

DOCTORAL THESIS



Falling through the cracks

A study on young adults with intellectual disability not involved in employment, education or daily activity

Renee Luthra



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*To Mom and Dad.
For teaching me always.*

Abstract

The time after finishing secondary school is marked by changes and milestones of adulthood. There is increased attention and knowledge that for some individuals in the general population, the time after secondary school consists of not participating in an occupation. However, there is limited knowledge and research on young adults with intellectual disability who after special upper secondary school find themselves in this situation. In this thesis, these individuals are referred to as Not in Employment, Education, or Daily activity (NEED). The general aim of the thesis is to increase knowledge about young adults with intellectual disability who after upper secondary school are NEED, by providing deeper understanding and analysis of the target group's characteristics and associations with NEED status, as well as to study the subjective experiences of becoming and being NEED. This is a compilation thesis consisting of two studies that have led to four articles, as well as an introductory comprehensive summary. The four articles have different focuses but together provide a nuanced understanding of the target group.

The first study is a register study, which is the basis for article I and II. The register study used the national Halmstad University Register for Pupils with Intellectual Disability (HURPID) and two other Swedish registers to conduct statistical analyses. Article I explored the situation after USSID for the NEED group in terms of background factors, financial support and the use of disability services. The findings showed the heterogeneity of the group. Many had financial supports, but few used disability services. Moreover, background factors, financial support and use of disability services had various significant associations with not having an occupation. Article II described and analyzed the group's family situation and how this relates to not participating in an occupation as opposed to being in an occupation of employment, education or daily activity. Family situation in the target group varied depending on sex, age, and immigrant background. Regression analyses illustrated the significance of family situation to occupational status; however the results differed between men and women. Factors of partnerships and having children were found to be associated with not participating in an occupation for women, but not for men. The second study is an interview study that is the basis for article III and IV. Interviews were conducted with 10 participants

from the target group and these were analyzed with thematic analyses. Article III analyzed first-hand experiences of becoming and being NEED, and encounters with agencies and institutions. The results indicated that the experience of not having an occupation is influenced by individual and environmental factors. It was common to experience limited post-school occupations, face challenges with finding an occupation, and difficulties with navigating and attaining appropriate formal support. The experiences of not being involved in an occupation is discussed as a form of social exclusion. Article IV examined the group's social relationships, networks and experiences of belonging. The results found that individuals had social relationships and networks in informal domains (family, friends, partners), but also in organized settings (the support and service system, recreational activities). These relationships provided feelings of acceptance, support, and care which all related to a sense of belonging. However, within their experiences of belonging these individuals were simultaneously striving for increased independence. This duality between belonging and independence at times clashed, as well as was influenced and amplified by dimensions surrounding having an intellectual disability.

The overall empirical findings are analyzed through the use of ecological systems theory, and theories of social exclusion and belonging. An ecological approach allows for organizing and identifying different aspects of the environment, characteristics of the individual as well as interactions occurring between them, that help in understanding becoming and being NEED. Social exclusion and belonging more closely examine different perspectives of not having an occupation. These concepts are regarded as existing on a continuum where individuals in the target group can experience varying degrees of both, depending on context and situation. Within both social exclusion and belonging, some people with intellectual disability are displaying an active choice. These individuals are resisting categorization by choosing to not partake in the supports and settings associated with an intellectual disability. The conclusion of this thesis is that young adults with intellectual disability who are not participating in an occupation is a complex phenomenon. To understand this more in-depth many different factors, interactions and experiences have to be considered. There is a great need to develop resources and services that have a holistic approach that also fit with individual needs and desires, in order to better promote participation and prevent individuals from falling through the cracks.

Keywords: Intellectual disability, Not in Employment, Education or Daily activity (NEED), post-school occupations, ecological systems theory, social exclusion, belonging

Sammanfattning (abstrakt)

Tiden efter gymnasieskolan präglas av förändringar och vuxenmarkörer. Forskning visar att tiden efter gymnasiet för vissa unga vuxna kännetecknas av att inte ha en sysselsättning. Det finns dock begränsad kunskap och forskning om unga vuxna med intellektuell funktionsnedsättning som efter gymnasiesärskolan befinner sig i en sådan situation, d.v.s. som varken arbetar, studerar eller har sin sysselsättning inom daglig verksamhet. I den här avhandlingen benämns dessa individer som Not in Employment, Education or Daily activity (NEED). Syftet med denna avhandling är att öka kunskapen om unga vuxna med intellektuell funktionsnedsättning som efter gymnasiesärskolan inte har sin sysselsättning i arbete, studier eller daglig verksamhet (NEED), genom att ge djupare förståelse och analys av gruppens karakteristik och samband med att vara NEED samt att studera de subjektiva erfarenheter av att bli och vara NEED. Detta är en sammanläggningsavhandling som består av två studier som har lett till fyra artiklar, samt en ramberättelse (kappa). De fyra artiklarna har olika fokus men ger tillsammans en nyanserad förståelse av målgruppen.

Den första studien är en registerstudie, som ligger till grund för artikel I och II. Registerstudien använde det nationella registret Halmstad University Register for Pupils with Intellectual Disability (HURPID) vilket har samkörts med två andra svenska register. Statistiska analyser har gjorts som beskriver och undersöker samband i gruppen. Artikel I undersökte situationen efter gymnasiesärskolan för NEED-gruppen utifrån bakgrundsfaktorer, ekonomiskt stöd och LSS-stöd. Resultaten visade att detta är en heterogen grupp. Många hade ekonomiskt stöd, men få hade LSS-insatser. Dessutom hade bakgrundsfaktorer, ekonomiskt stöd och LSS-stöd olika samband med att inte ha en känd sysselsättning. Artikel II beskrev och analyserade gruppens familjesituation och hur detta relaterar till att vara NEED. Familjesituationen i målgruppen varierade beroende på kön, ålder och om man har invandrarbakgrund. Regressionsanalyser visade att familjesituation har betydelse för att vara NEED, men resultaten skiljde sig mellan män och kvinnor. Exempelvis, faktorer som partnerskap och att ha barn var signifikanta för att vara NEED för kvinnor, men inte för män.

Den andra studien är en intervjustudie som ligger till grund för artikel III och IV. Intervjuer genomfördes med 10 personer från målgruppen och analyserades med tematisk analys. Artikel III analyserade erfarenheter av att bli och vara NEED, samt mötet med olika myndigheter och institutioner. Resultaten visade att upplevelsen av att inte ha en känd sysselsättning påverkas av individ och miljöfaktorer. Det var vanligt att uppleva att alternativen efter gymnasiesärskolan är begränsade, samtidigt som det finns utmaningar med att hitta en sysselsättning och svårigheter att navigera och få stöd från olika stödsystem. Dessa erfarenheter diskuteras som en form av social exkludering. Artikel IV undersökte gruppens sociala relationer, nätverk och upplevelser av tillhörighet. Den visade att individer inom NEED-gruppen har sociala relationer och nätverk som är informella (familj, vänner, partners), men också i organiserade miljöer (stöd- eller vårdsystem, fritidsaktiviteter). Dessa relationer bidrog till känslor av acceptans och stöd som var centrala i upplevelser av tillhörighet. Inom sina erfarenheter av tillhörighet strävade individerna samtidigt efter en ökad självständighet. Det resulterade i en dualitet mellan tillhörighet och självständighet, som ibland hindrades, påverkades eller förstärktes av att ha en intellektuell funktionsnedsättning.

