Participation through ICT - studies of the use and access to ICT for young adults with intellectual disability

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PARTICIPATION THROUGH ICT
– STUDIES OF THE USE AND ACCESS TO ICT FOR
YOUNG ADULTS WITH INTELLECTUAL DISABILITY

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- STUDIES OF THE USE AND ACCESS TO ICT FOR YOUNG ADULTS WITH INTELLECTUAL DISABILITY

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Abstract

The right to full participation in society is stated in law to ensure that vulnerable groups such as people with intellectual disability have the same rights and possibilities as the general population. Technological development has changed the conditions of participation in society, including the types of interactions, information and societal services. Many young adults with mild to moderate intellectual disability require support in daily life. In Sweden, this is provided by the government, and each municipality is responsible for the provision of social care for people with disability. The changes in society and technology require that the providers of social care adopt technologies to enable participation.

The overall aim of the thesis was to identify the prerequisites for and aspects that enable the use of information and communication technology (ICT) and their effects on participation in daily life among young adults with mild to moderate intellectual disability (ID) resident in municipal disability services.

Using a quantitative descriptive approach, this thesis starts by mapping the organizational support throughout the country. This is followed by three qualitative studies. Focus group interviews with staff in residential care were conducted and analysed in Study II (a narrative analysis) and Study III (a content analysis). These studies focused on staff perceptions of the use of ICT by these young adults and how staff’s way of work enabled or hindered ICT use by these young adults. Study IV included interviews of young adults with mild to moderate intellectual disability living in municipal residential care about their daily ICT use.

The thesis findings show that the municipal organizations lack a comprehensive strategy of support for the use of ICT and instead trust staff to provide the needed support to the young adults in daily life situations. Staff members described the difficulties they encountered when providing this support for ICT, which were partly because of the lack of organizational resources. Despite these perceived problems, staff members displayed enthusiasm about introducing and supporting ICT use for young adults with mild to moderate ID if adequate resources would be provided by the organization. They described both positive and negative aspects of ICT use by these young adults in relation to service provision and the young adults’ private lives.
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use for social relationships, entertainment and solitary pastime. Participation is described through ICT in several life spheres.

*Keywords:* Environment, Information and communication technology, Intellectual disability, Participation, Social care
List of Papers


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<th>Description</th>
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<tbody>
<tr>
<td>DSO</td>
<td>Disability service organization</td>
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<tr>
<td>HSO</td>
<td>Human service organization</td>
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<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
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<td>ICT</td>
<td>Information and communication technology</td>
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<td>ID</td>
<td>Intellectual disability</td>
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<td>IQ</td>
<td>Intelligence quotient</td>
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<td>LSS</td>
<td>The Swedish Act Concerning Support for Persons with Certain Functional Impairment</td>
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Introduction

Disability service organizations (DSOs) are complex organizations. Providing support in daily life to people with a disability entails both support and protection. In other words, staff must constantly make decisions about how to act in the service user’s best interest. Staff must also manage the balance between their work situation and working conditions; for example, by meeting clients in their home (in the client’s most private life sphere), which simultaneously becomes the staff member’s work environment. Similarly, people needing support, here young adults with mild to moderate intellectual disability (ID), must adapt to being a part of a welfare organization and simultaneously trying to be a part of, and participate in society.

An accepted basic assumption in the Swedish welfare system is that all people have a right to full participation in society. Participation in society is often conditional but is seldom achieved by people with mild to moderate ID. Despite the generous and rights-based law, this group is one of the most vulnerable in society. In addition, the means of achieving participation and the arenas for participation change over time. Technological development is one example where it has markedly changed the way people interact, find information and access societal services. The right to full participation remains, but the means to achieve this have also changed and now involve the use of ICT. Therefore, the technologies used when providing support must also be adapted to societal changes and individual user needs.

Providing and adapting support provision involves complexities and consequences on several levels and for several actors. The complexities are both of research and practical interest to me. I am particularly interested in increasing the understanding of how support can be provided to meet the ambition of full participation through information and communication technology (ICT) use, how social care organizations can be a hindrance or an enabler at the different levels and the interactions at different levels in the effort to achieve full participation.
This project was conducted in the area of social work, within the interdisciplinary research area of *Health and Welfare* at Mälardalen University. The World Health Organization has stated that all people have the right to the highest attainable standard of health, as a part of its declaration of human rights. The right to health involves the entitlement to a system of protection and services that provides equal opportunities for health for everyone. Hence, governments have a great responsibility (Backman, 2012; United Nations, 2000; World Health Organization, 1946).

This thesis focuses on young adults with mild ID living in municipal social care. This group of persons experience worse living conditions than the general population in terms of not having living circumstances that enable participation in society and different life spheres. For the young adult as a service user, the organization is expected to embody the values of trust, responsiveness to human needs and commitment (Hasenfeld, 2010a; Provan & Milward, 2010).

There is a lack of knowledge about the role of ICT in supporting participation throughout the different life spheres. Staff members of social care organizations are key to the provision of support for the participation of young adults with mild to moderate ID in different life spheres and health and welfare. The purpose of this thesis was to obtain new knowledge that would be relevant to both social care organizations and the social insurance agency and that could be used in the education of social workers, staff in residential care and care managers in the social services. Especially, the knowledge can benefit young adults with ID resident in municipal social care.
Background

Swedish disability policy and practice

The Swedish welfare system is unique in its tax-based financing, and Sweden is the only country with rights-based law to ensure good living conditions for people with disability (Hort, 2014; Laragy, 2010; Tössbro et al., 2012). The Nordic countries are acknowledged to have the most comprehensive disability services among the European countries (Tschanz & Staub, 2017). Support and service are provided to those having received a diagnosis and with a need for support that cannot be met otherwise. Social care for people with disability is unique because of the legislation and its cornerstones, which provides equal rights and value for people with disability, social and financial security, and good health, including full participation in societal life (Government of Sweden, 1993:387).

Each municipality bears the responsibility of service provision to people with disability. In Sweden, municipalities are politically driven and self-governing. The Act Concerning Support for Persons with Certain Functional Impairments (LSS) is a rights-based law that entitles people with ID to societal support. Those eligible for support are defined in the law as three groups: (1) persons with ID or autism; (2) persons with permanent brain injury caused by injury or disease in adulthood; and (3) children, young people and adults with permanent physical or mental disability not caused by normal ageing (Government of Sweden, 1993:387).

According to the law, municipalities should promote life conditions for those with disability that are equal to those provided for people without disability, and full participation in societal life. Activities should be provided that are relevant to each service user’s self-determination and integrity (Government of Sweden, 1993:387). Activities conducted based on the law’s objectives can be interpreted and designed in various ways given that they are based on the national law as a framework (Tössbro et al., 2012; Vallgårda, 2008).
The LSS includes 10 different areas in which support can be provided and includes residential care, daily activities and support that enables leisure activities. Residential care and daily activities are the most common forms of support. People with ID or autism are the largest group receiving services according to the LSS and they receive 89 per cent of the total services. In 2016, the number of individuals receiving services because of ID or autism was 62,182 of a total 71,404 receiving services according to the LSS. ID is an administrative definition that makes a person eligible to receive support and services, if needed. However, the services provided are adapted to each person’s functioning in daily life rather than to the diagnosis (Swedish National Board of Health and Welfare, 2016).

Municipal organizations are organized according to different structures and political ideologies. This makes all 290 municipalities unique as organizations (Government of Sweden, 1993:387; Swedish National Board of Health and Welfare, 2009). Additionally, the law constitutes a rights-based approach to disability, which means that all are entitled to rights according to the law. To fulfil this aim, support requires a needs-based approach that focuses on an individual’s specific needs. According to the LSS, support can be provided when specifically asked for. However, support can also be seen as a solution in itself, even though not necessarily providing adequate response to the actual problem. This paradox was described by Carlhed, Björck-Åkesson and Granlund (2003), who noted that this can result from miscommunication between professionals and clients because clients often describe what support they want instead of the problem itself. Hence, professionals tend to interpret the provision of support as the solution to the problem even though it might not. When this occurs, the problem and need may remain, but according to the rights-based approach a solution has been provided.

Approaches to disability from the historical perspective

The modern disability policy in Sweden derives from the 1960s, when the debate started to focus on difficulties created in society for people with disability and, primarily, the voices of people with disability. Consequently, disability became more of a political question compared with previous times when disability was regarded as an individual trait or weakness. Some issues that were highlighted then remain cornerstones of the national disability policy are housing, support in housing and access to recreation (Swedish ministry of health and social affairs, 2000).
The different approaches to disability and, therefore, the ideological foundation have changed over time and as well as conceptual use and meaning of disability. The term *handicap* has been replaced by the term *disability*. An important development is the conceptual difference between the terms *impairment* and *disability*. Although impairment describes a bodily impairment, disability refers to the hindrance that occurs in the relation between the individual and the environment that may create an inability to function or act in a social context (Swedish National Board of Health and Welfare, 2009).

Models of disability

Historically, disability has been viewed from several standpoints, which have formed the public national ideology, and people with ID have been treated accordingly. In Sweden, this has meant that people with disability have been viewed as “unteachable”, “idiots” and “imbeciles” (Grunewald, 2008). From the historical perspective, the medical model of disability has been prominent, and disability has focused on the individual and has been described as a personal tragedy occurring as a result of pathology. From this perspective, disability is associated with body functions, and any limitations that might occur in relation to the environment can be overcome by medical, psychological or educational treatment with the purpose of compensating for the impairment (Arvidsson, 2013; Grunewald, 2008; Shakespeare, 2013). In different eras, the ideology about people with ID has fluctuated, but the societal solution has consistently been institutionalization. The argument for institutionalization has varied between *protecting society from persons with ID* and *protecting persons with ID from society* (Grunewald, 2008).

The social model of disability arose as a counterpart to the medical model. The strong social model advocates that disability is a social construction that results from an unavailable society and is not related to body structure or body function. Disability is considered to be only a social problem caused by societal constructs and features that systematically create physical and social barriers to participation and access to society. From the social perspective, the solution to overcome disability is through social change (Gustavsson, 2004; Oliver & Barnes, 2010; Shakespeare, 2013). The medical and social models of disability can, in their extreme forms, be considered as different ends of a continuum, in which the medical model does not consider the environment and the social model does not consider impairment.
Both the medical and social models of disability have strengths and limitations, and a more recent relational model of disability has become the preferred perspective, especially in the Nordic countries (Shakespeare, 2013; Swedish National Board of Health and Welfare, 2009) as well as the wider international perspective (World Health Organization, 2001). The relational model of disability comprises the national formal approach in Sweden and advocates that disability occurs in the relationship between the individual and the environment. Therefore, disability exists because of the combination of impairment to body function and barriers in the physical, social and attitudinal environments (Gustavsson, 2004; Swedish National Board of Health and Welfare, 2015; World Health Organization, 2001). According to this view, support and services in Sweden should be conducted from the relational perspective, and the relational model of disability has been applied in the thesis.

**Intellectual disability**

The diagnosis of ID is based on the intelligence quotient (IQ) and adaptive skills, and occurs during the developing years (before the age of 18 years). Adaptive skills are assessed in three domains. The social domain (i) includes reading, writing, reasoning, language, and mathematics. The conceptual domain (ii) comprises traits such as empathy, social judgement, ability to make and maintain friendships and interpersonal communication. The practical domain (iii) includes self-management such as personal care, money management and organization of work tasks.

