader perspective with respect to boys and girls with and without physical disabilities.

Given the variety of activities that can be performed via computers the results of Study II provide a more nuanced picture of the physically disabled children's activity patterns. Even if their involvement in formal and physical activities is limited, they remain well to the fore in the field of ICT. The findings that children with physical disabilities often use a computer and for many different activities outside school also indicate that they have good digital skills, i.e. knowledge of computing and software. These are skills that they have acquired outside school and which are useful in school and moreover in society (Kuhlemeier & Hemker, 2007; Notley, 2009). One implication of these findings is thus the specific inclusion of computer tasks when identifying activity limitations outside school for children with physical disabilities. This is relevant since it is these activities that children want to do, enjoy doing and want to do more of (Study II) and which are important activities if they are to keep apace of "the digital generation".

We also need more research into the use of computers in relation to the health of children with disability, since previous research has mainly applied to children without disabilities.

## Environments provide different opportunities- for developing and using digital skills

When comparing computer use in school and outside school, differences appear and one explanation for the difference can be environmental factors (Kielhofner, 2008; WHO, 2001). Findings in this thesis show that the environments; in school and outside school, provide different opportunities for developing and using digital skills. For example, in Study IV it was found that children with physical disabilities have limited involvement in ICT-activities at school compared to children in general. This is a remarkable result since the relationship was the reverse outside school as is noted earlier (Study II). Schools do not provide children with disabilities with opportunities to fully exploit the digital skills they acquired outside school through their frequent use of computers in many different activities.

The school and home environments differ in several ways, and these can both facilitate and hinder participation, for example location of and access to computers, access to one's own computer and computer-based ATDs (Studies I-IV). There were no difference in the percentage regarding access to computers at home and at school (Study IV), although there can obviously be limited opportunities to use computers in school if many children have to share only a few computers. However, many more children had access to their own computer at home than at school (Study II, IV). Since ATDs are designed to support participation in activities in school and outside school, it is surprising that the children do not have the same computer facilities at home and at school. The fact that the children have even more ATDs at home than at school may explain their dissatisfaction with and limited participation in computer activities in school (Study III-IV).

Another environmental aspect is how structured the respective environments are and the children's possibilities to influence their computer use. There are differences from the perspective of the children's possibilities to influence when they want to use the computer and for what, depending on whether the environment is structured or not. At school, the teachers are the ones who decide what the children should do and when the computers are to be used (Study I). Outside school the children probably have a lot more freedom to decide what and when they use their computers. Moreover, the rate at which children are expected to carry out activities

differs; the children have a more busy time schedule at school than at home where they are more likely to do activities at their own pace.

Access to computers and ATDs and the culture of the environment, as presented above, are environmental factors that partly explain why the children are less involved in computer activities in school than outside school and this indicates a potential for future improvements that can increase the children's participation in computer use in schools (WHO, 2001). Thus, the implications of this research are that in order to increase children's participation in computer activities in school changes should be made in the environment such as; access to one's own computer, coordination of ATDs between the school and outside school environments, planning of teaching so the children have the opportunity to use the ATDs they already have at their disposal.

However, when looking only at activities in school and comparing children with and children without physical disabilities regarding their participation in these activities, the results show that children with physical disabilities participate in a less diverse range of computer activities (Study IV). The need to use an ATD can be one explanation for the difference. The results from Studies I, III and IV show that children who use ATDs do not have the same opportunities to be involved in computer activities in school. For example in the sense that they do not use their ATDs to the extent they would like to do.

However, it is difficult to understand the differences in computer use among children with physical disabilities who do not use ATDs and children without physical disabilities (Study IV). Children with physical disabilities that do not use an ATD have good digital skills; they can write with a pen and have less mobility aids, all of which indicates a milder physical disability (Study II-III). It is difficult to explain why these children have limited participation in computer activities in any other way than that it depends on the child's environment. Organisational problems (Hemmingsson, et al., 2007), lack of knowledge in the use of ICT among teachers (Brodin & Lindstrand, 2003), teachers' attitudes resulting in children's digital skills not being utilised (Dix, 2005; Subrahmanyam, Kraut, Greenfield, & Gross, 2000) are some examples of environmental factors that may explain the results.