De samlade empiriska resultaten diskuteras genom användning av ekologisk systemteori, samt teorier om social exkludering och tillhörighet. Ekologisk systemteori gör det möjligt att organisera och identifiera olika miljöer och karakteristik hos individen men också interaktioner som uppstår mellan miljöerna och individen, vilket bidrar till en förståelse för att bli och vara NEED. Social exkludering och tillhörighet används för att närmare undersöka olika perspektiv på att inte ha en sysselsättning. Begreppen diskuteras finnas på ett kontinuum där individer i målgruppen kan uppleva olika grader av båda beroende på kontext och situation. Inom både social exkludering och tillhörighet, visar vissa av personer med intellektuell funktionsnedsättning ett aktivt val. Dessa individer motstår kategorisering genom att välja att inte delta i arenor eller stödsystem som förknippas med en intellektuell funktionsnedsättning. Som en slutsats visar denna avhandling att situationen för unga vuxna med intellektuell funktionsnedsättning som inte har en känd sysselsättning är ett komplext fenomen. För att förstå detta mer ingående måste många olika faktorer, interaktioner och erfarenheter beaktas. Det finns ett stort behov av att utveckla resurser och stöd som har en helhetssyn – men som även är individanpassade – för att främja ökat deltagande och förhindra att individer faller mellan stolarna

Nyckelord: Intellektuell funktionsnedsättning, Not in Employment, Education or Daily activity (NEED), sysselsättning, systemteori, social exkludering, tillhörighet

List of articles

- I. Luthra, R., Högdin, S., Westberg, N., & Tideman, M. (2018). After Upper Secondary School: Young Adults with Intellectual Disability not Involved in Employment, Education or Daily Activity in Sweden. *Scandinavian Journal of Disability Research*, 20(1), 50–61. <https://doi.org/10.16993/sjdr.43>
- II. Luthra, R. (2019). Young adults with intellectual disability who are not in employment, education, or daily activities: Family situation and its relation to occupational status. *Cogent Social Sciences*, 5. <https://doi.org/10.1080/23311886.2019.1622484>
- III. Luthra, R., Westberg, N., Högdin, S., & Tideman, M. (2018). ‘Just because one has attended a special class does not mean that one isn’t capable’: the experiences of becoming and being not involved in traditional occupations for young people with intellectual disability. *Nordic Social Work Research*. <https://doi.org/10.1080/2156857X.2018.1553734>
- IV. Luthra, R. (Submitted). The Experience of Belonging of Young People with Intellectual Disability not Participating in Traditional Occupations.

Abbreviations

AAIDD	American Association on Intellectual and Developmental Disabilities.
DSM-5	The Diagnostic and Statistical Manual of Mental Disorders (Version 5, The American Psychiatric Association).
HURPID	Halmstad University Register on Pupils with Intellectual Disability. A national register used in articles I and II.
ICD-10	International Statistical Classification of Diseases and Related Health Problems 10th Revision.
LISA	Longitudinal Integration Database for Health Insurance and labour Market Studies. Register used in article I and II.
LSS	The Swedish Act Concerning Support and Service for Persons with Certain Functional Impairments. Ten disability services provided under the LSS Act.
NEED	Not in Employment, Education or Daily activity. Refers to young adults with intellectual disability not participating in traditional occupations and the target group of this thesis.
NEET	Not in Employment, Education or Training. Refers to people in the general population who are not participating in an occupation.
USSID	Upper Secondary School for pupils with Intellectual Disability. A special secondary school form available in Sweden.
UVAS	Unga som Varken Arbetar eller Studerar [young people who neither work nor study]. Refers to young people in the general population in Sweden who are not participating in an occupation.

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Introduction

The transition after secondary school is an important time for young adults. Many will embark on changes such as living independently, finding employment or pursuing further education. This is also a time where one's identity continues to develop, and new roles and expectations emerge. Arnett (2004) refers to this stage in life as emerging adulthood, which is characterized by identity exploration, instability, self-focus, feeling in-between/in transition, and a time of possibilities. The transition after graduating from secondary school has changed over time. Instead of transitioning from school direct to an occupation, which was more common in the past, today young people's transitions are more individual, unstable, and transpire over a longer time period (Olofsson, 2014). A marked phase of adulthood involves finding an occupation. The type of post-school occupation will vary between individuals and the school system has a part in preparing for this phase after secondary school.

One type of occupation that has high value in society is employment. Employment has been found to provide daily structure, monetary income and social networks, as well as relates to increased well-being, quality of life, and better physical and mental health (Andrews & Rose, 2010; Beyer et al., 2010; Lindqvist, 2009; Robertson et al., 2019). At the same time, Sweden has seen an increase in unemployment rates for young adults (Germundsson & Runesson, 2014) and increased attention on individuals who are not participating in the workforce (Swedish Government Official Reports, 2017:9; Swedish Government Official Reports, 2013:74). Not being involved in an occupation, such as employment, has been linked to individual consequences of insecure future employment, crime involvement, psychological distress, poorer health (mentally and physically), and poorer social relations, as well as broader societal consequences of economic loss (Eurofound, 2012; Gutierrez-Garcia et al., 2017). One of the groups particularly affected in regard to not having an occupation and difficulties with establishment in the labour market is young people with disability (Engdahl & Forslund, 2015; Germundsson & Runesson, 2014). The right to work and gain a living is outlined in the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006, Article 27); however, people with disability, particularly intellectual disability, face

great challenges in entering the labour market (National Board of Health and Welfare, 2010a).

The transition from secondary school and into adulthood is marked by various milestones. People with intellectual disability may encounter challenges and require greater forms of support to achieve these markers. On an individual level these challenges will vary depending on for example the degree of the disability, but on a structural level challenges exist in systems, demands in the labour market, and attitudes towards people with a disability. Society has a responsibility through for example, preparations in schools and available formal support, to aid and guide individuals through these markers of adulthood. Young adults with intellectual disability in Sweden attend Upper Secondary School for pupils with Intellectual Disability (USSID). After secondary school, they can face various difficulties with establishing and maintaining an occupation (Arvidsson, 2016; Ellenkamp et al., 2016), having limited social networks (Foley et al., 2012), and increased financial vulnerability due to low income rates and the use of financial support from the government (Swedish Agency for Youth and Civil Society, 2012). These difficulties are amplified by changes in the labour market and negative perceptions (Andersson et al., 2015; Germundsson & Runesson, 2014). Research finds that people with intellectual disability do not have equal quality or standards of living conditions compared to the general population, such as in areas of employment, income, leisure activities and social networks (Tideman, 2000; Umb-Carlsson & Sonnander, 2005). Together these challenges lead to vulnerability and risks for people with intellectual disability.

In 2009 Halmstad University launched a research project in the interest of studying and increasing knowledge on post-USSID occupations for people with intellectual disability. Due to the lack of available national data for these former students, the national Halmstad University Register on Pupils with Intellectual Disability (HURPID) was created. HURPID is based on final grade documents for 12,269, essentially all, former USSID students who graduated in Sweden between the years 2001-2011. HURPID has been linked with two other Statistics Sweden registers that contain information on for example, disability services, employment, financial support and subsidies. In a first study, Arvidsson et al. (2015) found that post-school activities for former USSID students could be classified into four categories. The first was employment and approximately 22.4 % of former students were variously employed, many with subsidized employment. Another category was to participate in daily activity, which are disability day programs, and applied to 46.9 % of former students. It has previously been assumed that the majority of former USSID students move directly from secondary school to daily activity; Arvidsson et al. (2015) demonstrated that this proportion is less than

expected. The third category, 6.6 % of the group, was in further education for example folk high schools which is adult education consisting of courses and study circles. A central finding was that the remaining 24.1% of former US-SID students were not participating in the above-mentioned occupations. Although this group of young adults who after secondary school are not participating in traditional occupations have been identified, there is limited knowledge about their situations or activities. Despite the increased focus on young adults in the general population who are not involved in an occupation or who are considered to be “outside” of the system (Eurofound, 2012; Swedish Government Official Reports, 2013:74), there has been limited focus specifically on young adults with intellectual disability who are not participating in an occupation. The gap in knowledge signifies the importance of increasing understanding of this target group, in order to also develop appropriate resources and actions to better support those who find themselves not involved in an occupation.

General aim and composition of the thesis

The general aim of the thesis is to increase knowledge about young adults with intellectual disability who after upper secondary school are not involved in traditional occupations of employment, education or daily activity, by providing deeper understanding and analysis of the target group’s characteristics and associations with not participating in an occupation, as well as to study the subjective experiences of becoming and being without an occupation. This is a compilation thesis consisting of two studies, a register study and an interview study, that have led to four scientific articles, as well as the following introductory comprehensive summary. The following chapters aim to place the individual articles and their empirical findings within a broader framework and discussion. I begin with some points of departure including establishing a concept for the target group and placing the thesis within the doctoral education field of health and lifestyle. This is followed by chapters on background, previous research, theoretical framework, aims, method, results, and discussion.

Not in Employment, Education or Daily activity (NEED)

On a national and international level research has been conducted on young people who do not have an occupation. This includes the classification NEET, referring to young people in general who are Not in Employment, Education

or Training. In 2011, it was estimated that in Europe 7.5 million young people between the age of 15 and 24 were NEET (Eurofound, 2012). The corresponding Swedish classification is UVAS (Unga som Varken Arbetar eller Studerar [young people who neither work nor study]). Approximately 8-10 % of young people in the age group 16-25 years old, were UVAS/NEET every year between 2006-2011 (Theme group young people in working life, 2013:3). An OECD report (2016) found a similar proportion of 9.5% of Swedish young people between the ages of 15-29 years old who were NEET in 2015. The proportions of NEET/UVAS have remained stable over the last 10-15 years (Swedish Government Official Reports, 2017:9). Figures and proportions on young people who do not have an occupation should be regarded with some caution, since definitions and measures can vary (for example difference between measures of youth unemployment versus NEET [Engdahl & Forslund, 2015]), and these could also be underestimations (Swedish Government Official Reports, 2017:9).