IQ can be tested, and the diagnosis of ID requires an IQ score of $\leq 70$, or about two standard deviations from a statistically normal IQ. However, in the assessment and diagnosis of ID, functioning (adaptive skills) is more important than IQ alone. That is, a person can have a low IQ score without being diagnosed with ID (American Psychiatric Association, 2016). Granlund and Göransson (2011) define adaptive skills as a person’s ability to adapt to daily life and to adapt daily life to oneself and one’s functioning in everyday situations.

In this thesis, the diagnosis of ID is relevant because it is required for societal support and service according to Swedish legislation (Government of Sweden, 1993:387). Arvidsson (2013) argued that, in terms of functioning in daily life, a person with a mild ID can experience greater difficulties in daily life than a person with more severe ID. Therefore, functioning described as a
consequence of disability may be more accurate than the medical label (Maxwell, 2012). In this thesis research, the term ID is used because of its role in determining societal support. However, the thesis focuses on the need for support and the consequences for participation in daily life rather than as a medical diagnosis or individual trait.

Participation from the social care context

Participation is a core concept of the Universal Declaration of Human Rights (United Nations, 1948) and has been used in Swedish law (the LSS) to ensure good living conditions for people with disability (Government of Sweden, 1993:387). The Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006) notes the importance of ICT, which refers to technology and systems including the Internet. This document highlights the recent technological developments, which have increased the use of ICT as a tool for participation and inclusion in society and societal services. The convention states that all state parties should enable access to ICT to create equal living conditions for all. In this thesis research, ICT is defined as including modern technology such as mobile phones, tablets with Internet access and computers.

In Sweden, people with ID are entitled to societal support in 10 specific areas, regulated by the LSS, such as daily activities, housing support and leisure (Government of Sweden, 1993:387). Despite societal support, people with ID participate less in several life areas than do people without disabilities (Umb-Carlsson, 2008; Umb-Carlsson & Sonnander, 2005). Even when participating in activities and interacting with others, participation occurs mainly within the disability community and not in the general community (Dusseljee, Rijken, Cardol, Curfs & Groenewegen, 2011).

There are gender differences in participation (Umb-Carlsson & Sonnander, 2006). For example, it is more common for men with ID to visit the cinema or a restaurant, to practice a hobby or to have friends without ID, whereas women with ID are more likely to read books (or listen to talking books) or visit the local library (Dusseljee et al., 2011; Umb-Carlsson & Sonnander, 2006). Other gender differences are found in daily activities, although gender differences in the general population are greater than within the disability community. Women with ID are more likely to participate in daily activities within the service area, whereas men with ID are more likely to participate in activities involving industry, forestry and gardening activities. However, most adults with ID have not decided by themselves which activities to engage in (Umb-
Carlsson & Sonnander, 2006). In other words, disability service organizations (DSOs) may be contributing to gender differences by offering or choosing opportunities and activities according to gender.

The relational model of disability has been adopted in Swedish DSOs. Studying participation among young adults with mild to moderate ID, and their use and access to ICT, may benefit from focusing on environmental factors that hinder or facilitate participation in relation to the individual’s functioning, (i.e. contextual factors). The barriers to participation are thought to be caused by environmental aspects, both physical and attitudinal, rather than resulting only from ID (Ineland, 2013; Umb-Carlsson, 2008; Umb-Carlsson & Sonnander, 2005, 2006).

Technological development and access in society
Society has moved into a digital and information age. ICT has transformed the way societal services are available and has become a cornerstone of interactions. For individuals, this means almost unlimited information, entertainment and opportunities for interactions through social media. Online interactions and self-presentsations allow the individual to be seen and acknowledged, which establishes a social reputation or status. Presenting and expressing oneself online is a participatory action that makes an individual a co-creator in the cultural and social content. Actions such as sharing pictures, writing comments and “liking” others’ posts confirm an individual’s presence as “being there”, which also helps to form an identity (Xinaris, 2016). In addition to an online identity, the mobile phone provides a physical device for self-presentation offline. Adapting ringtones, a device cover and background to be more personal helps a person express his or her personality (Peuravaara, 2013; Stald, 2008). Along with technological developments, ICT has become an important means for social, political and civic participation and a positive influence in daily life (Boulianne, 2015; Xenos, Vromen & Loader, 2014).

Formation of an online identity as part of online participation requires access to a device. In the early days of the technology, unequal access to devices because of socio-economic differences created the so-called digital divide. However, inequalities in access to ICT are considered to have decreased in recent years. The lack of material access (availability) was once considered to be the main issue by both policy makers and public opinion, and the thinking was that the problem would be solved once everyone has access to an ICT
device and Internet access. Nevertheless, a relative structural inequality between groups emerged because of differences in skill and use of ICT, which remains despite the increased availability (Lussier-Desrochers et al. 2017; van Dijk & Hacker, 2003). Differences in use and skill can occur for several reasons. One reason is a lack of interest or unattractiveness of a new technology. Another reason is differences in ownership of devices and/or Internet connection, although this effect has decreased as both ICT and the Internet have become more available. Another reason is the lack of user friendliness of devices or insufficient social support (van Dijk & Hacker, 2003).

No gender differences in access have been identified, but older persons use ICT less frequently than young adults do. The most frequent ICT users are the young adults (born in the 1980s and later), who are considered to be “digital natives”. This group is assumed to have experience of ICT as a natural part of their daily life and are, therefore, more likely to have experience with broad ICT and Internet use, and to use the Internet as the first source of information (Findahl & Davidsson, 2015; Helsper & Eynon, 2010).

Sweden has among the highest Internet penetration rate in the world (International Telecommunication Union, 2013). Despite this, there are inequalities in ICT use between people without and those with disability (Scholz, Yalcin & Priestley, 2017). Inequality in access and use carries the risk of unequal participation in daily life. Compared with other European countries, Sweden has the smallest gap in Internet access between people without and those with disability. However, this comparison is based on self-reported disability status (Scholz et al., 2017) and most likely does not include people with ID. People with ID are often missing in these kinds of statistics and form one of the most vulnerable groups in society in terms of education, socio-economic and health status and participation in the wider society (Ineland, 2013; Umb-Carlsson, 2008).
Use of ICT by young adults with ID

From the broad perspective, ICT and e-services can create opportunities for participation in the community for people with disability (Manzoor & Vimarlund, 2017; Verdonschot, de Witte, Reichrath, Buntinx & Curfs, 2009). Among young adults with mild to moderate ID, ICT has been described as important for empowerment, self-determination, social relationships and leisure. The Internet provides access to social networking sites for finding information to facilitate transport or participation in other activities (Parsons, Daniels, Porter & Robertson, 2006b; Renblad, 2003; Sallafranque-St-Louis & Normand, 2017). Nevertheless, the use of ICT is lower in young adults with ID compared with their peers in the general population and they have fewer opportunities for participation through ICT use (Bryen, Friedman, & Carey, 2007; Chadwick, Wesson & Fullwood, 2013; International Telecommunication Union, 2013; Lussier-Desrochers et al., 2017; Scholz et al., 2017).

Young adults with ID use ICT as a mean of self-presentation. One strategy in their striving towards participation is to be viewed as an “intellectually abled” person. This can be expressed by presentation of clothes or by carrying a computer or mobile phone, which is regarded as representing able-bodiedness, normality and inclusion. By doing so, young adults with ID perceive that they can blend in and pass as an able-bodied person. In this sense, the device becomes important in itself, regardless of its use (Peuravaara, 2013; Söderström, 2009b).

It has been noted that ICT enables social relationships, both as an extension of offline relationships and in purely digital form. This allows a person to present him or herself according to interests and personal attributes, and to avoid being seen as disabled. ICT can also provide a common ground for interactions in offline relationships by facilitating interest in and discussion of activities such as games or YouTube videos. In this way, online activities and interests can help to develop and support existing offline relationships (Sallafranque-St-Louis & Normand, 2017; Söderström, 2009a).

Support persons and parents are often worried about whether people with ID are vulnerable when participating in online activities, such as being harassed or exposed to inappropriate online content (Löfgren-Mårtenson, 2008; Molin, Sorbring & Löfgren-Mårtenson, 2015; Seale, 2014; Seale & Chadwick, 2017). Adequate support and education are needed to make ICT accessible and are necessary for both people with ID and support staff (Mavrou, Meletiou-Mavrotheris, Kärki, Sallinen & Hoogerwerf, 2017; Parsons, Daniels, Porter & Robertson, 2008). Parents of young adults with ID believe that
the Internet offers opportunities for friendship, playing games and listening to music. However, they also fear that the Internet can isolate their offspring from offline social life and relationships (Sorbring, Molin, & Löfgren-Mårtensson, 2017). On the other hand, teachers are less worried about social exposure and social isolation because of Internet use by young adults with ID (Molin et al., 2015).

Even though facilitated communication and independence acquired through ICT enable participation by people with ID, participation may be hindered in those who lack the required ICT skills (Mavrou et al., 2017). These can include technical skills, cognitive skills and understanding of online social codes and behaviours (Lussier-Desrochers et al., 2017). Difficulties related to these skills can be problematic for people with ID (Harrysson, Svensk, & Johansson, 2004; Li-Tsang et al., 2006; Tanis et al., 2012). The lack of skill may include difficulties navigating ICT and managing the volume of text and of information, and problems with working memory or cognitive understanding of what appears on the screen (Harrysson et al., 2004; Lussier-Desrochers et al., 2017; Tanis et al., 2012). Assistive devices can reduce some of these difficulties (Li-Tsang, Lee, Yeung, Siu, & Lam, 2007; Mavrou et al., 2017). Other solutions include personalized support for ICT use to enable social participation (Raghavendra, Newman, Grace & Wood, 2013; Sorbring et al., 2017).

Although prior research indicates that there are both positive and negative aspects of ICT use by people with ID, research regarding availability and support for ICT from the social care context is sparse. However, a clear organizational aim can help to motivate staff to prioritize ICT use in daily life for young people with ID. Additionally, employing support staff with knowledge about ICT may be useful, and organizational support appears to be crucial to enabling the use of ICT as part of social care for people with disability (Hegarty & Aspinall, 2006; Parsons, Daniels, Porter & Robertson, 2006a; Parsons et al., 2008). It has been argued that a focus on protecting young adults with ID from social exposure may prevent them from engaging in valuable opportunities (Seale, 2014; Seale & Chadwick, 2017).

Difficulties for young adults with ID in ICT use seem to be consistent over time and place. Availability and access can differ because of different environmental factors. Enabling a person to participate in a situation requires a good fit between the individual and the environment (the context). Young adults with mild to moderate ID in Sweden often receive support according to the LSS. Therefore, the organizational environment plays a role in the young adult context and how they use ICT as a tool for participation. The influence
of the environment and context on ICT use has not been studied thoroughly, especially in Swedish DSOs. It is important to understand the organizational environment and the interactions between organizations and young adults with ID, such knowledge will help social care facilitate the use of ICT as a mean of participation in society by young adults with ID.
Theoretical approach

Participation

Participation is a wide and, in many contexts undefined, concept. Closely-related concepts such as involvement, inclusion or engagement, are sometimes used synonymously (Arnstein, 1969; Granlund, 2013). The meaning of participation is not defined or explained specifically from the political perspective of DSOs in Sweden. In the academic context, several attempts have been made to define participation clearly. One core aspect is the eligibility of those deciding whether participation exists in a specific situation and more specifically, the difference between subjective and objective participation (Arvidsson, 2013; Hemmingsson & Jonsson, 2005; Maxwell, 2012). Subjective participation depends on the feelings or perception of participation and implies that only the individual can decide whether he or she is participating or not. On the other hand, in objective participation, a third party decides whether a given individual is participating.