Another possible explanation for why children with physical disabilities who do not have ATDs are less involved is that they are in need of an ATD, but lack

access to one. Alternatively, the children have a prescribed ATD, but they are not able to use it to the extent they would like to use it (Study I). Thus, if there is a gap between the child's capacity and performance, caused by the lack of an ATD (environmental factors) this may imply a participation restriction (WHO, 2001). The exploration of this gap will also provide possible explanations to the child's restricted participation. These explanations can guide us to which interventions may be needed in the child's environment, for example, which ATDs are appropriate and in what activities they should be used, based on the child's needs. The research from a child perspective is sparse, when it comes to finding explanations to why children with milder physical disabilities have restricted participation in computer activities in school, in comparison to children without disabilities. Along with findings, more explanations for why children with minor physical disabilities have limited participation in school compared with children without physical disabilities are needed. A clinical implication is thus that children with physical disabilities should have the opportunity to receive occupational therapy at school (Munkholm, 2010). Any activity limitations a child may have can, through close cooperation between teachers and occupational therapists, be identified and this should then allow them the opportunities to participate in a variety of computer activities in school just like all other children. It is important for all children to have the same opportunities to benefit from education through ICT, as the literature found that digital skills even affect academic skills (Ilomäki & Rantanen, 2007).

## Social participation in the digital generation

Research in Study II shows that children with physical disabilities use the computer and the Internet as a social media to a greater extent than children without disabilities outside school. These findings can be interpreted that the computer and the Internet as social media offer opportunities for children with disabilities to social contacts/interactions and social relationships/friendships between them and other persons/friends. Earlier research has shown that children with disabilities have fewer friends (Skär & Taam, 2002), difficulties in making contact with other children (Brodin & Lindstrand, 2004; Koster, et al., 2009) and in taking part in outside school activities (King, et al., 2010; Law, King, et al., 2006; Shikako-Thomas, et al., 2008). Hinders are for example environmental factors such as difficulty with transportations



and that the physical accessibility is not satisfactory for children with disabilities (Howard, 1996; Imms, 2007; Majnemer, et al., 2008). To communicate by video over the Internet (e.g. by Skype and video conferences), both in school and outside school therefore provides new opportunities to "meet", see and hear each other online of face-to-face. A positive finding related to this issue was also the correlation between meeting friends and using the computer as a social media (Study II) where children who use the computer to *e-mail* and *visit communities* (e.g. Facebook) also *meet friends* outside school to a higher degree. This finding is also contrary to the fears of isolation and loneliness through high computer use that is described in the literature (Ziviani, Desha, & Rodger, 2006). Thus, the findings in current research raise the issue of social participation among children with disabilities in relation to on-line communication and Internet-based environment.

Since previous research has documented that children with disabilities have limited social participation and this research indicates that computers and the Internet can be an opportunity for change in this issue needed more knowledge is needed to confirm the results in the current study. Regarding ICF, social interpersonal interaction is defined in a broad way and may be with strangers, friends, relatives etc. in a contextually and socially appropriate manner (WHO, 2001, p. 159). This definition is useful in the manner that ICT is often used as a social media, in an interaction between both people the child knows and people in the virtual world. In contrast to Koster, Nakken, Pijl and van Houten's (2009) definition, based on a literature review which is more specific and suitable for the social participation of children with special needs in regular education, i.e., in a special environment. However, Koster et al.'s (2009, p. 135) definition of social participation is useful to understand when she, together with colleagues, subdivided social participation into four themes. The themes are; "a) the presence of positive social contact/interaction between these children and their classmates; b) acceptance of them by their classmates; c) social relationships/ friendships between them and their classmates and d) the pupils' perception they are accepted by their classmates". Based on the findings in this research and definitions above it is important to discuss the fact that the diagnostic category does not significantly affect the intensity and diversity of participation. Therefore, it is important to understand more clearly how personal, environmental, and family and other personal factors influence the child's involvement in everyday activities, such as participating in computer-based activities in school and meeting friends outside school. The concepts are; friends,

contacts/interactions and social relationships/friendships in relation to computers and the Internet as social media.