Research finds that although NEET and UVAS populations are a diverse group with varying characteristics and situations, people with disability are highly represented in these (Swedish Government Official Reports, 2017:9). This subgroup has not received sufficient attention, and previous data limitations in following young adults with disability in relation to the labour market, including following people with intellectual disability after USSID, further limited the knowledge about young adults with disability who are not participating in employment or education (Swedish Government Official Reports, 2017:9; Swedish Government Official Reports, 2013:74). Some young adults with intellectual disability who are not involved in an occupation have likely been part of the wider NEET and UVAS discourse. However, this subgroup has not been specifically identified or studied in these contexts. In the research project at Halmstad University mentioned in the introduction, Arvidsson et al. (2015) initially referred to the individuals with intellectual disability who were not participating in employment, education or daily activity as “elsewhere”, signifying the unknown destination of the group. Since the present thesis built on these findings, it also became important to establish a clear designation for the target group. Therefore, to accurately and specifically identify this target group the present thesis establishes the use and implementation of the concept Not in Employment, Education or Daily activity (NEED). This concept intentionally alludes to the more general concept of NEET, in order to illustrate potential commonalities while also specifically identifying the target group. The abbreviation of NEED may signal the notion of being “in need” or “individuals in need of help”, which is not necessarily always the case. Individuals have varying degrees and types of needs,

including individuals who may not be in need at all. If individuals are “in need”, the question of being in need of what? is also raised.

A thesis in the field of health and lifestyle

This thesis is conducted within the doctoral education field of health and lifestyle with a specialization in disability studies at Halmstad University. The following section aims to place the topic of this thesis within the context of health and lifestyle.

There are various definitions and understandings of health and lifestyle. Health can relate to an assumption that it is something observable, quantifiable and measurable (Svensson & Hallberg, 2010). Another assumption is to view health from a holistic perspective, where feelings and experiences contribute to a multifaceted understanding of an individual’s health status (Svensson & Hallberg, 2010). Emerson et al. (2020) discuss subjective or personal well-being as related to health, which focuses more on the individual’s experiences and assessments of various aspects of their lives. This suggests that health has multiple dimensions and is not merely a question of disease. As Emerson et al. (2020) describe, the idea of a multidimensional understanding relates the Constitution of the World Health Organization’s (WHO, 1946) definition of health (although this has been critiqued as well, see for example Fritzell & Lundberg, 2007). Similarly, poor health is regarded as having various dimensions including symptoms and their consequences (Fritzell & Lundberg, 2007). This thesis is about people with intellectual disability, who have been assessed as having an intellectual disability. This is a lifelong disability that affects individuals' in various ways. In addition to the disability, there can of course be various types of diseases, which, individually or in combination with the disability, can affect the individual's health and lifestyle. The concept of lifestyle is generally regarded as the circumstances and ways that constitute how people live their lives. Lifestyles can be regarded as determinants of and influential to health showcasing their close proximity to each other, for example having social relationships or enjoying one’s job are determinants of health (Caton et al., 2012; Hallberg, 2010). Although individual differences contribute to health and lifestyle, it is also attributed to inequalities that arise from social structures (social class, sex, education etc) (Fritzell & Lundberg, 2007). For example, in their study, Emerson et al. (2020) found lower personal well-being reported among people with disability compared to people without disability, and illustrated that social determinants related to age, gender, ethnicity, partnerships, education, and employment impact this difference.

The nature of this thesis has various links to the field of health and lifestyle. The first is the value of having an occupation and how the lack of an occupation relates to social exclusion. Research provides evidence that to participate in an occupation, such as employment, is meaningful and influences various aspects of the individual's life including feeling a sense of purpose and self-worth as well as social networks and finances (Forrester-Jones et al., 2004; Jahoda et al., 2009; Lövgren & Hamreby, 2011). In a literature review by Robertson et al. (2019), the authors identify that despite limited studies in the field, paid employment was associated with better physical and mental health outcomes for people with intellectual disability. Whereas a lack of an occupation is often associated with negative consequences, including impacting physical and mental health such as psychological distress, and impacting relationships, families, and future employment opportunities as well as increasing the likelihood of engaging in risky behaviour (Eurofound, 2012). The second link to health and lifestyle is the thesis' theoretical framework that includes belonging (see chapter "theoretical framework"). A sense of belonging relates to increased well-being, and research finds that social networks and friendships connect to improved well-being, activity, and health for people with and without intellectual disability (May, 2013; Wilson et al., 2017). As such, the aspects of health and lifestyle are present in the thesis through studying the situation and experiences of young adults with intellectual disability who are not participating in an occupation, as well as how this relates to one's daily life including their living situations and social relationships.

Background

The following chapter presents background information and context for the thesis. First, disability models and the perspective that is implemented in the thesis are discussed, followed by discussing intellectual disability, upper secondary school, and concluding with the available formal supports for people with intellectual disability.

Disability models

Throughout history there have been different perspectives on disability. The medical model has historically been dominant, which focuses on the individual and sees disability as the result of cognitive and biological impairments (Ineland et al., 2013; Lindqvist, 2009). In contrast, the social model emphasizes the variation in abilities that exists in the population, and disability is the result of barriers in the environment that do not accommodate these variations (Tideman & Strandberg, 2018). The disability is thus created as a result of the inaccessibility and barriers that society has in place (Lindqvist, 2009). Finally, the relational model combines these two, and sees disability as a combination of individual and environmental barriers. In other words, a disability is the result of the relation between an individual with an impairment and an environment that is not accommodating or adaptable (Tideman & Strandberg, 2018). As outlined by Söder (2013) this model, and subsequent disability research, emphasizes “factors and processes that make impairments into disabilities” (p.102); however, the author also addresses criticism of the model being vague and too broad. The relational model is the prevalent perspective for disability legislation in Sweden (Larsson Tholén & Danermark, 2016; Mineur, 2013).

This thesis uses the relational model as a perspective and to discuss disability. In this model, disability is created in the interaction between the individual and the environment meaning that a disability, how it manifests and its meaning for the individual, can vary depending on the situation and context (Lindqvist, 2009). According to Bhaskar and Danermark (2006) other disability models, such as the medical and social, tend to focus on only one aspect,

but each of them provide an element of understanding disability. Depending on which perspective is used and implemented it will have different outcomes or proposed solutions. An example provided by Lindqvist (2009) is in education. From an individual perspective, special education will provide efforts aimed at improving and training individual skills; whereas a social perspective will lead to efforts focusing on for example changing the structure and organization of the tasks and environment.

The relational model applies to understanding people with intellectual disability who are NEED. The focus tends to fall on the individual and their so-called shortcomings as reasons for not having an occupation. Additionally, the solutions tend to focus on how the individual should make changes or adjustments in order to find an occupation. However, this adheres to the medical model of disability and does not consider the whole picture. The environment, and the interactions with the environment are also central factors. By considering these elements together we gain a better understanding of what produces and creates NEED status.

Intellectual disability

In this thesis the definition of intellectual disability has been restricted to persons who have attended USSID (see the following section “Special schools and Upper Secondary School for pupils with Intellectual Disability” for further description of USSID). The main reason being that the criterion for attending USSID is having an intellectual disability. However, there is acknowledgement that there is variation in diagnoses and severity of former students of USSID, not to mention some that have been misplaced in USSID (see Swedish Schools Inspectorate, 2011).

People with intellectual disability are a varied group; yet there are common criteria used for diagnosis. These criteria can be found in various classification systems (Swedish National Agency for Education, 2013b) and definitions of intellectual disability, including in ICD-10¹, DSM-5, and AAIDD². According to The American Psychiatric Association and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), intellectual disability is defined by three criteria. The first criterion for the diagnosis refers to intellectual functions (reasoning, abstract thinking, planning etc.) and is measured through intelligence test (IQ tests), where an IQ score of approximately 70 or below

¹ ICD-10: International Statistical Classification of Diseases and Related Health Problems 10th Revision

² AAIDD: American Association on Intellectual and Developmental Disabilities

is given for an intellectual disability. However, the DSM-5 highlights that IQ scores alone are insufficient and instead place more emphasis on the second criteria: adaptive functioning (criterion B). Adaptive functioning relates to conceptual, social, and practical domains and where “deficits in adaptive functioning (that) result in failure to meet developmental and sociocultural standards for personal independence and social responsibility” (American Psychiatric Association, 2013, p.33). The final criteria (criterion C) is that the symptoms should already be present during early development. The severity of an intellectual disability is defined as mild, moderate, severe, or profound. A diagnosis of mild intellectual disability is most common compared to the other degrees (Mineur et al., 2009). According to the DSM-5 (American Psychiatric Association, 2013), the prevalence rate for intellectual disability is 1 % in the general population.