From the political perspective, objective participation is preferred because it focuses on the right to equal conditions for participation and not on the experience. The subjective experience of participation is necessary as it is first then one actually knows if participation has been achieved (Molin, 2004). From both the political and service-provision perspectives, the task is to provide conditions that enable participation, although the experience of participation (subjective participation) cannot be ensured. Therefore, participation can never be decided by another person but can be enabled by opportunities, although each individual must choose to engage in the situation.

Participation is related to power. True participation means being able to influence decision-making in addition to being informed or to providing advice, and implies a type of partnership in decision-making (Arnstein, 1969). Applied in the social care situation, the young adult with ID must be enabled, and trusted, to make decisions and not simply be informed or asked without having any real influence. True participation also requires more than attendance at an activity or in a situation. The International Classification of Functioning, Disability and Health (ICF) has provided a widely used definition of
participation as *engagement in a life situation*. This definition stresses that participation brings more to a situation than simple attendance or taking part in an activity: it requires engagement in the situation. Therefore, participation focuses on the lived experience but has been operationalized as *performance of an activity* (World Health Organization, 2001).

Participation has been argued as being situated within the relationship between individual functioning and the environment (i.e. contextualized). In a similar way, disability involves the relationship of aspects of functioning in daily life by considering both body functions and the everyday environment (Arvidsson, 2013; World Health Organization, 2001). The aim of the ICF is to integrate the medical and social perspectives of disability as complements to each other by building on a biopsychosocial model and advocating a relational approach to disability. The ICF is divided into four different domains: (i) body functions; (ii) body structures; (iii) activities and participation; and (iv) environmental factors. The domain body functions includes psychological and physiological functions, and the domain body structures includes anatomy (i.e. deviance from what is considered to be normal for persons of the same age).

A person’s functioning is influenced by aspects in the environment that can hinder or facilitate individual functioning through their absence or presence. Functioning is used as an umbrella term that includes body functions, activity and participation. In the same way, disability is used as an umbrella term that includes impairment, activity limitations and participation restrictions (World Health Organization, 2001). Activity and participation are considered to be two separate items for assessment, despite their close connection. Activities are those actions that an individual can do (capacity) in a standard environment, and participation reflects those actions that an individual actually does (performance) in the current environment. However, the ICF does not measure the subjective experience because the qualifier “performance” represents participation (i.e. what a person does in the current environment). This lack of inclusion of the subjective experience has been criticized because it is argued that the subjective experience provides more information about engagement in a situation/activity than its performance (Arvidsson, 2013; Hemmingsson & Jonsson, 2005).

The ICF emphasizes engagement in the definition of participation but lacks operationalization of this definition. Batorowicz, King, Mishra and Missiuna (2016) defined engagement as “the physical or behavioral (e.g. attendance), cognitive (e.g. expectations, beliefs) and emotional involvement” (p. 1210). Environmental factors that enable participation include the physical, social
and attitudinal aspects of the surrounding environment (Pless & Granlund, 2011; World Health Organization, 2001). Explained more explicitly, the environment refers to the surrounding structures that influence people, such as cultural, economic, historical and technological circumstances and processes at the macro level, as well as community organizations, networks, family and individuals. The social context describes the experience of places, activities, objects and time. The environment affects opportunities for and availability of activities (in this thesis, this specifically addresses ICT), whereas the context refers to the interaction between the environment and an individual and, thereby, the social experience in the environment (Batorowicz et al., 2016). Therefore, a person’s functioning in the current environment depends on the interaction between the individual’s ability and the environment, which is described as the context (Batorowicz et al., 2016; World Health Organization, 2001).

Choice of activity is an important aspect of participation (Batorowicz et al., 2016; Imms et al., 2016) because it represents motivation and, more importantly, implies control and autonomous decision-making. In other words, choosing an activity by oneself reflects personal motivation as well as the environmental opportunities, expectations and emotional involvement in the activity (i.e. engagement). Engagement can occur because of the activity itself but also because of other aspects, such as others who will join the activity (Batorowicz et al., 2016).

Participation is a central concept in this thesis and has been examined through both the subjective and objective perspective. Despite the lack of operationalization of the subjective experience of participation in the ICF (Arvidsson, 2013; Hemmingsson & Jonsson, 2005), the self-chosen use of ICT is interpreted as participation because it also describes the context (Batorowicz et al., 2016; Imms et al., 2016). It may therefore be assumed that self-chosen use of ICT reflects some extent of engagement in the situation. By contrast, self-chosen use of ICT is not interpreted as participation if related to actions that could be done but were chosen not to be done because this indicates activity rather than participation.

In this thesis, ICT use has been studied as a means of participation among young adults with a need for support in daily life, which implies residential support. The use of ICT is interpreted as participation when it was self-chosen and provided engagement in an online or offline activity. The studies described in this thesis are based on guidance of the ICF (World Health Organization, 2001) about how environmental and contextual aspects affect availability (Study I), access (Studies II and III) and use of ICT (Study IV) to enable
participation. These have been analysed in the context of the physical, social and attitudinal hindrances, and opportunities provided within municipal social care. These studies are also based on the ICF’s definition of participation as engagement in a life situation as operationalized as performance of an activity, here the *self-chosen use* of ICT.

**Neo-institutional approach to human service organizations**

To understand participation within municipal social care, the environment and context in which participation takes place should be considered. For a young adult with ID who needs support in daily life, the organizational structure, policies, type of housing and relationship with staff are aspects that can be classified as environmental aspects (World Health Organization, 2001) that can influence a person’s functioning in the social context. Therefore, organizational theory can be applied to understand the environment and context in which participation takes place. In addition, organizational theory can enhance the practical implications of the findings by providing a tool to explain the mechanisms underlying the barriers to and opportunities for participation that are enabled in the environment and/or context.

Human service organizations (HSOs) can be defined as all types of organizations that work with humans as an outcome, for example school, health care, elderly care, social services and disability services (Hasenfeld, 2010b; S. Johansson, Dellgrän & Höjer, 2015). The neo-institutional approach comprises concepts that can be applied to understand the processes in an organization or the outcome of an organization (R. Johansson, 2006). Specific to a neo-institutional approach is that an organization is always seen in relation to the social and cultural environment in which it is embedded. The analytical perspective focuses on the organizational field instead of the specific organization because organizations within a specific area, such as disability services, tend to have a similar formal structure (i.e. they are isomorphic). The formal structure can be isomorphic, but organizations can differ in their technologies (i.e. what is actually done). The relationships between an organization and its social and cultural environments raise a criticism about the assumption that the environment favours rational, goal-oriented and efficiency-oriented organizations, as assumed in many other organization theories (Hasenfeld, 2010c; R. Johansson, 2006; Meyer & Rowan, 1977).
Societal legitimacy is central for the survival of an HSO (Hasenfeld, 2010a; Levin, 2013; Meyer & Rowan, 1977). To gain legitimacy, organizations must have a formal structure that seem effective. The formal structure and formal actions are assumed to produce organizational results. This is called the “institutionalized myth” and is supported and reinforced through laws and regulations. Decoupling can be explained as a consequence of the societal expectations on the organization when the formal structure is not consistent with the daily needs of the service user (Levin, 2013; Meyer & Rowan, 1977). Decoupling (i.e. the difference between the formal structure and the technologies) can occur if the controlling function and audits of the extent to which the practices correspond to laws and policies becomes too strong. The audit, which aims to increase evidence of support provision, takes a top-down perspective. It may not be instigated by the professionals/staff but may instead be a mean of control by a higher authority. This may institutionalize a lack of trust between workers in different levels of an HSO (Lindgren, 2015; Power, 1997), which may in turn limit staff discretion in interactions with service users (Hasenfeld, 2010d).

Eight characteristics have been identified by Hasenfeld (2010c) to describe, explain and define HSOs. The first characteristic is the people as “outcome”, people constitute the raw material. Referring to humans as the raw material here is not intended to portray them as objects to the organization, but the well-being of humans is considered to be an outcome of the organization. This makes HSOs different from other types of organizations. All work done in an HSO can be characterized by three technologies: people-processing technologies, which categorize and classify people to assign rights and obligations to individuals (e.g. diagnosing); people-sustaining technologies, which retain capacity and ability; and people-changing technologies, which change behaviours to solve “problems”. Being a recipient of societal support can involve one or more of these technologies. The second characteristic of HSO is moral work. Because people are the outcome, all work in an HSO implies some form of interference in people’s private spheres; therefore, work within an HSO is always considered to be moral work. At the macro level, moral assumptions derive from strong political interest groups, which can influence the development of social policy. In this way, the moral agenda of these groups becomes institutionalized with explicit or implicit moral values in the form of social policy, which welfare departments are expected to deliver. However, these moral assumptions can conflict with local moral assumptions, which is why upper-level politicians allow for considerable discretion for implementation at the local level. Officials at the local level can adapt
the design of programmes to fit the local economy and local moral assumptions. The organization itself is also a source of moral assumptions that influence how service users are treated by the service technologies and which are justified by rationality and/or efficiency to, for example, produce moral consequences for the service user. Regardless of whether the organizational technologies are consistent with societal norms, they are important for guiding staff and institutionalization within the organizational practice. Moral assumptions within the organization are mutually reinforcing and thereby reproduce themselves over time (Hasenfeld, 2010c).

Although HSOs are seldom presented as doing moral work, morality underpins the services and actions. Hasenfeld (2010a) specifically described moral work and its consequences for service users within HSOs as “Because they are embedded in the organizational routines, they become part of the ‘visible hand’ that controls workers’ behaviors and actions. Yet, I would propose that it is the moral decisions that determine and justify the actual services clients obtain” (p. 13). Interventions to interfere in people’s lives are therefore built on the assumption that the organization is upholding the societal moral worth. Staff also act as moral entrepreneurs through their actions in support situations. Staff members are expected to exercise considerable discretion in such situations, and the organization is therefore dependent on staff acting as moral entrepreneurs. Organizational resources and time play a significant role in the development of work practices by staff and take this into account when prioritizing the provision of staff support to make their work situation manageable. Service users, especially those who lack power, are dependent on staff to construct their cases.

Given the assumption that HSOs perform moral work, organizations must also seek legitimacy for what they do. Legitimacy can be gained by making reference to the moral systems in the surrounding environment in which the organization is embedded. Therefore, the third characteristic of HSO is the institutional environment which is central to the organization’s survival. In a broader sense, this also relates to a heterogeneous and pluralistic society with competing and diverse logics of moral as well as a changing society. Therefore, what was acceptable at an earlier time might not be acceptable today; an example is the institutionalization of people with disabilities in the past (Hasenfeld, 2010a).