Regarding friends and contacts/interactions, it was found that fewer children with physical disabilities in Study II *met friends* outside school than children in general. *Meeting friends* in this context means peer interaction face-to-face, i.e., with a person the child has a friendship with or relation to, which is in accordance with Koster's et.al. definition (Koster, et al., 2009). In this context the terms friendship/relationship becomes important to discuss. Who is a "friend" for children of the digital generation? Are friends those who the child knows personally and hangs out with? Is a friend also a person on the Internet world that the child knows through online communication, such as participating in the same groups with similar interests but whom the child has never met personally? The answer to these two questions has an important role in the concept social participation but also in measuring social participation, as well as the interpretation of the results in the current research. These questions and the results stating that children with disabilities were frequent users of the Internet as a social media (Study II) highlight that the child can be physical alone but still using the computer and the Internet and still have a sense of friendship and relationship. The focus in this thesis has not been the child's subjective experiences of feeling lonely or not, but research in children without disabilities found that group discussions, computer games online, or "meet" classmates or "other friends" through communities, such as Facebook creates feelings of social participation and belonging to a group (Brodin & Lindstrand, 2004; Notley, 2009).

According to the definition of social participation by Koster et al. (2009), the clarification of "friends" is missing in the theme friendship/relationship. For example, a child can be friends with a classmate outside school when playing computer games together online, but they do not play together in school. Therefore, a suggestion is to include friends from the Internet-based environment in the definition, and friendship and relationships need to be exemplified more broadly to also include friendship and relationships developed and used on the Internet. The suggestions may be useful in measuring and in interventions to increase the children's social participation.

With regard to Koster's et al. (2009) the theme interactions/contacts and the findings in Study II show that children with physical disabilities use the computer as a social

media to a higher degree than children in general. This provides possibilities to use the Internet-based environment for interactions and contacts with people the child knows but also persons they do not know. For example e-mailing and chatting are, activities where children direct their communication to someone they probably know, in contrast to playing computer games that can be an interaction between someone they know but also someone from the Internet-based environment.

The examples used by Koster et al. (2009) in the theme interactions/contacts playing together, working together on tasks, participation in group activities, all together indicate a physical personal interaction. These examples of interaction/contacts can also be made with use of a computer in the Internet-based environment as a tool e.g. interaction in play with friends and siblings and in educational activities together with classmates.

Findings in this thesis therefore suggest that the theme interactions/contacts in social participation (Koster, et al., 2009) includes activities and persons in the virtual world. Research in this study indicates that children with physical disabilities use the computer as a social media which can enable the child to make contacts with persons they know but also create new contacts which was found to be difficult in the group of children with special needs (Koster, et al., 2009).

## METHODOLOGICAL CONSIDERATIONS

The studies contribute new knowledge about children and youth with physical disabilities' use of ICT and participation in computer activities and satisfaction with their use of computer-based ATD in school and outside school. However, the findings of this thesis must be seen in the light of several methodological limitations which have influenced the results and conclusions drawn. Methodological limitations are discussed and critically reflected upon in this chapter.

### Children as informants

The UN Convention on the Rights of the Child Article 12 (United Nations, 1989) states that children not only have a right to articulate their opinions with regard to issues which affect them but they also have a right to have their opinions heard in research (Davis, 1998; Priestly, 1998; Sturgess, Rodger, & Ozanne, 2002). Therefore, the studies of this thesis were designed to allow children with physical disabilities to participate as informants. However, it is documented that when interviewing and

observing children (Study I ) (Curtin, 2000; Kvale, 1997; Ljusberg, Brodin, & Lindstrand, 2007), and asking them to respond to a self-reported survey instrument (Studies II-IV) (Oppenheim, 2003; Sturgess, et al., 2002) particular challenges must be considered.