In Sweden, and in this thesis, an administrative definition is used. This entails that people who due to intellectual difficulties (in line with the criteria mentioned above) are also in need of and utilize supports and services through for example special legislation and/or special schools such as USSID, are defined as persons with intellectual disability (Mineur et al., 2009; Swedish Government Official Reports, 2003:35; Tideman, 2000). It is the emphasis of utilizing supports and services that make up the administrative definition (Mineur et al., 2009; National Board of Health and Welfare, 2005). A person’s evaluation of needing support, such as attending the special school form of USSID, is based on psychological, medical, pedagogical and social assessments. When comparing proportions of the population that have an intellectual disability across countries, the statistics therefore vary if various definitions are used. In for example the USA where there is emphasis on intelligence level, there may be higher proportions of persons with intellectual disability compared to Sweden. The proportions in Sweden may be lower if persons with IQ under 70 do not receive support, services or special education and thereby are not visible in the administrative definition (Sonnander & Emanuelsson, 1993). Ineland et al. (2013) discuss that it is difficult to establish how many people in Sweden have an intellectual disability, since the administrative definition only presents how many people receive special education and/or support due to having an intellectual disability. As the authors state, this means that on the one hand people who are in USSID or receive supports under the LSS Act are categorized as having an intellectual disability, while on the other hand there may be individuals who have an intellectual disability but do not receive special education and/or support and thereby are not visible in the estimated proportions.

Special schools and Upper Secondary School for pupils with Intellectual Disability (USSID)

School and gaining an education are meant to provide individuals with knowledge, skills and preparation for adult life as contributing citizens (Lindqvist, 2009; SFS 2010:800). For persons with intellectual disability, the Swedish school system is composed of special school options. There is a compulsory special elementary school, followed by the optional Upper Secondary School for pupils with Intellectual Disability (USSID). Municipalities bear the responsibility for ensuring that this option is available and implemented (SFS 2010:800).

In order to attend special schools certain criteria has to be met. Regarding special elementary schools the Education Act (SFS 2010:800) outlines that having an intellectual disability is the main criteria:

Children who are expected to not reach up to elementary school proficiency because they have an intellectual disability, should be received in special elementary school. The question of admittance in special elementary school is examined by the child's municipality in which they live. A decision of admittance to special elementary school should be preceded by an investigation consisting of a pedagogical, psychological, medical and social assessment. Consultation with the child's guardian will take place during the investigation. (SFS 2010:800, Translated from chapter 7:§5)

The child's guardian needs to give consent before admission to a special school can occur; however, there are special circumstances when the municipality may go against the guardian's decision (Swedish National Agency for Education, 2013b). To be admitted to USSID, the criteria is similar and apply to students who have ended compulsory school, are starting their secondary education before age 20, and who are assessed to not reach up to secondary school proficiency due to having an intellectual disability (SFS 1985:1100, chapter 6:§7; Swedish National Agency for Education, 2013b). For a decision to attend USSID, the pedagogical, psychological, medical and social assessments must be conducted if these have not been done prior or if there are other reasons that make this necessary (SFS 2010:800, chapter 18:§5).

According to the Education Act (SFS 2010:800, chapter 18:§2), the aim of USSID is to provide an adapted education which prepares for professions and continued studies, and also contributes to the individual's development and participation in society. USSID is composed of four years and offers students various types of programs. The register study in this thesis uses data of students who finished USSID between the years 2001-2011, which is based on the old system of USSID. In the old system three types of programs were

available: national programs, special designed programs, and individual programs. The first two types of programs were intended for individuals with mild or moderate forms of intellectual disability. In 2013 a new format for USSID was launched. This included changes of additional national programs as well as more structure in national programs, removal of special designed programs, more flexibility in choosing courses, and increased cooperation between USSID and mainstream secondary schools, for example the option to attend introduction programs in mainstream secondary school (Swedish National Agency for Education, 2016; Swedish National Agency for Education, 2013a). In the former Education Act (SFS 1985:1100), which the old USSID form adhered to, the decision that admission to special school should be preceded by a pedagogical, psychological, medical and social assessment was not clearly stated. Special school forms such as USSID may be beneficial if it entails adaptations that suit the individual, but also poses risks of exclusion and segregation. Anderson et al. (2014) describe that exclusionary practices within education for people with disability continue to occur in many countries, including segregated schools or exclusion from activities and peers; whereas inclusive education that fosters participation, achievement and individual value generates greater benefits for the individual and society.

Formal support for people with intellectual disability

After secondary school, people with intellectual disability may require formal supports and services provided by various agencies and organizations in the welfare society. These supports may be surrounding finding an occupation or regarding other everyday tasks and activities. The Social Services Act and the Health and Medical Services Act apply to and service everyone in the general population, including people with intellectual disability. However, additional services for people with intellectual disability are provided by The Swedish Act Concerning Support and Service for Persons with Certain Functional Impairments (The LSS Act, LSS 1993:387). This LSS Act is part of the social safety net that provides 10 different services and supports in the everyday life of people with disability. The aim is to provide support and promote participation (National Board of Health and Welfare, 2015) and includes contact persons, companion services and various forms of short and long-term accommodation. The eligibility criteria for LSS are divided into three disability categories, the first of which includes intellectual disability (National Board of Health and Welfare, 2015).

One of the supports under the LSS Act is daily activity, which aims to provide (unpaid) meaningful activities and contribute to increased

possibilities for future employment (National Board of Health and Welfare, 2008). Although municipalities are responsible for implementing daily activities, cooperation with other agencies such as the Swedish Public Employment Service or Social Insurance Agency, is also important for the quality and utilization of the daily activity (National Board of Health and Welfare, 2010b). It is the LSS service that has had the greatest increase and is most used (National Board of Health and Welfare, 2010b). Many who seek daily activity, according to The National Board of Health and Welfare (2010b), are young people who have attended USSID or have tried to find employment with little success. USSID does not qualify for any other higher post-secondary education in Sweden. It only qualifies for further education in for example folk high schools, which is adult education consisting of courses and study circles.

Other types of formal support available in Sweden are provided by various agencies such as the Swedish Public Employment Service, Social Insurance Agency or Social Services. Long-term financial subsidies known as activity compensation is available to persons between the ages of 19-29 years old and who have a reduced ability to work due to disability or illness (Social Insurance Agency, 2020). Once individuals reach the age of 30 years old, they can instead be eligible for sickness compensation. Other financial supports include unemployment benefits, parental benefits, and social assistance. There are also various programs provided by for example, the Swedish Public Employment Service aimed at facilitating people with disability gaining employment in the labour market. These programs or services focus on providing subsidies to employers who hire people with disabilities (Engdahl & Forslund, 2015). All these services and supports are considered part of the social safety net available to persons with disability. After secondary school, young people with intellectual disability can be eligible for these supports and services. However, not everyone may have, need or desire these supports. Those who are employed, studying, or have their needs fulfilled through other means may not use these available supports; whereas others may choose to not receive these supports.

Previous research

The following chapter presents previous research that is relevant to the topic of this thesis. As previously mentioned, there is limited knowledge that directly focuses on people with intellectual disability who are not participating in an occupation. Coupled with the complexity of the phenomenon, this led to an initial approach of exploring and studying many different areas of previous research. The result of this, presented below, is research that is relevant, contributes to a greater context, as well as covers various areas related to the situation of not having an occupation. In addition, both national and international research is presented with the motivation that the Swedish context is central, but international connections provide broader contexts and understandings.

The chapter begins with research on the transition after secondary school, including USSID and the transition after USSID, to illustrate the important time period this entails. This is followed by discussing central topics that occur during the time after secondary school, including post-secondary school occupations for people with intellectual disability, the available system of formal supports and services, and family and social relations. The final section presents research on young people in general who do not have an occupation (NEET), in order to provide additional relevance internationally and to the general population.