Technologies must be acceptable and consonant with the dominating moral values. The fourth characteristic is the institutional basis for technologies. These technologies constrains the organization, which must select technolo-
gies primarily to receive legitimacy from other institutional actors such as regulatory agencies, interest organizations as well as academic and research organizations. The available repertoire of technologies and practical solutions can be applied only if consonant with the institutional environment (Hasenfeld, 2010a). In this view, people are considered to be an unstable raw material. Therefore, the fifth characteristic of HSO is that organizations operate with indeterminate technologies and lack predictability and knowledge about how to achieve the desired outcomes. People are subjective and changeable. Interventions that have been shown to be effective in cause-and-effect relationships through experiments and clinical trials may not be as effective in a real-life situation because of intervening contextual factors not included in the clinical trial. The outcomes are difficult to measure, which explains why organizational goals are often vague and abstract (Hasenfeld, 2010a).

At the organizational level, resources, quality of staff and internal control systems affect how technologies are practiced. At the worker level, aspects such as personal beliefs, experiences and conditions of work affect how staff members apply each technology. For service users, the attributes of interventions can vary between individual service users and can interact with other attributes and the environment in ways that cannot be predetermined or controlled. Therefore, the relationship between staff and service users is a core activity and constitute the sixth characteristic of HSOs. Staff members are key personnel in meeting and supporting service user needs in daily life. The relationships and interactions form the core of support provision. The personal belief system by staff members plays a significant role in operationalizing the moral assumptions delivered through service technologies and thereby also shape the staff–service user relationship. Staff members within a team often have similar experiences, background and communication with each other, and may therefore share a similar belief system. This process of sharing can contribute to the institutionalization of a staff belief system in organizational practices, as seen in the patterns of interaction between staff and service users (Hasenfeld, 2010c).

Within the relationship between staff members and service users, both actors use their emotions as a way to communicate and influence each other; this is one reason why HSOs are characterized as involving emotional work. Hence, emotional work is the seventh characteristic of HSOs. Organizations often define the appropriate display of emotions by staff within the organization. There are several means to ensure the appropriate expression of emotion, such as the type of staff recruited and their training, supervision and socialization. In response, staff may sometimes display inauthentic feelings, which
can lead to staff exhaustion. The organizational setting for emotional work defines how staff should act in encounters in which emotions are displayed and the emotions they should respond to.

Historically, women are the predominant gender of staff employed by HSOs. Women have been viewed as ideal care providers as an extension of their role as family carers, and motivated by love. The eights characteristic of HSO is gendered work. Women predominate especially in direct service provision. It is argued that women, as front-line workers, bring values of empathy, nurturing, caregiving and co-operation. Male-dominated bureaucracies (e.g. management of DSOs) reward individualism, competition and instrumentalism while simultaneously devaluing typical feminine characteristics. This conflict can result in the subordination of women in an organization. However, the bureaucratic structures inhibit women’s capacity to optimize the technologies and fail to adequately reward them (Hasenfeld, 2010a).

These eight characteristics have been adjusted to the Swedish context with the addition of the political and democratic situation (S. Johansson et al., 2015). However, the adjustment to the Swedish context lacks an explicit definition of moral work, as defined by Hasenfeld (2010c) and which forms part of neo-institutional theory. Moral work is not explicitly included in the adaptation to the Swedish context by S. Johansson et al. (2015) but is related to the importance of providing support and services that are consistent with cultural and social norms. Therefore, by using the eight characteristics as described by Hasenfeld (2010a) complemented by considering the political governing, the four studies of this thesis will help to better understand the relationships between the environment and context that will enhance the use of ICT as a tool for participation by the young adults with ID. The different perspectives considered in the four studies interconnect the rights-based perspective (i.e. what is ensured by law) and the needs-based perspective (i.e. what individuals need in their specific situation) on ICT as a tool for participation in daily life for young adults with mild to moderate ID.
Swedish law states that people with intellectual disability (ID) have the right to full participation in societal life (Government of Sweden, 1993:387). Municipalities are responsible for providing societal support according to LSS. It is therefore important to understand how the environmental aspects enable participation. However, social care is permeated by moral values and is in need of societal legitimacy, which can affect the provision of support (Hasenfeld, 2010a).

The Internet penetration rate in Sweden is among the highest in the world (Scholz et al., 2017), and young adults are the most frequent users (Findahl & Davidsson, 2015). Young adults with ID have a lower degree of participation than the general population and experience problems with access to ICT. In the general population, young adults use ICT to participate in civic, political and social life. Lack of, or restricted, access to ICT can increase the risk of social exclusion (Lussier-Desrochers et al., 2017).

Environmental aspects can enable or hinder the access to ICT. Prior research has focused on the use of ICT at the individual level but lacks contextualization of ICT use and its possible impact on how ICT becomes available and used. It is necessary to better understand the current conditions and how these may or may not be supportive of ICT use by young adults with ID. In Sweden, most young adults with mild to moderate ID have residential support. Therefore, deeper understanding is needed about enabling ICT use by young adults with ID, including both the young adults’ use of ICT and support from DSOs in terms of policy and strategies as well as staff perceptions and support of ICT use.
Overall aim
The overall aim of the thesis was to elucidate prerequisites for and aspects that enable the use of information and communication technology (ICT) and their impact on participation in daily life among young adults with mild to moderate intellectual disability (ID) resident in municipal disability services.

Specific aims

Study I
To describe how municipal organizations in Sweden structure support in terms of policy and strategies to enable the use of ICT in social care for young adults with mild to moderate ID.

Study II
To reveal staffs’ way of work with young adults’ with mild to moderate ID independence and participation through ICT.

Study III
To describe staff perceptions of the role of ICT and its influences on daily life in young adults with mild to moderate ID living in residential homes.

Study IV
To describe the use of ICT from the perspective of young adults with mild to moderate ID in a municipal social care context.
Methods

The thesis comprises four empirical studies (table 1), one with a quantitative design and three with a qualitative design. Three different data collection methods were used: a questionnaire, focus group interviews with staff and individual interviews with young adults with ID. Both Studies II and III were based on the empirical data from the focus group interviews. All studies were conducted in accordance with the ICF (World Health Organization, 2001) and included both environmental and contextual prerequisites in the design as a framework for enabling the use of ICT as a tool for participation in the different levels of the organization.

Table 1. Overview of methodology in the four studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Sample</th>
<th>Data collection</th>
<th>Analysis</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Quantitative</td>
<td>290 municipalities</td>
<td>Questionnaire</td>
<td>Descriptive statistics</td>
<td>Published</td>
</tr>
<tr>
<td></td>
<td>cross-sectional</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>Qualitative</td>
<td>15 staff working in residential care for young adults with mild to moderate ID</td>
<td>Four focus group interviews</td>
<td>Narrative analysis</td>
<td>In manuscript</td>
</tr>
<tr>
<td>III</td>
<td>Qualitative</td>
<td>17 staff working in residential care for young adults with mild to moderate ID</td>
<td>Four focus group interviews and two individual, semi-structured interviews</td>
<td>Content analysis</td>
<td>Accepted</td>
</tr>
<tr>
<td>IV</td>
<td>Qualitative</td>
<td>11 young adults with mild to moderate ID</td>
<td>Semi-structured interviews</td>
<td>Content analysis</td>
<td>Published</td>
</tr>
</tbody>
</table>

The use of different qualitative approaches can reveal different ways of understanding the phenomena (Patton, 2002). Therefore, both content analysis and narrative analysis were used to analyze the focus group interviews. This made it possible to highlight staff members’ perceptions of ICT use (Study
III) as well as how they position themselves in relation to ICT use in their work supporting young adults with mild to moderate ID (Study II).

All included studies show how ICT can affect participation by young adults with ID in ICT. The starting point was the ICF, and the thesis research focused on the environmental and contextual aspects relevant to participation. Study I operationalized the objective aspects of participation by focusing on organizational policies and strategies for enablement of ICT use. Studies II and III operationalized both the objective and subjective aspects of participation from the perspective of staff. In Study IV, the young adults described their self-chosen ICT use, which provided information about the subjective aspects of participation. Thus, the thesis covers both the objective and subjective aspects of participation.

Context

The thesis was conducted within Swedish municipal social care. The empirical data were collected at different levels of a social care organization. Study I was a national survey that included all Swedish municipalities (n=290). The other data collections (Studies II–IV) was conducted within municipal social care in a large city in central Sweden, which has six residential homes where young adults with mild to moderate ID live. Both staff and young adults from these six residential homes were invited to participate in the studies. Participants were staff from four residential homes and young adults with mild to moderate ID from four residential homes. As shown in Table 2, all residential homes except for one (home E) were represented by staff and/or young adults. An inclusion criterion for the residential homes was that they must house young adults (aged 18–30 years) needing support primarily because of ID. All staff and young adults who met the criteria were invited to participate.

Table 2. Distribution of participants in each residential home

<table>
<thead>
<tr>
<th>Residential home</th>
<th>Staff</th>
<th>Young adults with ID</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>B</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>C</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>D</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>E</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>F</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
All residential homes were part of the municipal regime, and the young adults’ apartments were part of residential care, although located in a regular apartment building. Staff members were available day and night in an office apartment nearby.

Participants and setting

Study I
Each municipality was contacted and asked to identify suitable representatives to complete the questionnaire. Most respondents worked with quality issues and/or development of social care, or as a first- or second-line manager.

Table 3. Distribution of respondents’ positions in the disability service organizations (n=147)

<table>
<thead>
<tr>
<th>Position</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality issues and/or development of the activities (residential care, day care activities and leisure activities)</td>
<td>46 (31)</td>
</tr>
<tr>
<td>Second-line managers</td>
<td>39 (27)</td>
</tr>
<tr>
<td>First-line managers</td>
<td>34 (23)</td>
</tr>
<tr>
<td>Registrars</td>
<td>8 (5)</td>
</tr>
<tr>
<td>Occupational therapists</td>
<td>7 (5)</td>
</tr>
<tr>
<td>Others</td>
<td>11 (7)</td>
</tr>
<tr>
<td>Missing</td>
<td>2 (1)</td>
</tr>
</tbody>
</table>

Email addresses were collected for each respondent, and a web-based questionnaire was sent to them.

Studies II and III
All staff working at the selected residential care with young adults with mild to moderate ID were asked to participate. The sampling method was criterion sampling (Patton, 2002), which enabled collection of data about a variety of experiences among those who shared this specific experience, namely working in residential care with young adults with mild to moderate ID. Sixteen women and one man participated, and their median age was 40 years (range 25–60). The average time working in social care was 13 years (range 10 months to 27 years). All interviews were conducted in the staff member’s office apartment or in a municipal meeting room.
Study IV
A consecutive sample (Polit & Beck, 2010) included 11 young adults with mild to moderate ID. The inclusion criteria were living in municipal residential care with support mainly because of ID, use of ICT in daily life, age 18–30 years, the ability to make decisions about participation in an interview, and reading and writing skills sufficient to read and understand the information letter and sign an informed consent form. Five women and six men agreed to participate (age 22–31 years, median 25 years). All participants lived alone in a two-room apartment that belonged to the residential care services, although these were located in a regular apartment building.

Data collection

Study I
A questionnaire was developed with the purpose of mapping the existence and extent of organizational support for ICT use for young adults in social care. The use of the single questionnaire made it possible to ask the same questions and include all municipalities. The survey design allowed the informants to complete the questionnaire at a time and place that suited them. Because the purpose of this study was to obtain a comprehensive representation of organizational support, the use of mostly close-ended questions was considered to be suitable (Polit & Beck, 2010).