Difficulties arose in Study I when interviewing the 20 participating children and youth with disabilities. For example, the conversations started with small talk as recommended (Oppenheim, 2003), but when some of the children were asked to talk more freely about their experiences of their ATD use, some of them gave short answers or only yes and no replies. Thus, there is a danger that data will not be as exhaustive as was the aim and this is common when interviewing children (Curtin, 2000; Oppenheim, 2003). Explanations to the short replies, may be that children may not always feel confident in an interview situation with a stranger (Curtin, 2000). The researchers tried to avoid this situation by adapting the interview strategy, such as giving the child a chance to warm up, listening carefully and asking short questions to clarify the previous sentence (Oppenheim, 2003).

Moreover, the observations made in Study I, provided a clearer picture of children's use of ATDs and participation in school activities, but also made it easier to ask questions about the child's ATD use in specific situations during the day which could facilitate the child's greater confidence in the interview situation. A methodological change which could be beneficial in helping the children to feel more comfortable expressing themselves was to carry out interviews on several occasions if the child was not in the mood to talk the first time.

Engaging children in survey research (Studies II-IV) also involves some challenges when it must be possible for the child to understand the questions, language and scales (Ejlertsson, 2005; Sturgess, et al., 2002), such as rating scales of Likert-type (Hartley & MacLean, 2006). This is an important aspect of the validity of the survey (Terwee, et al., 2007). Although most of the questions in the survey have been used by children before, it is not certain that the children participating understood them correctly and in accordance with the purpose of these studies. As a consequence of the fact that the children may not all have been independent with respect to reading and writing, dependent on their age, cognitive levels, reading and writing skills, there was a risk that some of the children in the study might have needed the assistance of parents to answer the survey questions and the scales. Under these circumstances it may be justifiable to ask to what extent the data represent the children's opinions or those of the parents. This is an important question but our view

is that it is better that the children get the assistance of parents to explain the questions, than that they guess. In both cases, it might have affected the result so the interpretations need to be made with caution. An easy option had been to include a question asking if the children themselves have answered the questionnaire or if they answered in cooperation with parents, to control for who was in fact the respondent.

Moreover, when the purpose of the studies was to have access to children's subjective perspective a number of method adaptations have been made to avoid some shortcomings. For example the age of the children was chosen to be > 9 years and children with intellectual disabilities were excluded. Nevertheless, to control for who the respondent is in future survey research on children, a recommendation would be to carry out interviews by telephone or in person, but both methods are time-consuming and above all costly in terms of personal interviews with many children (Troost, 2001). Consequently, a postal survey was the method that was feasible within this project.

### Sample and representativeness

The number of participants in Study I was small, as the study was predominantly qualitative. This research approach does not seek generalisation, but instead, analytical generalisations can be utilised considering the extent to which the findings in one study can be used as a guide to understanding what might occur in other situations and samples (Kvale, 1997). The children in the sample were selected by an occupational therapist from the caseloads of the HCs included, with the intention to obtain a variation in data with children of different ages, from different schools and with different levels of disabilities. Thus, the variety of the participants' demography can be seen as strengthening the study (Polit & Beck, 2006). However, the broad age range and cognitive developmental levels of the children may have influenced the results, since it is assumed that children and youth participate in different activities and they have different requirements in education. For that reason, age was considered in the analysis and taken into account for all the results obtained. However, we did not find any specific age-related differences with respect to our main themes. At all ages represented in this investigation, the children weighed the ATD's functionality against the psychosocial influence it had on their everyday lives in school and it can be useful to understand that this might occur in other situations and samples when using ATD.

The representativeness, i.e., the extent to which the sample is similar to the population, is an important concern in quantitative studies with regard to a study's statistical conclusion validity (Polit & Beck, 2006). Therefore, the possibilities of generalising the findings of Studies II-IV warrant some comments. For example, the sampling plan, the sample size, the sample's homogeneity, and response rates are all important concerns (Polit & Beck, 2006). Further, the sampling strategy was not optimal in Studies II-IV since no data register of children with physical disabilities is available in Sweden. Another option, used in earlier research (Bjerre et al., 2004; Hemmingsson, Stenhammar, & Paulsson, 2008), was to get help from the HCs in the data collection. This data collection method provides a target population in Studies II-IV that could be considered to be representative regarding Swedish children with physical disabilities since the HCs are responsible for all children with physical disabilities in the age group (Bjerre, et al., 2004) in an eligible population in the four HCs caseloads.