Transition after secondary school

For young people in general the transition from school, or the transition into adulthood has variable markers that define this stage in life. However, due to changes in the traditional understanding of adulthood, where many markers such as marriage or having children are delayed, the concept of emerging adulthood may better define this phase between adolescence and not yet reaching full adulthood (Arnett, 2004). One feature of this “in-between/in transition” time, according to Arnett (2004), is that employment may be in low-wage or service-oriented settings and young people change jobs often, whereas the meaningfulness and seriousness of one’s job becomes more

distinct as people get older. The time after leaving secondary school is then regarded as a period filled with several changes, but also characterized by flexibility and instability. Olofsson (2014) discusses the transition from secondary school to an occupation as being individualized and resembling a yo-yo pattern. The author describes these transitions as characterized by longer time periods and alternating between having and not having an occupation. This contrasts with earlier patterns where transitions typically consisted of going from school to work (Olofsson, 2014).

Special schools for people with intellectual disability aim to provide an education that is adaptive to the individual and prepare them for adult life in terms of work, living situation and leisure (Swedish Government Official Reports, 2011:8). During the early 90's there was a rise in the number of students enrolled in special schools in Sweden (Tideman, 2000). The findings of this increase, as Tideman (2000) discusses, in part relates to financial cutbacks in resources, where students with difficulties in mainstream schools became registered in special schools with the argument that they would receive better resources. However, the author explains a consequence of this was the increase in social categorization of these students as deviant. Attending special schools can entail different experiences and outcomes. The results of a doctoral thesis by Mineur (2013) show that students' experiences of attending USSID emphasize increased support and personal growth; yet leads to difficulties for future employment opportunities and some students expressed insecurity with attending this school form due to the negative stereotypes. According to other research, persons in USSID are a diverse group, where some choose to identify themselves with this school form and accept having an intellectual disability, while others distance themselves and rather identify with students in mainstream schools and as normal (Molin, 2004; Szönyi, 2005).

The transition after secondary school for people with intellectual disability may include deciding and finding their next occupation. The transition may additionally include personal changes such as finding a partner, having children or living independently for the first time. Salt et al. (2019) found that young adults with intellectual disability express similar perspectives on the concept of adulthood as young adults in general, centering around for example increased autonomy and responsibility. The authors explain that the transition for young people with developmental delay may have a longer time span, therefore these individuals' feelings towards gaining independence may be more mixed, yet many see themselves as being independent in the future. Moreover, these young adults view decision-making as occurring with their parents, where parents tend to have influential and final say. The perspectives and measures of adulthood for young people with intellectual disability may be viewed differently between families and service providers (Redgrove et

al., 2016). It is also suggested that for this target group, the concept of emerging adulthood-as somewhere between leaving behind child status yet not reaching full adulthood- may be a more relevant concept (Redgrove et al., 2016). Research shows the transition from USSID to adulthood entails employing different strategies (Molin, 2008); while some accept having an intellectual disability and use supports through the care system, others seek normality (Molin, 2008; Szönyi, 2005). Björquist (2016) found that caregivers of young persons with disabilities communicated that their child's transition was stressful and worrisome, where for example navigating various services was difficult. What was needed during the transition to adulthood, as conveyed by the young persons with disabilities and their caregivers, was individualized support and more information (Björquist, 2016).

International research that examines the transition from secondary school to adulthood for persons with disability provides insights and comparisons. However, there needs to be consideration that countries vary in their welfare systems, school systems and structural elements. Some studies have looked at the success of persons with disability in gaining employment after secondary school, especially with the aid of vocational programs (Gold et al., 2013). Others have shown that persons with impairments (visual, hearing, speech) continue to be “behind” compared to persons without impairments in terms of finding employment and living independently (Janus, 2009). The transition can lead to increased worry and distress for persons with intellectual disability, where concerns revolve around fears of being bullied, having a close friend or family pass away, fear of failure, and concerns with keeping and making friends (Forte et al., 2011). According to several previous studies, the available services for assisting the transition from school to adulthood is described as inadequate, uncoordinated, and short-term (Foley et al., 2012; Palisera et al., 2016; Young-Southward et al., 2017). It has been found that parents experience their child's transition as worrisome, a strain on the family, lack of professional support, or stressful to navigate programs (Biswas et al., 2017; Leonard et al., 2016), and thereby employ various strategies to cope with the transition period (Biswas et al., 2017). Parents can show great concerns for their child with intellectual disability being able to secure future employment, for example in terms of social and communication skills or the ability to apply, find and get hired for a job (Blustein et al., 2016). Leonard et al. (2016) discussed that parents play a key role in transition planning and decision making, at times greater involvement than the person with intellectual disability themselves.

Post-secondary school occupations for people with intellectual disability

In Sweden, there tends to be three main post-secondary school occupations for people with intellectual disability: employment, daily activity, or further studies. However, these alternatives are limited since they are variously attainable and desirable.

Employment is a wide concept that varies in its definition and meaning. In general, work can be understood as “(...) an activity people conduct to produce valuable goods or services for others, and the meaning is determined by a society’s beliefs and values” (Ferrari et al., 2008, p.438). Work is described by Ferrari et al. (2008) in terms of intrinsic and instrumental value. The intrinsic value is based on how the individual personally places significance on their work, whereas the instrumental value includes being able to fulfill needs, apply skills and knowledge, and develop one’s identity (Ferrari et al., 2008). Employment can entail working in the regular competitive labour market, but also subsidized employment and sheltered workshops (National Board of Health and Welfare, 2013a as cited in Lövgren et al., 2014). Moreover, the concept of work depends on the individual’s subjective meanings and concepts. Ferrari et al. (2008) found that the concept of work among people with and without intellectual disability centered on the benefits it contains in the form of economic and psychological advantages, social needs, and skills and knowledge. The researchers found that most of the people with intellectual disability conveyed the positive economic and psychological benefits of work. As the exact forms and types of employment can vary, so too do their conditions, benefits, and drawbacks. Jobs in the competitive labour market entail income or working with others without a disability, whereas sheltered workshops tend to be workplaces for people with disability and have lower income opportunities (Ferrari et al., 2008). In the present thesis, given that employment is one central topic, I acknowledge that the definition of employment has different meanings for different people and contexts, and also depends on the individual’s own personal understanding of work. Therefore, a more open definition is applied where employment encompasses a range including a job in the regular labour market, practicums, or activities and programs that provide various financial incomes.

International and national previous research emphasizes that having a job is a central feature of adulthood and is meaningful for participation, financial stability, daily structure, self-worth, and quality of life (Jahoda et al., 2009; Lövgren, 2013; Lövgren et al., 2014). Paid employment has been found to relate to greater physical and mental health for people with intellectual disability (Robertson et al., 2019). At the same time, aside from its benefits,

employment can have negative consequences. For example, working in non-standard employment or insecure employment has associations with poor health for people with and without intellectual impairments (Emerson et al., 2018). People with disability, including intellectual disability, face challenges in entering and participating in the labour force, as seen in the low employment rates (Lövgren et al., 2014; McMahon et al., 2019; Statistics Sweden, 2017:2). According to the National Board of Health and Welfare in Sweden (2010a), persons with disability supported by the Law of Support and Service for certain disabilities and/or the Social Services Act, only 10% are reported to have a link to the labour market. The corresponding figure for persons without disability is 80% (National Board of Health and Welfare, 2010a). Patterns of higher unemployment rates is seen in young people with disabilities compared to young people in general (Swedish Government Official Reports, 2013:74; Statistics Sweden, 2017:2). A rise from 13% to 19% in young people with a disability registered with a code at the Public Employment Service has occurred between the years 2011-2016 (Labour Market Committee, 2017/18:2). These figures are in part explained by increased diagnosis yet can also be an underestimate if people who should be registered as having a disability are not represented in the statistics (Labour Market Committee, 2017/18:2). Various factors have been found to be associated with the high rates of unemployment among people with disability (see for example, Lövgren & Hamreby, 2011). On a broader structural level, changes have occurred in the labour market including higher demands, increase in temporary employment and flexibility which can lead to unstable jobs, and having higher educational qualifications (Germundsson & Runesson, 2014). It is likely that these changes affect those who have a weaker position in the labour market (Germundsson & Runesson, 2014).