Questions were based on prior research in the area and the ICF (World Health Organization, 2001) as a theoretical foundation for environmental barriers and daily functioning. The questionnaire was initially reviewed by two municipal officials who were familiar with the area, and their views led to further development of some response options. An outside researcher (with a PhD) with specialist knowledge of the ICF gave valuable input to clarify some of the concepts. The questionnaire was reviewed finally for face and content validity (Streiner & Norman, 2008) by a reference group. All nine participants in the reference group worked within social care, although they had different positions and were at different levels of the organization.

The questionnaire comprised 22 questions, four of which were background questions, 16 were about the existence of support and how it was provided, and two asked for comments and contact information. Open-ended questions were used to provide the opportunity for the respondent to clarify information provided in prior close-ended questions. For example, if the municipality had
a policy on ICT, an open-ended question asked the participant to state the purpose of the policy. Another open-ended question asked the participant to describe ICT-related projects that they had participated in. The questionnaire was distributed as a link in an email.

The questionnaire was web-based and was distributed by email to one official in every municipality in Sweden (n=290). It was possible to forward the email with the link to the questionnaire if the respondent believed that a colleague was better suited to completing the questionnaire. Two reminders were sent at 2-week intervals. The information in the email stated that a paper version could be sent on request, but no participants requested this. The data collection was completed in March 2014. After the two reminders were sent to non-respondents, the response rate was 51% (n=147).

Studies II and III
Studies II and III were based on focus group interviews. The focus group comprised a number of participants, a moderator and an assessor. The participants, here the staff, were asked to discuss specific questions or topics about their experiences. Because staff in the same team usually have similar experiences, focus group interviews were considered to be suitable as the data-collection method for these studies.

Four focus group interviews were conducted with staff working in municipal social care for young adults with mild to moderate ID. Each group comprised three to five participants (Holloway & Wheeler, 2015) employed in the same residential home. The focus groups included a total of 15 staff members (Studies II and III). Two complementary individual interviews were conducted for some staff because it was not possible to put together a focus group in that team (Study III).

In addition to the moderator, an assessor participated in all focus group interviews. The assessor’s task was to observe the interactions in the group and to ask supplementary questions towards the end of the discussion. The moderator had three overarching themes for the focus group to discuss, which were complemented with probing questions when needed. The themes were:

- Experiences and perceptions of young adults with ID ICT use in daily life
- Their own role as support persons in relation to daily ICT use by the young people with ID
- Perceptions of the organizational support and whether the organization provided the prerequisites needed to support the service users.
The focus group interviews ranged from 43 minutes to 1 hour 13 minutes (median 47.5 minutes). The two complementary individual interviews included the same themes and lasted 35 minutes and 51 minutes, respectively.

In Study II, data from the four focus group interviews were used, but the two individual interviews were excluded.

**Study IV**

Semi-structured interviews with 11 young adults with mild to moderate ID living in residential care were conducted. Semi-structured interviews allow the participant to talk freely about the topic of interest, but the structure ensures that the interviewer cover the same areas (Polit & Beck, 2010). An interview guide framed the areas that the interview aimed to cover, but the questions did not have to be followed chronologically. Instead, the interviewer’s role was to encourage the participant to talk freely about the topic. To let the participants tell their stories, the interviewer aimed to make the interview conversational. As the interviewer tried to ensure that all areas were covered, the participants were encouraged to elaborate about the dimensions that were important to them (Polit & Beck, 2010).

Before the interviews, two preliminary interviews were conducted to test the interview guide. The test interviews led to small changes in the interview guide. The test interviews were not included as data and were conducted in another municipality than that for the data collection.

The young adults with mild to moderate ID were initially informed and asked to participate by staff at their residential home and were allowed to decide themselves whether to participate in an interview alone or to have a staff member present. A mild to moderate ID can affect the ability to make a decision, but does not prevent that ability (APA, 2016; Barron 1999). Therefore, the young adults with ID who were invited to participate in an interview were provided with opportunities to make an informed consent by themselves. One step in this process was to first have staff provide information and then to ask the young adult about his or her interest in participating. Written information was also provided beforehand to enable the presumptive participant to go through the information several times and to discuss with staff or next of kin. To advocate for and enable independence is consistent with the Convention on the Rights of Persons with Disabilities (United Nations, 2006), and the procedure was discussed with a jurist at the Swedish National Association for Persons with Intellectual Disability. Consequently, all participants were prepared and expected to be interviewed at the given time.
Questions were asked about how the participants used ICT in daily life and which products and activities the participants usually engaged in. The areas included were social relationships, interactions, civic life and support. Nine of the eleven interviews used in the study took place in each participant’s home and, for two participants, in a shared apartment. The interviews ranged from 15 to 68 minutes (median 32 minutes). A tablet with Internet access and a mobile phone were brought as a support during the interviews, but no participant used these devices to show their use. Instead, some participants preferred to use their own mobile phone or tablet to show how they used it in their daily life. All interviews were voice recorded with the participants’ consent.

Data Analysis

Study I
The questions included in the questionnaire were about the existence of support. Thus, the data were on nominal or ordinal scale (Plichta Kellar & Kelvin, 2013), and were analysed using descriptive statistics and are presented as frequencies and percent. To manage the data, SPSS for Windows version 19 (IBM SPSS) was used. Presenting summaries provides a more meaningful representation of the data and is easier for the reader to grasp the essence (Plichta Kellar & Kelvin, 2013). Additional qualitative data from open-ended questions are presented as support and clarification. Because of internal loss, a few questions were excluded in the presentation.

Study II
Study II was a narrative analysis (Bamberg, 2004) with an interactionist theory (Goffman, 1967) as additional analytical tool. Narrative analysis of “small stories” can be seen as constructive of characters in space and time. Hence, positioning oneself, and simultaneously the other conversationalist(s) creates identity (Bamberg & Georgakopoulou, 2008). In this study, the narratives of, and about staffs’ way of work reveals their positioning within the relational work; how staff position themselves and also the young adults’ with ID. This allowed me to highlight the relational work concerning ICT use in service provision. The analysis works on two levels; how staff position themselves within the story (ie. the relational work) and how staff positions themselves in
relation to master narratives (cf. discourses) (Bamberg, 2004; 2008). By focusing on how staff position themselves (and thereby also the young adults) in the relational work, staffs’ way of work as support persons in relation to ICT is revealed.

In practice, the first step of the analysis was to read through the transcribed focus group interviews. During the reading, notes were written in the margins to identify the characteristic of the staff work and what is narrated in the focus groups. This is an important phase in which the empirical material can be sorted and categorized, and conceptualized in terms of interactionist theory and narrative analysis. Quotations to support the categorizations were grouped together, and the most illustrative was chosen for the analysis.

Studies III and IV
Study III and IV were analysed using content analysis, although with a slightly different approaches. Content analysis is a method for managing a large amount of data. In qualitative content analysis, the researcher conducts a naturalistic inquiry, meaning that the researcher tries to capture a social phenomenon in a real-life setting (Patton, 2002). According to Patton (2002), content analysis refers to “any type of data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings” (p. 453). Both Studies III and IV used an inductive approach, by which the patterns of categories (Study IV) and themes (Study III) were formed from the empirical data. Content analysis lacks a clear ontological and epistemological starting point. The qualitative data derive from a social constructivist world view (Patton, 2002), and the concept participation guided the theoretical perspective in both studies.

Study III included a latent content analysis, as described by Graneheim and Lundman (2004). The latent approach allows some interpretation and understanding of the underlying meaning in the conversation (Graneheim & Lundman, 2004; Patton, 2002). The focus group interviews and individual interviews were transcribed verbatim and read through. Meaning units related to the study’s aim were chosen, these often comprised a part of the group’s discussion but sometimes only a sentence. These meaning units were condensed into shorter items with a focus on the core of the discussions. All condensed meaning units were then given a code that captured the core to facilitate categorization. Subthemes that captured the staff members’ experiences of the role of ICT were created and further abstracted into a common theme.
Table 4. Examples of the analysis process used in Study III

<table>
<thead>
<tr>
<th>Meaning unit</th>
<th>Condensed meaning unit</th>
<th>Code</th>
<th>Sub-theme</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>… but also to show pictures. I was with our new guy on a study visit, and then he thought that a person looked like someone. He has some speech impediments, so we have difficulties understanding him. However, it was something he wanted [to tell us] and then he took out his mobile phone [to show], a picture, because he thought this girl looked like a, ah, one of his mother’s friends. So, then he went forward, and showed, and then she [the girl who looked like his mothers friend] also understood…</td>
<td>Has speech difficulties and we have difficulty understanding him. He picked up the phone and showed a picture, and then she understood.</td>
<td>Communication support</td>
<td>A balance between social inclusion and social exposure</td>
<td></td>
</tr>
<tr>
<td>The downside is when they get into situations that they can’t manage. For example, considering Facebook and such, when they cannot really decide what makes them end up in situations they can’t really master, and other people take advantage of their ignorance, then it becomes difficult.</td>
<td>Can be exploited and meet the wrong people, then our users get into trouble and have difficulties saying no.</td>
<td>Being exposed</td>
<td>Bringing out the vulnerability in a risky environment</td>
<td></td>
</tr>
</tbody>
</table>

Study IV used an inductive content analysis, as described by Elo and Kyngäs (2008). To maintain the participants’ own words through the analysis and in that way to ensure that inclusion of perspective and voices of the young adults with mild to moderate ID, the abstraction processes remained close to the text when moving from codes to categories. The analysis process started with verbatim transcriptions of the interviews. These were read through, and notes were written in the margins. Meaning units comprised a sentence or a part of the dialogue related to the study aim. The meaning units were collapsed into subcategories based on similarities and differences. Subcategories were abstracted into two generic categories and finally further abstracted into one main category that captured a thread, which is consistent throughout the analysis.
Table 5. Examples of the analysis process from Study IV

<table>
<thead>
<tr>
<th>Meaning unit</th>
<th>Code</th>
<th>Subcategory</th>
<th>Generic category</th>
</tr>
</thead>
<tbody>
<tr>
<td>(talking about a friend) Yeah, we can write to each</td>
<td>Friendship</td>
<td>Interactions based on interests</td>
<td>Social relationships</td>
</tr>
<tr>
<td>other from 7 am to 10 pm! <em>laughing</em> So it’s quite</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>long chats we have!</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Ethics

Study I was performed in accordance with the Declaration of Helsinki (World Medical Association, 2013) and Swedish law regarding ethics in research involving humans (Government of Sweden, 2003:460). The questionnaire only included questions about the existence of policies and strategies in the organization and did not involve questions about any specific people. Respondents agreed to participate by responding to and returning the questionnaire.

Studies II, III and IV were approved by the Regional ethical vetting board in Uppsala (dno: 2015/209). An amended application (dno: 2015/209/1) approved the recruitment of informants from a wider geographic area than first applied for.

All participants received written and verbal information about the project and the ethical guidelines before the interviews or focus group interviews and signed a consent form.
Summary of findings

The findings of the four studies of the prerequisites, enablers, hinder and use of ICT in municipal social care for young adults with mild to moderate ID are summarized under three main headings: Support for ICT use within the organization, Different aspects of the purpose of ICT, and Perceived risk as a hindrance to participation.