Regarding the sample size, Trost (2001) argues that the sample size in relation to the percent of a target group is not interesting, instead it is the deliberations made to obtain a sample that represents the target group that are important, for example the power calculation relating to the research questions. However, the power calculations in Studies II-IV, made by a statistician, indicated that for the present sample ( $n=287$ ) there was a margin for an unanticipated loss of data and it should therefore be large enough to answer the research questions. These factors together strengthen the possibilities to generalise the results in children and youth with physical disabilities aged 10-18 years in Sweden.

Another important issue for the possibilities to generalise the results to other children with physical disabilities was the homogeneity, i.e., this sample was a miniature of the population of children with physical disabilities regarding diagnosis, boys and girls, and variety of ages of the children in the sample (Polit & Beck, 2006). Further, similar distribution of diagnoses in groups of children with physical disabilities have been documented, except that slightly more children with cerebral palsy diagnosis were reported in earlier studies (Hemmingsson, et al., 2008; Law, King, et al., 2006). Nevertheless, analyses indicated no significant differences between diagnosis and dependent variables in Studies II-IV, which is accordance with previous research (Eriksson & Granlund, 2004b; Law, et al., 2004). Moreover, a selection bias might have affected the outcome and the possibility to generalise the findings as the participants comprise slightly fewer youths (age 16-18 years) than

children (age 10-15 years). This can be explained by the fact that fewer older children/youths were registered at the habilitation centres because proportionally more resources are given to younger children than to school children, consequently those children dropped out (Bjerre, et al., 2004). Age may be a shortcoming since the results in Studies II and IV partly indicate that youths with physical disabilities participate in more varied computer activities both in school and outside school than do younger children. Thus, if more youths had been represented, the participants' satisfaction with their computer use might have been higher in our investigation. The distribution between participating boys and girls is not remarkable, it is in accordance with available statistics (Paulsson & Fasth, 1999).

The response rate in Studies II-IV was 62%, and in fact, postal surveys in this area often consist of small samples (<200) and low response rates (Polit & Beck, 2006; Trost, 2001). According to Krosnick (1999) representativeness does not necessarily increase with higher response rates since it is the variation in the sample that is more important. Nevertheless, it is possible that children with a special interest in computer usage would have been more interested in answering the questionnaire than the others who abstained, which could affect the generalisation of the results. However, it could also be the opposite, i.e. that those who were not satisfied with the use of ICT, were more interested in participating as they wanted to express their views.

The demographic information in the target group included only diagnosis, sex, age or place of habitation, and this can be seen as a shortcoming. However, analyses for response bias regarding these three variables indicated no significant differences between respondents and non-respondents ( $p < 0.05$ ).

### Mixed method

To use a mixed method approach is an emerging trend (Polit & Beck, 2006), and its strength is implied in a triangulation in terms of methods (Kvale, 1997) which in Study I meant that data were generated through observations, interviews with occupational therapists and children. One example was the possibilities to investigate the trustworthiness by cross-checking the use of ATDs in both numbers, types and through the children's experiences to determine if explanations from diverse methods converge. Despite this, the quantitative part and the statistics analysis in Study I was only descriptive in numbers i.e. no statistical analysis was performed and therefore this result should be interpreted with caution.

The timing of the observation in Study I may be a possible shortcoming (Oppenheim, 2003). All the children were interviewed and observed at school and this meant that the child's teacher was the one who decided when the visit should take place to best suit the child and the class. This may be a limitation if the teacher did not understand the information in the cover letter and the purpose of the research and the observation, i.e., the researcher wanted to take account of "an ordinary day" including a variation of school activities with possibilities for the child to use an ATD. It would have been desirable to participate over several days to observe the children's use of ATD in a variety of different activities. However, the children's interviews did supplement information concerning their use of ATDs in activities that were not included during the day of observation.