One of the commonly discussed barriers for entering the labour market is employers' attitudes (Andersson et al., 2015; Statistics Sweden, 2019:2). People with various types of disabilities report discrimination via employers' negative attitudes, with women having higher reports of discrimination (Statistics Sweden, 2019:2). Research finds that employers may perceive workers with disability as less capable to do the job, compared to persons without a disability (Kaye et al., 2011). Different studies have found that the desirability to employ a person with a disability varies depending on the type of disability, where intellectual disability often generates a lower ranking compared to for example physical disability (Andersson et al., 2015; Kocman et al., 2018). Additionally, the severity of the intellectual disability has been found to relate to employment outcomes (Bush & Tassé, 2017). The perceived lack of skills among persons with intellectual disability or lack of suitable jobs due to high requirements, have also been shown to be barriers for their employment

(Kocman et al., 2018). Previous experiences of people with disability influences employers' hiring decisions (Andersson et al., 2015; Gustafsson et al., 2014), and wage subsidies exist that help compensate and support employers when hiring people with disability (Gustafsson et al., 2014; Tideman et al., 2017).

Supported Employment is one well-known method that is used to increase people with disability's participation in the labour market. Supported employment follows the idea of people developing skills while in the workplace, so-called "place, then train" (Tideman et al., 2017). It focuses on individual and on-going support by a job coach (Gustafsson et al., 2014). In a study evaluating work-oriented initiatives for young people with activity compensation, a Social Insurance Report (2017:5) found that Supported Employment had better effects in gaining employment compared to two other methods (a reference group and Case Management group). Research by Gustafsson et al. (2018) shows that supported employment's aim of matching a job with an individual's preferences lead to greater feelings of meaningfulness and social inclusion in one's job. Moreover, feeling valued affected the worker's sense of belonging.

The second post-school option is to participate in daily activity which is one of 10 services provided by The Swedish LSS Act (LSS 1993:387). There is national and international criticism towards daily activities and vocational activities, since they pose a risk of a lock-in effect and limit successful transition to employment (National Board of Health and Welfare, 2008; Tideman et al., 2017). An example of a lock-in effect is when good workers are kept in daily activities as a means for the organization to keep operating (Tideman et al., 2017). The experiences and perspectives of daily activity vary. According to Engeset et al. (2015), on the one hand, people with intellectual disability may enjoy the activities and view this as their work. On the other hand, the tasks may focus more on keeping workers busy as opposed to fostering productivity or the opportunity for an income, as such evoking a sense of welfare and caregiving instead of work (Engeset et al., 2015). When choosing between sheltered workshops and employment, Migliore et al. (2008) demonstrated that factors of for example safety, transportation, and long-term placement influence people with intellectual disability and their families' choices. Parents tend to highly value part-time or full-time employment for their children with intellectual disability after high school (Blustein et al., 2016). Moreover, disability services have been found not to be very encouraging of people with intellectual disability gaining integrated employment outside the sheltered workshops (Migliore et al., 2008).

The third post-school option is to continue with further education. Higher education shows positive employment outcomes for people with intellectual

disability (Kaya, 2018). However, USSID only qualifies for further education in for example folk high schools, which is adult education consisting of courses and study circles. USSID does not qualify for any other higher post-secondary education in Sweden.

As presented in the introduction of this thesis, Arvidsson et al. (2015) demonstrated the occupations of former USSID students, and the proportions that were in employment, daily activity, further education, or “elsewhere”. In Arvidsson’s (2016) doctoral thesis, the author discusses multiple factors and circumstances that influence an individual’s post-school occupation, including gender, where one lives, parents’ background, as well as broader issues of preparations in school and the effects of categorization. Arvidsson (2016) relates her discussion to the concept of social justice and highlights the need for greater recognition of people with intellectual disability’s capabilities and their subsequent contribution to society and the labour market. Moreover, that society must encourage and support individual’s pursuits of an occupation.

The system of formal supports and services

Tideman (2000) discusses that the normalization principle in Scandinavia manifests in greater emphasis on people with intellectual disability having equal living conditions and opportunities as the general population, and less emphasis on the individual to “be ‘made’ or become normal” (p.329). One way this principle is actualized is through special legalization, supports and services that aim to promote achievement of equal living conditions. The existence of a formal system of services should provide support for people with intellectual disability in various areas of their lives; however, previous research shows that people with intellectual disability have mixed experiences. Ineland et al. (2013) discuss that a diagnosis of intellectual disability is an opening for support and resources to be received; at the same time this labels the individual as different. The authors continue that society and our welfare system is designed in a way that a person must first receive a diagnosis in order to get the required support, in other words they must first be labelled as “different” in order to get support that further stigmatizes them as not being like everyone else. Receiving multiple job-related services has been found to lead to better employment outcomes (Kaya, 2018). However, according to Olin and Ringsby-Jansson (2009a), people may choose to distance themselves from services as a result of not identifying with the diagnosis, refuting a client role, or show mistrust and fear towards services. Olin and Ringsby-Jansson (2009a) assert that services can be stigmatizing and unsuitable,

among for example people who see themselves as having been misplaced in special schools or fall on the border of having a disability.

There are various types of formal supports and services available to people with an intellectual disability in Sweden (see “background” chapter). Financial supports provide security and income, but their implementation and use have been viewed in a critical manner. A common criticism is the potential for a lock-in-effect, where the individual has limited options or opportunities to move on from receiving these subsidies. Activity compensation is one type of financial support that provides financial security for individuals with a reduced ability to work, and opportunities to participate in activities that increase work abilities (Swedish Social Insurance Inspectorate, 2017:5). Research demonstrates a heterogeneous group receiving activity compensation, ranging from those who will likely never work to those who with proper support can gain employment (Social Insurance Report, 2017:5). At the same time, it’s been shown that the proportions of young people receiving activity compensation has increased, with long periods of use and with few exiting the compensation and instead gaining employment or pursuing education (Social Insurance Report, 2017:5). Apart from limitations in the transition to work or education, the Swedish Social Insurance Inspectorate (2017:5) criticized that activity compensation has not provided sufficient activities that promote establishment in the labour market. Arvidsson (2016) discussed that financial compensation and subsidies, although positive when properly implemented, may pose long-term problems. The author provides an example with subsidized work, which does not often transition to regular paid work over time, and consequently places the individual with intellectual disability in a locked position of never being fully employed.

Individuals may require support from multiple and different agencies, highlighting the need for cooperation and coordination among services (Swedish Government Official Reports, 2013:74). Danermark and Germundsson (2016) outline dimensions of legislation/regulations, organization, and perspectives of cooperation as important to study and how these facilitate or hinder successful cooperation. When cooperation between various agencies and services are experienced as uncoordinated, it leads to added responsibility placed on the individual or being caught in between agencies (Östlund & Johansson, 2018). Research demonstrates that support for people with intellectual disability should focus on the individual, as well as be flexible, coordinated, long-term and holistic (Kaya, 2018; Lövgren et al., 2014; Tideman et al., 2017).

Family and social relations

Multiple previous studies find that for persons with disability, including intellectual disability, family may have a particularly important role in terms of support during the transition to adulthood, where families assist in facilitating services and assistance, give support related to employment, and provide security, care, and social relationships (Pallisera et al., 2016; Pérez et al., 2015; Petner-Arrey et al., 2016; Ringsby-Jansson & Olsson, 2006; van Asselt-Goverts et al., 2015). Family members are found to be a main component of one's informal social network (Kamstra et al., 2015). Yet dissatisfaction with family relationships and isolation also occurs (Mineur et al., 2009; Swedish Agency for Youth and Civil Society, 2012:3). Families and parents are influential in several aspects. Sullivan et al. (2016) demonstrate family's influence on the living situation of persons with intellectual disability, by making decisions or preventing them from living independently; while Wilson et al. (2017) show their influence on facilitating social participation and interactions. In the area of work, family's support and practical help, combined with their socioeconomic status, aid in people gaining and maintaining a job (Tideman et al., 2017). Mothers have been found to have an especially central role in decision making and act as strong advocates (Dyke et al., 2013).

Research finds that social isolation and limited social networks is common among people with disability, and intellectual disability (Pallisera et al., 2016; van Asselt-Goverts et al., 2015; Velsvik Bele & Kvalsund, 2016). Their social relationships and networks tend to be within their families, with professionals, or in transition programs (Forrester-Jones et al., 2006; Kamstra et al., 2015; Dyke et al., 2013; Schneider & Hattie, 2016; van Asselt-Goverts et al., 2015). Another source for social relationships is to participate in structured or organized social settings, for example with others who have a disability. Findings suggest these settings provide social support and opportunities that increase networks, well-being, health, and belonging (Wilson et al., 2017). However, social relationships may primarily be with others who have a disability, while research demonstrates that interactions with people without disability is scarcer (Dusseljee et al., 2011; Umb-Carlsson & Sonnander, 2005).