Support for ICT use within the organization

The findings from the questionnaire show that there is a lack of policies and strategies for the comprehensive organizational support for access to ICT in municipal social care for people with disability in Sweden. The staff also acknowledge this lack of support in their daily work. Support and resources to develop ICT use by young people with ID are lacking at the organizational level why staff do not have adequate resources to provide the necessary support. This is described to restrict the use of ICT for these young adults (Studies I and II). Organizations requested a need for more knowledge and information about ICT to be able to develop adequate support. Only nine of the responding municipalities reported the existence of a policy about access to ICT. One of the most common strategies to support ICT use (65 of 147 municipalities) was to offer ICT devices to service users (Study I).

There seems to be a general expectation in social care organizations that day-to-day support for the use of ICT by young adults with mild to moderate ID should be provided by staff. However, in-service training about the use of ICT is not often provided for staff (Study I), and the young adults turned primarily to family members rather than to staff for support (Study IV). In addition, staff describe a lack of resources in terms of technical devices to be able to use ICT in a meaningful way in support provision (study II). Nevertheless, staff were enthusiastic about introducing and supporting the use of ICT if the resources would be provided by the organization (Study II).

Staff noted that the lack of organizational resources left them unable to introduce or support ICT use for young adults with ID. They perceived this
lack of devices (e.g. smartphone or tablet) as a barrier in their interaction with the young adults. Being able to use ICT in their service provision was conveyed as something positive, but difficult, because old devices were considered not to be user friendly. In addition, staff described the lack of modern devices as a hindrance to providing the support needed when introducing ICT to young adults with ID. They noted that they lacked a natural forum, such as a smartphone or tablet would if provided by the organization. Because of this lack of organizational support, staff did not perceive it to be their responsibility to provide this support for ICT. However, they often used their own device to show or introduce something, even though this was not allowed by their manager. Using the young adult with ID private products were not always a choice either, as the young adult could resist considering it is their private product and letting staff see it could be experiences as invading the private sphere (Studies II and III).

Different aspects of the purpose of ICT

Staff were divided in their telling about ICT as a tool for participation for young adults with mild to moderate ID versus ICT as a tool for providing support. This division was reflected in different perceptions of the appropriate use of ICT in the daily life of these young adults with ID. Overall, staff were supportive when describing ICT as a tool for service provision or educational purposes. For example, ICT use helped in communication and facilitating household chores (Study III). Staff could phone or send a text message as a reminder or with simple information, which was considered to facilitate the daily work of staff. Further, staff argued that providing digital instead of face-to-face support allowed the young adults with ID to maintain their independence and staff felt that using ICT in daily contact would facilitate for themselves. They argued that such interactions provided service users with personal space and decreased the perception of staff as nagging (Study II).

Within the services, staff noted that ICT could be used as a mean to support service users’ independence in situations such as cooking or increased participation in planning meals for the week. Staff speculated about how they could use ICT for educational purposes by offering get-togethers with a specific theme, or when they could use a tablet to teach and talk about specific topics. In this way, staff could be supportive of the young adults as they develop interests and learn about the use of ICT for areas of interest. This would also provide a forum for talking about Internet behaviour and further development
of ICT skills (Study III). Staff perceived ICT to have a positive impact on service users’ participation in daily life at home because it enabled the service users to perform activities in the home independently (Studies II and III).

Another aspect of ICT use of concern was private use of ICT by these young adults with ID. This use was not related to service provision but rather to self-chosen activities. Staff perceived that ICT enabled and facilitated the independence in activities such as playing games, watching videos, listening to music and maintaining social relationships (Study III). The young adults with ID had similar perceptions (Study IV). The young adults described their ICT use in daily life for social relationships and for leisure activities in several different ways. These young adults considered self-chosen activities such as maintaining social relationships with family and friends, and participating in social forums with unknown people with a shared interest, as important. In this way, they could use ICT to participate on their own in discussions about things they thought were interesting. One example mentioned was engaging in group discussions about pets as an arena for interaction with others in an area of personal interest (Studies III and IV).

Providing these young adults with ID with information about ICT use allowed them to also take part in activities in an offline environment. Therefore, ICT enabled participation both online and offline. Examples of offline activities included going on a cruise, visiting the cinema and attending a music performance (Studies III and IV). In this way, ICT became a tool for participation by providing access to online environments as well as a means for participation offline. For the young adults with ID, this made it easier to obtain information and to plan their participation in activities. One example explained more explicitly was planning to visit the cinema. ICT could be used to find movies showing on a specific day, to determine whether a movie was of interest and to watch the trailer before attending to understand the movie better before deciding to attend. This entire process could be done independently, which made both the visit to the cinema and the movie self-chosen activities. Staff could be supportive by booking tickets and helping to decide on the amount of money needed for the ticket and snacks. Sometimes staff members were requested to ask whether others living in residential care wished to join in the visit to the cinema, which required staff to act as a mediator of the communication between the service users. Staff support in booking tickets and counting money helped the young adults with ID to be confident about performing the activity without the need for further support.
Perceived risk as a hindrance to participation

Staff described online social relationships as a potentially problematic aspect of ICT use. Because of the difficulties of managing online relationships and behaviour, the Internet is not always regarded as an appropriate arena for young adults with ID. The online environment was described as having inherent social risks for people with disability, such as being harassed. Staff noted that it was difficult when a young adult with ID was treated badly online, but they also noted that this was not always one-sided. The online social difficulties involved both harassment of, and by, the young adults with ID (Studies II and III). To manage these risks, staff talked about themselves as moral guardians concerning ICT use. This was often done by indirectly suggesting to the young adult in what way ICT was appropriate for the service users, and in what way it was not. In this way, they could also be a barrier for the young adults to access social media sites. As noted by staff, their lack of organizational resources often made it difficult to create space where they could talk to the young adults with ID about managing online situations and in that way also support them (Study II).

The staff felt that the environment did not provide adequate support to create a context for these young adults with ID to engage in ICT use. Staff recognized this as both an organizational and environmental problem, but they also noted that the presence of ID alone can make ICT use problematic. In recognition of the environmental barriers, staff noted a lack of understanding of ICT among individuals with ID. They perceived that these young adults can be naïve and easily fooled, and that social media and online interactions could be a social and economic risk. They argued that the lack of understanding of online behaviour placed the young adults with ID in a vulnerable position. The speed and extent of online interactions and actions were also perceived as problematic, especially because these young adults with ID seldom understood the consequences of expressing emotions online. They acknowledged that the inability of young adults with ID to think through the consequences and general problems in online social behaviour are the main problem. Therefore, it was argued that ICT, and especially online forums, were not always an appropriate environment for young adults with ID (Studies II and III).

Economic exposure was another risk mentioned by staff. Advertisements in the online environment often describe deals that seem more advantageous than they really are, and some sites incur costs to visit them. This was a worry for staff because they did not hear about a problem until later, if at all. As
noted above, these young adults with ID lacked the experience and understanding to avoid becoming victims (Studies II and III), and did not recognize the risks involved (Study IV). Because they could identify the potential social and economic risks, staff perceived that young adults with ID are sometimes incapable of using ICT independently. This attitude may act as a hindrance to staff support of the use of ICT by young people with ID.
Discussion

General discussion

The overall aim of the thesis was to elucidate prerequisites for and aspects that enable the use of ICT and their impact on participation in daily life among young adults with mild to moderate ID resident in municipal disability services. Participation in a social care context can be regarded objectively in terms of opportunities for participation, while the assessment of subjective participation provides answers about whether the opportunities are sufficient. The interplay of opportunities, the environment and the subjective experience contribute to the understanding of social care as a context for enabling ICT as a tool for participation. This discussion aims to explain the findings in relation to theories of both how ICT enables participation and how the prerequisites and enablement can be understood from the organizational perspective. The findings are discussed in relation to both theory and prior research under three headings: Structural (lack of) support for ICT, Influence of moral values and Participation in online and offline contexts.

Structural (lack of) support for ICT

The thesis results show two parallel approaches to ICT use. The first approach concerns the young adults’ use of ICT for purposes such as independence and participation. The other relates to ICT as a mean of support for service provision and the focus on how ICT can facilitate for staff.

Previously, the county council provided all types of technology, such as assistive devices, to support or facilitate daily life for people with disability. Assistive devices aim at facilitating specific activities in a person’s life and therefore require a people-changing technology (Hasenfeld, 2010a). When a private ICT device is used without a specific assistive purpose, the purpose becomes that of sustaining the individual’s use without further input. There-
fore, from the organizational view, the responsibility for provision of ICT devices remains with the county council or the individual (although staff may provide support).

As shown in Study I, the institutional environment and organizational technologies are seen to be in the process of change regarding ICT use by young adults with ID. The age difference in ICT users within the general population is probably reflected in differences between staff and clients receiving support from DSOs. Therefore, the use and norms of an older generation, such as older staff, may not be directly relevant for a younger population (young adults with ID in this case). This will change with time, as more younger people begin to work within DSOs. In the current situation, the young adults and/or interest groups may become disappointed because of the young adults with mild to moderate ID lack of participation in society, which remains an unresolved social problem. This indicates that young adults with ID see their ICT use as a means for participation and that this poses a new challenge for DSOs.

There seem to be low expectations by both organizations and young adults with ID of the support for use of ICT in municipal social care. The results from the survey (Study I) indicated that organizations expect staff to manage the support for ICT when needed, without support from the organization. However, prior research (Parsons et al., 2008; Clifford Simplican et al. 2018) shows that organizational support is crucial for staff being able to prioritize the support of ICT by service users in their daily life. At the same time, young adults with ID in social care noted that they more consistently turn to family for help and support with ICT than to staff (Study IV).

Policies and strategies in municipal organizations may not be reflected in the actual daily activities in these organizations (Levin, 2013; Meyer & Rowan, 1977). Policies can be seen as an initiative or solution to a problem, although they do not by themselves constitute the action to provide a solution (Kingdon, 2003) or reflect the institutional environment (Hasenfeld, 2010a). It is reasonable to expect differences throughout the country (Kingdon, 2003) because of differences in the social influences of the surrounding society (Hasenfeld 2010a). Nevertheless, the findings from Studies II and III, which involved staff, do not support the idea that the organizational levels are decoupled. On the contrary, staff described the lack of support for ICT as a hindrance to further develop the use of ICT in their daily work and the provision of ICT support to young adults with ID similar to Study I. This may indicate that the priority of ICT support is dependent on other levels of the organization and therefore remains low at all organizational levels. It could be the opposite as well, that is, that the organizations do not develop comprehensive support
strategies because these have not been requested by the front-line workers. Therefore, the organization may believe that the support is not a priority and that staff can, and do, provide the needed ICT support on a day-to-day basis without needing further organizational support.

In the project, the median age of staff was 40 years of age, which may affect ICT support. Age has the greatest influence on the difference in ICT use, that is, young adults are more frequent users than middle-aged or older people but, in general, there are no gender differences in ICT use (Findahl & Davidsson, 2015). The fact that DSOs are a women-dominated work place (Hasenfeld, 2010a) should therefore not specifically affect the use of ICT. Nevertheless, power relations between staff and service users, and among staff in the team and in relation to other interest groups are always present in DSOs (S. Johansson et al., 2015). The age difference between staff and young adults with ID in the studies could possibly be an explanation for differences in their relationship with ICT.