### Cross-sectional study

The cross-sectional design adopted in Studies II-IV does not make it possible to discuss cause and effect, because the findings only provide a description of what the children respond to at the time of measuring (Domholdt, 2005; Oppenheim, 2003). Although the assumption is that the use of ICT in school promotes participation, the opposite may also hold true. Therefore, the discussion in Study III about the correlation between those who responded that it was difficult to play computer games and/or search on the Internet and those children who lacked a computer-based ATD when doing some computer activities outside school, and the finding in Study IV where four factors were associated with "*participation in computer activities in school*" for children with physical disabilities have to be interpreted with caution and be tested further.

### Instrumentation

Not using a validity or reliability tested survey instrument is a limitation (Domholdt, 2005), and this, among other things, must be taken into account with regard to generalising the results (Terwee, et al., 2007). One of the arguments for creating a new survey was the opportunity to compare the results from children with disabilities with norm data. The survey instrument has been modified from two national surveys of students' use of ICT in educational computer activities in school (Skolverket, 2005) and outside school activities (Mediarådet, 2006). Attempts have been made to improve the validity and avoid bias by ensuring that a good study design is used and by paying attention to details (Terwee, et al., 2007). For example face validity was used by



discussing the questions with scholars in this area and with a statistician (Switzer, et al., 1999), pilot-testing the survey on four children (Terwee, et al., 2007), test-retesting the stability over time (Krosnick, 1999; Switzer, et al., 1999), and analysis of internal consistence with Cronbach's alpha has been made (Krosnick, 1999). Nevertheless, there were methodological shortcomings, for example, the test-retest was made after an interval of about 6 months and a better option has been to make the test-retest with a shorter time-lap as recommended (Switzer, et al., 1999). The test-retest was made to measure the stability of the questions that are not expected to change over time and the items from the survey instrument used in the current study were analysed by Kendall's tau for ordinal scales (Polit & Beck, 2006) among 29 children with physical disabilities which showed  $\tau = 0.48$ . The personal agreement was not as good, which can be partly explained by the long interval between the tests and retest, which needs to be addressed in the future. However, the agreement at group level was found to be 75.4% (Krosnick 1999).

### Data analysis

The differences in size of the comparison groups, i.e., children with and without disabilities, was a shortcoming in the comparison between the groups of children with physical disabilities (n=287), and the reference group in Study II (n=940) and in Study IV (n=1379). This limitation was discussed with statisticians and it had to be taken into account, which can affect the interpretation of the results. In the analysis of differences there was a danger in the analysis of the larger group (non-disabled children) that the null hypothesis was rejected if the p-value was too high and vice versa for the smaller group of children without disabilities (Altman, et al., 2001). Therefore analysis was done with a p-value at both 0.05 and 0.01 to report significant differences between children with and without disabilities (Study II and III), and between girls and boys (Study II) to ensure that the hypothesis was not be rejected or be accepted.

## ETHICAL CONSIDERATIONS

The Ethics Committee at Karolinska Institutet, Stockholm approved the studies in this thesis (2005/91/03 and 2006/1101-31). According to Curtin (2000) the ethical considerations when involving children in research must always be taken with caution and with respect for their integrity, so adaptations may have to be made to the method applied.

### Information

It can be difficult for children to understand what participation in a study involves dependent on the children's ages and development levels. It is a challenge for the researcher to make the information appropriately available. In Studies II-IV the researcher made efforts to explain the purpose of the study in different ways and the cover letter to the families was written in three different versions to suit parents, children < 15 years, and youths  $\geq$  15 years, respectively. Despite the fact that the cover letter to the children was briefer with simpler wording and even used symbols in order to make the information accessible to those without reading skills, there was no guarantee that the children understood the information. There is always a risk that children may be subjected to investigations and interventions that they have not understood. It was therefore of the greatest importance that each child understood that their participation was voluntary and that they could terminate their participation without any explanation (Davis, 1998; Ljusberg, et al., 2007).

There is a risk that adults place too much responsibility on the child, it is therefore particularly important to inform parents that they must ensure that their child understands the information and the concept of freely given informed consent (UNESCO, 2010), although it is the parents who ultimately give this informed consent. The parents' responsibility in this issue could have been explained more clearly in the information letter to the parents.