Young people in general who do not have an occupation (NEET)

NEET refers to young people in general who do not have an occupation. This research area highlights risk factors and consequences associated with NEET. Several structural and individual factors are demonstrated to relate to NEET

status or young people facing challenges with securing employment, including incomplete education, poor and disadvantaged backgrounds, immigrant background, parents who are unemployed or with low education, living in rural or small cities, health problems or a disability (Celikaksoy & Wadensjö, 2018; Engdahl & Forslund, 2015; Eurofound, 2012; Olofsson, 2014; Olofsson, 2018; SEU report, 1999; Swedish Government Official Reports, 2013:74). Poor health or having a disability is one aspect represented in NEET populations. According to Swedish Government Official Reports (2013:74), people with a disability are unemployed at higher rates and face challenges in transitioning from NEET status to participating in employment or education. Olofsson (2018) reports that increased mental illness among young adults in general contributes to disengagement from employment and education and relates to the rise in financial support such as activity compensation. Differences between men and women are also present among NEET. Taking care of children and early parenthood are linked to women not participating in employment or education (Swedish Government Official Reports, 2013:74). Similarly, Tamesberger et al. (2014) present gender differences in risk factors for becoming NEET in Austria. For young women risks include early school leaving, childcare responsibilities for children under age 3, health related impairments, and preliminary unemployment experiences. For young men, the same risk factors exist with the major difference being that responsibilities related to having children are not present. A major risk factor that is stressed for both men and women is early school leaving or incomplete secondary school education (Swedish Government Official Reports, 2013:74). The research focusing on NEET shows that there are many different factors, risks and consequences surrounding this situation. It seems likely that a similar complexity may also be relevant for understanding people with intellectual disability who are not participating in an occupation.

Concluding remarks

Previous findings present a large proportion of young adults with intellectual disability (24.1%) who are not participating in traditional occupations after secondary school. The body of previous research above demonstrates that the transition after school, including establishing an occupation, service and support, and family and social relations are important but can be challenging for people with intellectual disability. However, there exists a gap in this previous research that more specifically studies how these various challenges influence and relate to young adults with intellectual disability who are NEET. Moreover, that aims to understand on both a comprehensive and in-depth

level what being NEED entails and the experiences of becoming and being NEED.

Theoretical framework

The theoretical perspectives in this thesis work as analytical tools to discuss the empirical findings and the phenomenon of NEED. The choice of theories began to form at the beginning of the research process and continued to evolve as the research developed. The theories I have chosen to employ are ecological systems theory, social exclusion, and belonging. The theories all have a different function as analytical tools, but together generate an approach to address the aim of increasing knowledge about people who are NEED. The NEED situation is complex and consists of many different individual and environmental factors that contribute to processes and experiences of not having an occupation. Bronfenbrenner's ecological systems approach allows for organizing and conceptualizing how different aspects of the environment, the individual, and the interactions between them influence not participating in an occupation. Theories of social exclusion and belonging are implemented to facilitate a discussion on different perspectives of the phenomenon, and the complexity in experiences of not being involved in an occupation. Social exclusion is discussed in article III and belonging is discussed in article IV; however, I want to develop these theories and their application further and more in-depth which is the rationale for using them here. The implementation of the chosen theories also provides a means of compiling and discussing the different findings from the register and interview studies.

Bronfenbrenner's ecological model

To have an intellectual disability, depending on the degree of the disability, one may be in need of various supports, adjustments and adaptations. To not have support and be outside or between society's services and systems makes this more challenging. This sheds light on that being NEED is a complex phenomenon beyond only the individual. Therefore, it is helpful to conceptualize and understand this using ecological systems theory. Urie Bronfenbrenner conceptualized the ecology of human development that focuses on development as occurring in connection between the individual and their environment. His models and theories are outlined in several writings, and he

continued to revise and evolve these over time (Bronfenbrenner, 1979, 1992, 1994; Bronfenbrenner & Ceci, 1993; Bronfenbrenner & Morris, 1998, 2006). The core of Bronfenbrenner's general model is to understand the interconnections between systems in the environment and the individual, and how these ultimately influence development. He described, in several writings (Bronfenbrenner, 1979, 1994), the ecological environment as a set of structures, with the individual and their closest settings at the center. These closest settings that the individual experiences directly, for example the family, school and workplace, are coined as the microsystem. The next structure beyond this is the interconnections and relations between immediate settings and is referred to as mesosystem. The third structure consists of settings that indirectly influence the individual and is called exosystem. The outermost structure referred to as macrosystem consists of the larger cultural and societal contexts and systems. The final system that Bronfenbrenner discussed is the chronosystem. The chronosystem is different in nature since this system is the changes that occur over time in the individual and in their environment at the micro, meso and macro levels, including changes in socioeconomic status or where a person lives (Bronfenbrenner, 1994; Bronfenbrenner & Morris, 1998). Bronfenbrenner's focus is how these structures and systems are connected and how they influence development, yet the individual is not passive in this occurrence rather they are dynamic in their interaction with their environment (Bronfenbrenner, 1979).

Criticisms of the earlier writings have been made by Bronfenbrenner himself and other researchers (Curry Sontag, 1996). Bronfenbrenner revised and developed his theory in later writings, where one emphasis was the role of the individual in their own development (Bronfenbrenner, 1992). The later work placed great emphasis on the role of processes between the individual and their environment (Tudge et al., 2009). Bronfenbrenner argued that the person's characteristics and the environment's characteristics in their joint interaction help to understand development; however, there needs to be explanation of the mechanisms or the processes that occur in the interaction between them (Bronfenbrenner, 1992). These became known as proximal processes (Bronfenbrenner & Ceci, 1993). As such, the evolved ecological model has two main propositions that account for properties of process, person, environmental contexts, and time (Bronfenbrenner, 1994; Bronfenbrenner & Morris, 1998, 2006). The first is that human development is understood as occurring through reciprocal and complex processes between a human (with their biological and psychological properties) and their environment (consisting of people, objects and symbols). Bronfenbrenner and Morris (1998) state that for these processes to have an effect on development they need to "occur on a fairly regular basis over extended periods of time" (p.996). These complex

and enduring interactions are proximal processes. The second proposition refers to the character and power of the process, suggesting that this will vary depending on the individual's characteristics, the environments' characteristics, the type of developmental outcome that is occurring, and time. With the property of time referring to both the changes that develop over the life course and in the given historical time period (Bronfenbrenner & Morris, 1998). Various examples of proximal processes are provided such as comforting a baby, playing with a child, activities between children, as well as reading and learning new skills and knowledge (Bronfenbrenner & Morris, 1998, 2006). Emphasis is placed on processes involving individuals partaking in an activity regularly and over time, as well as the activity being reciprocal in nature whether this is with other people, objects or symbols (Bronfenbrenner & Morris, 1998, 2006). Reciprocity in relation to objects and symbols means those which evoke exploration and imagination (Bronfenbrenner & Morris, 1998).

Bronfenbrenner's theories have been applied in fields such as education, special education and disability (Anderson et al., 2014; Curry Sontag, 1996). Criticism of the theory includes that translating its many and complex aspects to research design and methodology can be a large task (Curry Sontag, 1996; Tudge et al., 2009), although incorporating all aspects may not be necessary (Tudge et al., 2009). Curry Sontag (1996) provides reflections within the disability context to not only focus on the characteristics of the individual and environment that are negative in nature, but also how such characteristics foster resilience and success.

It is important to state how Bronfenbrenner's work is applied in a study; researchers need to distinguish between citing and using the theories as fundamental grounds for their study so not to misrepresent its use (Tudge et al., 2009). In this thesis, the aim is not to use all details of Bronfenbrenner's complete work, but rather to organize, identify, and discuss how different systems and settings in the environment in various proximity to and in interaction with the individual, together influence not having a traditional occupation. The outcome of interest is to understand the situation and experience of becoming and being NEED. Similar to Anderson et al. (2014), NEED status can be understood as constructed through the relationships between people and societal systems. These include immediate settings of family and friends, as well as broader settings of the school system, welfare system, systems of formal support, and how disability is viewed by society. It is the web of relations and processes between the environment and the individual that begins to unfold the complexity in understanding NEED status. The aim is not to simplify a complex phenomenon, but the approach of this theory aids in conceptualizing a framework for studying a phenomenon in its complexity (Anderson et al., 2014). Similarly, an important first step is to begin to identify systems and

settings in the environment and how these interact with the individual to influence NEED status.