Age differences were also highlighted as a barrier by some younger staff members in Study III. In practice, this may indicate that staff support for ICT use may depend on the staff member’s age. If so, there is a risk that older staff may provide less support for ICT than younger staff. Because of the age-related differences in ICT use in general, organizations may need to consider how age-related differences in experience, knowledge and attitudes between staff and service users might affect the use of ICT by service users in their daily life. Concerns about the risks of use of ICT and the Internet may be one aspect of age differences and are probably partly related to age and experience of ICT.

Influence of moral values

The moral values of staff as well as those inherent in the organization can affect the provision of services (Hasenfeld, 2010c; Levin, 2013), such as the opportunities for ICT use by young adults with ID resident in a DSO. Similarly, Seale and Chadwick (2017) have argued that normal ICT use for people with ID is synonymous with what is considered to be appropriate ICT use. That is, what is morally accepted is therefore the same as what is socially accepted and is hence considered to be normative use. Following this line of thought, societal legitimacy becomes a characteristic of HSOs (Hasenfeld, 2010a) in terms of the staff support for ICT in social care situations. The influence of the surrounding social values on people with ID and their social
worth can affect the service provided to young adults with mild to moderate ID (Hasenfeld, 2010c; R. Johansson, 2006). Staff recognition of the appropriate use of ICT is related to the moral assumptions of both ICT use and young adults with ID.

The findings of Study II show how staff use their discretion to act as enablers of ICT use by the young people with ID. The staff considered the lack of organizational support and resources to use ICT in a meaningful way to be a barrier in their daily work with these young adults. They noted that they circumvented these barriers by applying their personal knowledge and sometimes used their own accounts on applications to make activities available on the devices of the young adults with ID. By doing so, staff members were able to promote ICT use and to support the young adults’ independence and participation in society in a morally excepted way. Study III also found similar engagement among staff, who spontaneously offered their ideas about how ICT could benefit young people with ID in a more extensive way on a daily basis. This illustrated their perceived importance of their relationships with and responsiveness towards these young adults as well as their analysis of the institutionalized technologies that influence their actions (Hasenfeld, 2010a, 2010d).

Moral values held by staff were also found to restrict ICT use. As explained by Hasenfeld (2010a), the moral values, experience, knowledge and personal beliefs at the worker level influence how staff apply different technologies. This was evident by a belief expressed by the group that ICT and the Internet created more exposure and risks than benefits for the young adults. Different conditions and opportunities were therefore provided to the young adults depending on where they lived and on the moral assumptions within the teams.

Staff who facilitate the use of ICT in this way showed their responsiveness to the young adults’ needs, which emphasizes the importance of the client–worker relationship as a core in DSOs (Hasenfeld, 2010a). As shown in Study II, staff in residential care act as moral guardians and, in different ways, support or control ICT use depending on their own moral values. According to Hasenfeld (2010c), moral values can be regarded as inherent in HSOs and are therefore unavoidable. In that sense, staff can act as a barrier to the use of ICT as a mean of participation by young adults with ID by acting on their morals by, for example, closing open tabs or social media sites being used by the young adults. Staff who positioned themselves as enablers (Study II) could on the other hand use their moral to be supportive for ICT use for the young adults with ID.
Others, such as parents, can also influence the institutional technologies in social care. Staff perceive that parents’ opinions about ICT use are final, as shown in Study III. In other words, moral values from the wider society may, through parental influence, affect the use of technologies, for example, by not supporting the use of ICT in daily life. The trustworthiness of staff and societal legitimacy (Hasenfeld, 2010a) can be at stake if staff do not act in accordance with parents’ opinions and morals. With this in mind, organizational support may be important, but societal moral values may be even more important. This shows the importance of both the institutionalization of technologies and the institutional environment. According to Hasenfeld (2010a), it is assumed that the technologies and morals reflect societal morals, which are reflected in the perceived appropriateness of ICT for young adults with ID.

Participation in online and offline contexts

ICT was described by both the young adults with ID and staff as a device that provides participation. ICT use was interpreted as a self-chosen activity that enables participation in the online world as well as opening possibilities for participation in the offline world (Studies II-IV). In that sense, ICT can be viewed as both the means of participation and the goal, participation. Decreased offline participation or interaction is not a necessary consequence of increased ICT use, which is a common argument against ICT (Caton & Chapman, 2016; Maïano, Aimé, Salvas, Morin & Normand, 2016; Sorbring et al., 2017), but instead may provide a means of achieving participation. I note that that the fact that the young adults with ID who participated in Study IV did not describe social difficulties using ICT does not necessarily mean that these difficulties do not exist. Therefore, the findings of their subjective experience of participation using ICT may be overly positive.

All of the young adults who participated in an interview used ICT on a daily basis. Much of this use was for self-chosen activities such as for the own amusement, watching movies or playing games, but also for social media use. This is similar to the findings of Sallafranque-St-Louis and Normand (2017). One difference between the thesis findings and these previous reports is that participants in the current study used Facebook to join groups based on specific interests, whereas none of the participants with ID in the previous studies did. Facebook provides opportunities for participation in life areas that are considered important for the individual. This difference between this thesis research and the study by Sallafranque-St-Louis and Normand (2017) may be
explained by the few participants with ID in the earlier study or by the inclusion criteria used in Study IV, namely that all participants should use ICT in their daily life.

An important new finding of the current studies is that ICT also enabled participation in the offline environment. In contrast to Hemmingsson (2015), who described ICT as enabling participation online as a complement to the unavailable physical environments for people with physical disability, ICT used by the young adults with ID studied here allowed them to take part in physical activities in the wider society. ICT use provided them with the information needed to take part in activities that were otherwise not accessible to them. Sallafranque-St-Louis and Normand (2017) concluded that ICT use is similar among people with ID and/or autism spectrum disorder and the general population, although fewer opportunities are offered because of the cognitive limitations of people with ID or autism spectrum disorder. Therefore, support to overcome the cognitive limitations that restrict ICT use is crucial to enable wider participation by people with ID.

Within the DSO, it is obvious that staff responsiveness and moral actions can constitute a barrier. That is, although cognitive limitations can be restrictive, they do not always become a barrier, but the lack of support can act as a barrier. This is illustrated in Study II, in which staff conveyed themselves in different positions as support persons in relation to ICT. For young adults in Study IV who were provided with support by staff, the availability of other activities and digital arenas increased. Although the young adults frequently used ICT without support, the opportunities for participation seemed to increase with increased support. Therefore, the results of Study II suggest that staff can act as important enablers of participation for young adults with ID.

Staff also described the use of ICT for service provision and for the relationship between staff and the young adults with ID. This changed the social context and enabled the young adults to perform activities and take part in life decisions to a greater extent. Considering the acknowledged importance of ICT use among young adults in general (Boulianne, 2015; Stald, 2008) and the aim of full participation in life similar to those without disability as a cornerstone in Swedish legislation (Government of Sweden, 1993:387), the low priority of ICT in municipal social care is noteworthy. Staff described the use of ICT as a way to increase the young adults’ influence and participation in service provision in a way that should be natural for the young adults because ICT is already part of their daily life. Thus, ICT becomes a tool and provides an environment for staff to use to “meet the person where he/she is” rather
than making the young adult adapt to the organization and its traditional technologies.

Methodological considerations

Both quantitative and qualitative methods were used to fulfil the overall and specific aims. Including data from different perspectives and levels in the organization in the thesis provides a better understanding of the service provision by staff and participation by the young adults with ID. Taken together, the different study results both identify the discrepancies within the organization and validate the findings.

The sampling method and the overall qualitative approach of the thesis makes it important to view the findings in relation to its context. The overall findings are consistent with the results of prior research, although differences and new knowledge have been revealed. The analysis of this thesis research has considered the dependability and confirmability (Patton, 2002), and the research group worked together during different phases of the analyses to achieve consensus about the categories and themes. The findings are consistent with prior research on the environmental aspects influencing the availability of and access to ICT over time and in different contexts (Lussier-Desrochers et al., 2017; Parsons et al., 2008), which strengthens the credibility of the thesis findings.

Enabling ICT use for young adults in social care requires methods to include different levels and approaches to and within the organization. The ICF was used as the framework for understanding the influence of the environment in Studies I–III and for operationalizing participation as performance of an activity. In Study IV, the ICF was used primarily as a framework for different life areas and for the use of participation as a concept, although these were complemented with the understanding that self-chosen activities indicate engagement in a life situation. Even though participation was used as a core concept in the thesis research, the focus was primarily on the environmental aspects related to access to and use of ICT by young adults with ICT, in other words, how participation is enabled through ICT. Using the ICF as a framework allows similar understanding of the perspective and concepts in different countries and disciplines, as well as in DSO practice.

The development of the questionnaire (Study I) involved professionals with different expertise to increase content and face validity. The research area was too narrow to be able to create a pilot study because no other target group
could respond to the questions. Therefore, conducting a pilot study would need to include the same participants as in the survey. As a consequence, a national survey would not have been possible. Construct validation can be described as whether the instrument measures what it is intended to measure. Logically, it is more challenging to judge the construct validity of an abstract concept than of a more concrete concept (Polit & Beck, 2010; Streiner & Norman, 2008). However, the questionnaire comprised questions with dichotomous response options or forced-choice questions. The questions focused on the existing policies and strategies and offered little or no space for opinions or estimations. To avoid forcing invalid answers because of a lack of adequate response options, the option “Other” was offered with space to describe this choice. This questionnaire becomes time sensitive because of development and changes within each organization.

One strength of focus group interviews is the interaction and synergy between the participants, which often provides additional information beyond that offered in an individual interview (Kamberelis & Dimitriadis, 2005; Krueger, 1994). Focus groups have been argued to be unsuitable because the participants share their experiences with each other (Krueger, 1994). In this regard, staff participants were asked only about their experiences in their practical work. One strength of the findings was that the outcomes of the focus group interviews were in agreement even though they had been conducted at different residential homes without communication or co-operation between them. One residential home stands out because it was provided with a tablet with Internet access by the organization. This focus group interview confirmed many of the reflections by the other focus groups about how ICT could be used for participation.

Even when starting a focus group interview with an appropriate topic, there is a risk that the discussion can be hampered because of internal, implicit power relations. Implicit power between staff was observed during the focus groups, although there were large differences between the groups. These actions were evident when some staff often looked at one specific person for validation of their statement or for a confirmatory or discouraging reaction. These actions were not examined further in the separate studies, but it is noted here as an aspect that may have influenced the discussions in the focus groups and what the members felt they were allowed to say.

The sampling method was criterion sampling in that participants were chosen based on the inclusion criteria and all participants who met the criteria were invited to participate. At most, this would have generated six focus
groups which is a manageable number of focus group interviews. The purposive sampling enabled all staff who fulfilled the inclusion criteria to participate in the study (Patton, 2002). The inclusion of several participants was necessary to obtain a variety of experiences and to understand how staff as a team make use of the relational work in day-to-day situations.