### Informed consent

Children and youths with physical disabilities may find it difficult to understand the consequences of accepting to participate in research and to understand the meaning of informed consent. In Study I for example, there was a risk that the children did not understand the consequences of what participation meant until the researcher came to

the school and started the observation, and by then they did not dare to withdraw their consent. Researchers are ethically responsible for sensitivity to these type of signs (Curtin, 2000) and although the researcher tried to be alert to the children's signs this was not easy when it was the first meeting with the child. For that reason a recommendation for further research is to spend some time with the child in a safe environment, for example the home, before conducting any observation in school in order to more easily be able to interpret signs of discomfort or doubtfulness.

There was also a risk that the children participated in the research against their will, when it is the parents of children and youths under the age of 15 who consent to the participation. The children in Studies II-IV were encouraged in the cover letter to respond unaided to the questionnaire, but they could get help from an adult if necessary. This could have meant that some parents put pressure on their child to answer the survey, but the opposite may also hold true, i.e., that parents with no interest in ICT and surveys did not give their younger child or a child with reading and writing difficulties the support needed to participate even if the child wanted to do so. Further, children between 15-18 years old were asked to give consent themselves (SFS 2003:460), and for that reason both parents and youths aged 15-18 years old received a personal letter with information on informed consent. However, the parents may not have been aware of the regulations and the information was perhaps not entirely clear in the cover letter.

### Confidentially

The children were informed about the confidentiality, but sensitivity was important in this issue since it can be difficult for a child to understand the meaning of confidentiality. There was a risk that the children felt that they were telling on the adults if they told the interviewer (Study I) that something about their ATDs was not working as they wished. The researcher in Study I, could also have ended up in an ethical dilemma when the child/family possibly had difficulties in differentiating between a research and a therapeutic interview (Kvale, 1997). The child/parents might have expected that the interviewer could address any shortcomings in the use or service of the ATDs used in school. It emerged during the interviews that some children were dissatisfied with the use of their ATDs in school, but the confidentiality made it difficult to pass this information on to the occupational therapist or teacher responsible for the child's ATD. If the children expressed concerns they were encouraged to talk to their teacher, if they did not want to do so, the researcher asked

if they would like the interviewer to talk to a professional about their ATD use in general terms. It would have been desirable if the observation and interview had been carried out on several occasions, to ensure that the child was more comfortable with the interviewer than could be expected on one day.

As all the participants in Studies I-IV were identified by the HC in the county in which the family received their service, there was a risk that the family experienced a dependency on their HC and therefore felt that they "had to" participate in the study. The participants in Study II-IV were assured confidentially, and the surveys were assigned with code numbers to prevent identification. There was, however, one omission; it was not clearly stated in the cover letter that either the researcher or the contact person at the HC knew the names of the respondents in the survey; the key code with the child's name and address was recorded at the HC and the completed surveys were filed by the researcher.

## Protection

In child research there is always a risk that the children participating have a sense of an imbalance of power with regard to the interviewer. Children are not often familiar and comfortable with interviews with unknown people (Davis, 1998) and may not be used to their concerns being taken seriously. Interviewing children demands special care and preparation and the dominance of the adults can be reduced by employing a variety of research techniques which allow children to feel comfortable and a part of the research process (Davis, 1998). To meet this requirement in Study I all of the interviewers had many years of experience of interviewing children and even experience of interviewing children who communicate using alternative augmentative communication, such as communication devices (symbols) and the Talking Mats method (Bornman & Murphy, 2006). As it was, none of the children indicated discomfort in the interview situation, but had that been the case, one strategy could have been to invite an adult well-acquainted with the child to sit beside them.

When conducting research in school with children with disabilities, there might be a risk of stigmatisation (Study I). In an attempt to minimise this risk, preparation was done to protect the child from feeling uncomfortable; the teacher introduced the researcher to the classmates, based on and taking into consideration their knowledge of the child and the class. In the observation the researcher acted as a partial onlooker and tried to follow the child discreetly in the classroom and during

breaks. Nevertheless, there was a risk that the child felt stigmatised and uncomfortable about having an adult observing him/her in this way.