Interviewing people with ID can be difficult. Communication difficulties are a common issue because of the inadequate responses of people with ID. This is directly related to the interviewer’s ability to ask good questions (Sigstad, 2014). The verbal communication and interactions can pose challenges for both the interviewer and interviewees. This was partly avoided in the interviews with the young adults because they were allowed to show how they used ICT instead of simply talking about it. To do so in the interviews, the interviewer asked the young adult to describe what they were doing. For those who chose to show their ICT use, this seemed to facilitate their description because it shifted it into something more concrete. To ensure that the demonstration was included in the transcriptions, the interviewer commented on what the young adults were showing and asked them to describe this verbally. Follow-up questions were used as another strategy to gain more information and to avoid acquiescence (Finlay & Lyons, 2002; Sigstad, 2014).

It would be beneficial to triangulate the interviews with participant observations, which might provide a more detailed description of the daily use of ICT. However, there can be major ethical considerations when conducting participant observations in a home setting and with young adults with ID, which is why this was not done in the current project. The young adults described similar use of ICT, with a few exceptions. The extent of the use of different social media sites or games differed and some barely used ICT at all because they had experienced malfunctions. The findings of similar use of ICT in their daily life among most participants in this research as well as when compared with other studies (Caton & Chapman, 2016; Sallafranque-St-Louis & Normand, 2017) strengthens the findings. Therefore, the transferability of these findings to other young adults with ID in municipal social care should be acceptable.

The interviews with the young adults with ID (Study IV) were analyzed using content analysis, as described by Elo and Kyngäs (2008). The analysis remained close to the text to retain the young adults’ words and to keep their perspectives intact as well as to avoid over-interpretation. The interviews were of a concrete character in the telling of ICT use (Elo et al., 2014). Keeping the analysis close to the text was also a choice to let the young adults’ descriptions
be prominent in relating their perceptions about the level of support provided by social care.

The focus group interviews in Study III were analyzed using latent content analysis, as described by Graneheim and Lundman (2004). Because of the data, as well as the aim, the abstraction level was higher in this study. Elo et al. (2014) described trustworthiness during the analysis phase in relation to the internal consistency of the categorization of the data in the group. Trustworthiness was managed in the analysis as suggested: the first author was responsible for the analysis, but the analyses were continuously discussed and carefully checked by the co-authors.

A narrative (Bamberg, 2004) and interactionist approach (Goffman, 1971) was applied in Study II, and this provided a deeper understanding of how the relational work with young adults with ID are part of and affect the provision of ICT support. This is important because staff members are key in the provision of support for young adults with ID. Understanding the staff members’ institutionalized belief systems helps to illustrate how these influence the relationships between staff members and young adults with ID as well as the provision of ICT service.

Content analysis and narrative analysis differ, mostly because of the theoretical assumptions. Content analysis do not bring any assumptions at all, but rather works as a tool to manage a large amount of qualitative data. Narrative analysis on the other hand, brings assumptions of narratives as being constructive of, and contextualize identities (Bamberg & Georgakopoulou, 2008. Further, the narrative approach allows to focus on staffs’ positioning in their narratives while Study III, the content analysis, focus on what is described in the text. Although one difference between Studies II and III lay in the method of analysis, it should further be noted that the data from the focus group interviews were divided in two. Hence, the studies also comprise different empirical data.

The combination of quantitative and qualitative methods in the thesis, as well as the different qualitative approaches, enrich the thesis findings by providing several perspectives on the topic. This may raise some ontological issues in summarizing and discussing the findings together. Simultaneously, different ontological and methodological perspectives show the different sides of, and confirm, the findings.
Ethical considerations

Power relations are always present in data collection procedures as well as within DSOs. The individual interviews with young adults with mild to moderate ID posed several complicated issues in relation to power. Both managers from the social services and staff are gatekeepers to the access to social care and, hence, to the young adults with ID. Staff members were the first to tell the young adults about the study and to ask if they were interested in participating in the interviews. The power relation between staff and the young adult should be considered with respect to possible acquiescence of the young adult (Barron, 1999). This procedure was used despite this caveat because it was believed to involve less of a power imbalance than if a researcher had approached the young adult at this stage. If the young adult expressed interest when asked by the staff members, a time and place were decided for a meeting with the researcher.

When a young adult with ID indicated a willingness to participate in an interview, the researcher and the young adult met and verbal information about the study and procedure was provided. This was a difficult situation in respect to voluntary participation, but many of the participants acted positively when first meeting the researcher by saying “Oh, I’ve been waiting for you!” or they stood in the doorway, waiting. One participant called a few days after the interview, when re-reading the information letter and said that if needed, he would participate in an interview again. This can be interpreted as indicating that the participant understood the interview situation as some kind of friendship and was flattered by the attention and was “seduced” by the atmosphere of participating in the interview in his home (Barron, 1999). However, this person was enthusiastic during the interview and had much experience to share, and after the phone call, he remained happy to have participated and understood that the interview only needed to be conducted once.

The imbalance of power in the relationship between a person with disability (interviewee) and a person without disability (interviewer) should be acknowledged (Barron, 1999). One way to try to manage this in the interview situation is to clearly express that the young adult was the one helping the interviewer and that the young adult was the one with the power to decide the length and content of the interview. This can be achieved by the interviewee choosing what to tell and what not to tell, including not answering some questions at all. In this sense, listening and following the conversation that the
young adult led was important to reducing the asymmetric power. Semi-structured interviews are supportive of this because the questions and topics can be covered naturally during the conversation.

The interviews were ended if there was any uncertainty about whether the informant wanted to continue. The informants were asked during the interviews if they wanted to stop the interview or to continue. Some informants became unfocused after a while and, when uncertainty was evident, they were asked about their willingness to participate. The interview was always ended if an interviewee seemed to be uninterested or unfocused when answering questions or in the interview situation.

During focus groups, power relationships both within the group and in relation to the researcher should be considered. In this case, managers were involved as gatekeepers in the recruitment of participants. To avoid the influence of managers in the decision whether to participate, all contact except information about the study was made directly with the staff, without the managers’ insight about this communication. The managers were also asked not to discuss with staff their participation in the focus groups.
Future research

There are two main directions for future research on the use of ICT for participation for young adults with mild to moderate ID. One is to focus on structures and support to enable the use of ICT to increase participation. The other direction is to study subjective participation and hence, to focus on how individuals experience participation in different life spheres. Both directions are necessary to fully understand the organizational structure needed to provide optimal support for the use of ICT.

The empirical studies in this thesis show a lack of organizational support in terms of policy and strategies and which was confirmed by the staff. Therefore, more research on the processes of organizational support and implementation, as well as managers perspective is needed. Observational studies of practices used on a daily basis by young adults with ID, including documentation, could be used to triangulate the results in this thesis and to understand better how support is actually provided. There are also other aspects to take into account. Stakeholder organizations, managers and family members are actors who could contribute their valuable perspectives. However, when advocating for full participation for people with ID, their own perspective and experiences are always central.

In some parts of the thesis, I have touched upon the question of responsibility for making ICT available to young adults with ID. Priorities and evaluation systems are needed to clarify how responsibility is distributed and negotiated within disability service organizations. These should be studied empirically in relation to the working conditions for staff and the resources in their daily work.
Practical implications

ICT is considered to be a normal part of daily life for young adults with mild to moderate ID. However, ICT is not considered to be a normal part of the daily work of staff who work with young adults with ID. This discrepancy can force young adults with ID to act as both a service user on one hand and as a young adult independent of the disability service organization (DSO) on the other. To promote participation of young adults with ID in society, it would be beneficial for DSOs to develop policies and resources for the support of young adults with ID rather than making these young adults adapt to a life within the DSO that may not fulfill the need for ICT as part of a normal life.

Support for ICT use needs to be improved within DSOs. Staff expressed several ideas about developing practices to increase the use of ICT to satisfy the needs and interest of young adults with ID. To realize these changes and to reduce the influence of staff personal attitudes about ICT, organizations need to provide better staff resources. The current expectation that staff should manage these increasing demands without support may adversely affect their working conditions and health. However, staff may also need to learn more about how young adults with mild to moderate ID use ICT to participate in various activities. These findings may be useful for developing guidelines for DSOs to provide support for staff aimed at expanding participation in society by young adults with ID beyond their existing ICT use.
Conclusions

The studies included in this thesis add to knowledge about how ICT use is enabled and hindered within Swedish disability service organizations (DSOs). Young adults with mild to moderate ID benefit from using ICT in terms of their independence and participation. Most importantly, the young adults perceived that their use of ICT enables their participation both online and offline. However, their use of ICT can be hindered by the lack of support, especially within the DSO.

ICT creates an imbalance between enabling participation and exposure to social risks that staff members find difficult to manage. This imbalance and risk illustrate how DSOs work with indeterminate technologies and the fact that morals often determine the type of service provided. Staff participants perceived the need to balance the protection of young adults with ID with support to participate in wider society. On the one hand, being online can facilitate the independent participation in social situations of young adults with ID. On the other hand, staff may not necessarily trust that these young people with ID can manage the social and economic exposure. Thus, the staff concerns about risk can become a barrier that hinders the use of ICT by young adults with ID.

The staff members’ personal beliefs influence service provision. Young adults with ID are dependent on staff providing, or in some cases hindering, support for the use of ICT. Staff participants noted that their ability to both introduce and to support ICT use by young adults with ID in residential care depends on the organizational support and resources. Staff further noted that one common barrier is the lack of smartphones at work, which was perceived as a frustration for staff that hindered their ability to use a phone to support their relations with the service users.

The lack of support for the use of ICT by young adults with ID was reported at other levels in DSOs. This suggests that, although DSOs recognize the problem, they are not aware of how they can support ICT use. Better organizational resources and support, but without increased control, are necessary for enabling staff to be supportive, as expected by the organization, to enable full participation for young adults with ID.
Sammanfattning på svenska


Inledningsvis användes en kvantitativ beskrivande ansats för att nationellt kartlägga det organisatoriska stödet för IKT inom den kommunala funktionshinderomsorgen. Detta följes av tre kvalitativa studier. Fokusgruppintervjuer med personal inom funktionshinderomsorgen genomfördes och analyserades i studie II (narrativ analys) och studie III (innehållsanalys). Dessa studier fokuserar på personalens erfarenhet av de unga vuxnas IKT-användning samt hur deras arbetssätt möjliggör eller hindrar de unga vuxna med lindrig till måttlig utvecklingsstörning att använda IKT. Den fjärde studien är en intervjustudie med de unga vuxna med mild till måttlig utvecklingsstörning, som bor i kommunal funktionshinderomsorg om deras dagliga IKT-användning.

Resultaten visar att de kommunala organisationerna saknar en övergripande strategi för stöd till IKT-användning men förlitar sig på att personal ska ge stöd till de unga vuxna i vardagssituationer. Personalen redogör å andra sidan för svårigheter att ge stöd för IKT, delvis på grund av bristande organisatoriska resurser. Trots detta visar personalen entusiasm inför att vara de som introducerar och stöttar användningen av IKT, förutsatt att adekvata resurser ges från organisationen. Dessutom beskriver de både positiva och negativa

Nyckelord: Delaktighet, Funktionshinderomsorg, Informations och kommunikationsteknik, Utvecklingsstörning
Tackord


En vanlig uppfattning är att doktorandtiden är ensam. Det är den på sätt och vis, men jag har haft turen att ha många doktorander runt mig (ingen

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References