In general, the ethical risks were judged to be minimal for the children in Studies II-IV, as the researcher's intrusion into the children's daily life was small. Despite this, there was a risk that the children and their parents did feel different and singled out as a result of their participation in a study that only targeted children and youths with disabilities. For example, the children were reminded of their limitations when handling computers and the Internet. On the other hand, they could get ideas about what opportunities computer-based ATD provided with respect to addressing activity restrictions.

## CONCLUSIONS AND IMPLICATIONS

The findings of this thesis have contributed new knowledge and insight concerning participation in the use of ICT and ATDs by children with physical disabilities in activities in school and outside school. The findings have clinical implications and provide useful knowledge for occupational therapists and other health professionals who do interventions for participation in everyday activities among children with physical disabilities. These findings can also benefit teachers.

The results demonstrate that children are not always satisfied with their use of the ATDs provided, they also indicate that the choice to use or not to use an ATD is not only the child's decision. This is an ethical dilemma when children both use ATDs they do not want to use, but also do not use ATDs they want to use. The main characteristics of ATDs that children with disabilities appreciated and wanted to use in school are the ATD's integration into teaching and learning and the students' experience that the ATDs enable functioning in everyday school activities without threatening or complicating their social participation with peers. As far as client-centred practice with children and youths is concerned, they need both verbal information and some practical experience of using the devices to be able to make informed decisions. Above all, this applies to ATDs used in an environment in which there is a risk that the child may feel uncomfortable with his/her ATDs.

Findings of this thesis show that computer-based ATDs are more common than mobility aids for children with physical disabilities. Computer-based ATDs need to be highlighted as an intervention in participation in everyday activities for children with physical disabilities. However children are not always satisfied with use and service of their ATDs in school and outside school. The clinical implication is that repeated follow-ups are important to detect the children's dissatisfaction. To measure the children's needs and satisfaction with their computer-based ATDs use, a reliable measuring instrument that is adapted to Swedish conditions and to children is required.

New knowledge is provided in this thesis when computer and the Internet activities are studied with more precision and are divided into several sub-activities. The results indicate that the activity pattern in children with physical disabilities is more varied than

earlier research studying ICT-activities has shown. ICT-activities also have the potential to act as a substitute for activities that children with disabilities are unable to do (due to physical or other limitations), and can bring meaning and enjoyment to the children. One implication is thus the inclusion of computer activities more specifically when identifying activity limitations outside school for children with physical disabilities. For example, to use the computer as a social media, to make contact with persons they know but also to create new contacts, which was found to be difficult in the group of children with disabilities.

The findings in this thesis show that the environments; in school and outside school, provide different opportunities for developing and using the digital skills of children with physical disabilities, who use and do not use a computer-based ATD. Digital skills developed outside school engage children with physical disabilities and provide them with increased access to society and benefit them educationally. Therefore, it is discouraging when schools do not provide children with disabilities with opportunities to fully exploit their digital skills in school, when the results indicate that children with physical disabilities participate in a less diverse range of computer activities in comparison with children in general. The implications of this research are that, in order to increase children's participation in computer activities in school, changes should be made in the environment such as; access to one's own computer, coordination of ATDs between the school and outside school environments, planning of teaching so the children have the opportunity to use the ATDs they already have at their disposal.

## **FUTURE RESEARCH**

This thesis has drawn attention to ICT-activities that merit further study. More research is needed which studies ICT from a broader perspective with respect to boys and girls with and without physical disabilities, where the earlier classification of computer activities, as being passive and performed in solitude, needs to be reassessed.

Many of the children are dissatisfied with the service and use of their ATDs in school and outside school. Therefore, there is a need to validate any existing instruments, or develop new ones, which measure children with disabilities' satisfaction with access and use of ATDs and computer-based ATDs for participation in activities, and social participation.

These studies indicate a need for intervention research in this field to study the implications of specific plans for each child with continuous monitoring of the ATD for its integration into the teaching, and so that the children have access to the ATDs they believe they need for both outside and in school. Further research is also necessary to establish how digital skills affect the academic skills of boys and girls with disabilities.



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