Social exclusion

To have an occupation and thereby participate in activities, social relationships and society, holds value and meaning for most people. Individuals with an intellectual disability who are NEED are as a result limited in their opportunities to participate in these arenas. Social exclusion refers to being denied rights and opportunities that lead to individuals and groups not being able to fully participate in the social, economic and political activities in the society in which they live (Taket et al., 2009). Social exclusion can be viewed as a process and/or a state and emphasis is placed on it being multidimensional and existing at various levels (Millar, 2007; Taket et al., 2009). This entails that exclusion can occur in and across various arenas and areas of life. There are various definitions of social exclusion, and Millar (2007) summarizes some commonalities: social exclusion has multiple dimensions, affects current and future situations, and exists in specific contexts.

Social exclusion can be determined or chosen, where the determined relates to exclusion that is involuntary and based on for example gender, disability or age whereas chosen exclusion is when individuals choose to not participate in society (Taket et al., 2009). Davidsson and Petersson (2016) distinguish between weak and strong social exclusion. The weak version focuses on the individual and their characteristics that cause them to be excluded, thereby also leading to proposed solutions that focus on the individual. The strong version, however, targets societal structures and agents that lead to people becoming excluded. It is not necessarily true that social exclusion versus inclusion is a dichotomous state or process. Being included does not eliminate also feeling excluded, since it is possible to experience both at different times and in various settings (Taket et al., 2009). Instead exclusion can be regarded as a continuum where “any particular individual at a particular time in a particular context can be characterized as a multiple combination of inclusion and exclusion” (Taket et al., 2009, p.13). Social exclusion and inclusion can exist at the same time at varying degrees. Welsby and Horsfall (2011) interviewed women with intellectual disability and found that they had jobs, but having open, full-time or meaningful employment was limited. The authors refer to “illusion of inclusion”, meaning that even though people with intellectual disability may be more present in society than they were previously, they are still isolated and not included. Simply being present does not automatically equal inclusion. Similarly, Hall (2005) discusses that inclusion

and exclusion are tangled into each other making it possible to experience both at the same time. This is exemplified through having employment (an aspect of inclusion), yet one can experience exclusionary practices, bullying, limited social relations, and discrimination at that workplace (Hall, 2005). Davidsson (2016) describes exclusion is often used in relation to the labour force, where inclusion generally refers to having employment. Anything outside of this is regarded as negative. The author argues that creating a norm that employment is ideal leads to further exclusion for those who are not able to attain it. This creates a stronger distinction between those who are included versus excluded and instead further perpetuates exclusion in society. Inclusion/exclusion revolving around standards of for example employment and subsequently not emphasizing other important topics, has been criticized by others as well (Renwick et al., 2019). One way to express this, according to Renwick et al. (2019) is that social inclusion revolves around neoliberal standards and expectations despite that these are not necessarily attainable by all individuals. Similarly, Hall (2010) problematizes that standards of inclusion (employment, independent living and participation in community), are not always attainable by people with intellectual disability. As a result, people may look for other arenas or paths of inclusion (Hall, 2010).

The conceptualizations, operationalizations and measures of social exclusion are diverse. Research in turn demonstrates that social exclusion manifests for people with intellectual disability in various ways. People with intellectual disability historically have been, and still are in many ways, socially excluded. They are regarded as being disadvantaged in multiple dimensions of community participation, poverty, poorer health and mental health, isolation, and unemployment that lead to social exclusion. Wang (2013) studied working-age adults with intellectual disability in Taiwan and three measures of social exclusion: independent living/living in the community, employment, and household economic situation. The results indicate that many of these adults presented one or multiple measures of social exclusion. Falling in multiple categories of social exclusion was a risk for older female adults with intellectual disability who had no spouse or partner, had lower education, and had more severe disability. Other background factors of gender, age, or where a person lives are also influential in social exclusion for people with intellectual disability (Nicholson & Cooper, 2013; Wang, 2013). Thomas (2006) highlights that when disability intersects with other factors of social exclusion (race, sexuality, class) it leads to further complexities and intertwined forms of social exclusion.

Due to its complexity and multidimensionality, social exclusion is often stated as hard to define and measure. Nicholson and Cooper (2013) express that there is no single measure for social exclusion. Instead, the authors

describe that various objective measures are often used, which can make the understanding of social exclusion diverse as well as these objective approaches do not account for first-hand experiences of social exclusion. This highlights that social exclusion is broad and needs to be measured on different levels in order to address its complexity. This presents methodological and operationalization challenges, yet also opens for multiple and comprehensive understandings. Mathieson et al. (2008) states:

The complexity of the concept of social exclusion - its multi-faceted nature including both objective and subjective elements – cannot be fully and sufficiently captured in quantitative measures and indicators and hence these cannot be an adequate foundation for policy and action. Rather, the nature and impact of exclusionary processes can only be adequately ‘represented’ through both quantitative and qualitative data – through indicators and stories. Only by combining the understanding of the nature and experience of exclusionary processes from both these sources will the effectiveness of policy and action be maximised. (Mathieson et al., 2008, p.49)

As illustrated above, there are various ways to view and discuss social exclusion. In this thesis, social exclusion is employed to understand how it manifests for the target group, as well as to discuss different and nuanced perspectives of being NEED. This allows for integrating findings from the register and interview studies as different approaches to understanding social exclusion. In addition, social exclusion for the target group is discussed in relation to the concept of belonging.

Belonging

There are several concepts used as the opposite of social exclusion. Social inclusion has various meanings, for people with intellectual disability it may refer to establishing social relationships and networks, as well as engagement in community and activities (Simplican et al., 2015). Social inclusion is also interchangeably used with for example the concept of belonging or connectedness (Crisp, 2010; Simplican et al., 2015). I have chosen to use belonging in this thesis. According to May (2013), belonging is defined as “the process of creating a sense of identification with, or connection to, cultures, people, places and material objects” (p.3). Belonging relates to our identity (May, 2013; Robinson et al., 2020), but May (2013) distinguishes and focuses on belonging rather than identity. She states that identity includes restricting and flat dimensions that categorizes people, whereas belonging more so focuses on the individuals experience of belonging and addresses the complexity that

a person can belong in various degrees and contexts. Three aspects of belonging that May (2013) outlined are relational (between people); cultural (the institutional order); and material (space and objects). These types of belonging are not separate aspects but rather overlapping. A sense of belonging does not only refer to relationships with other people, but can manifest in recreational activities, or in meaningful places and settings like home (Robinson et al., 2020; Strnadová et al., 2018). A physical place itself does not automatically cultivate belonging, but is developed through subjective meaning that we give it based on the activities and people that we experience in that place (May, 2013). Therefore, belonging has various sources and develops in different contexts.

Belonging relates to subjective feelings and experiences. There are many positive characteristics and feelings used to describe belonging in the literature. These include feeling valued, understood, safe, needed, respected, accepted, attached, comfortable, sense of insidership, and fitting in (Hall, 2010; Mahar et al., 2012; Robinson et al., 2020). Social belonging (as well as chosen solitude) has been found to relate to well-being and quality of life (Umb-Carlsson & Lindstedt, 2011). Apart from a sense of belonging stemming from subjective feelings, it has an element of reciprocity. The literature finds that feelings of belonging are not only individual, but rather have a collective dimension where others accepting and reciprocating these feelings are central (Mahar et al., 2012; May, 2013). Similar or shared experiences and understandings are significant to developing this reciprocity (Mahar et al., 2012). Belonging emphasizes a deeper meaning and value that people experience. It highlights the difference between simply being present in the community versus fitting in with the community (Power, 2013), or being only included versus truly accepted (Renwick et al., 2019). From the perspective of youth with intellectual disability themselves, Renwick et al. (2019) presented a framework for conceptualizing belonging that highlights the following elements: engaging in social relationships, interacting with similar people, negotiating meaningful roles in the community and navigating norms and expectations.

May (2013) discusses that belonging can encompass positive feelings and at the same time be something which we distance ourselves from. Belonging is determined for us by societal structures while other forms of belonging are chosen or resisted. This illustrates an aspect of choice in the experience of belonging, but also that it is bounded by where one is permitted or allowed to belong. As Mahar et al. (2012) describes, connectedness to others or to a context is influenced by the individuals' choice and wants, as well as where they feel they are permitted to belong. An example of these two aspects of belonging, determined and chosen/resisted, is variations of feeling a sense of belonging with others who have an intellectual disability versus those who do

not have an intellectual disability. Similar to May (2013), a non-identification can lead to resistance in belonging with people who have a disability and instead choose belonging with people without disability. Belonging is not a static state, it changes over time, stems from different sources and varies depending on our own characteristics (May, 2013). An example of this, provided by May (2013), is that a person can feel a sense of belonging with others within the same religion, and at the same time feel that they don't belong with others at one's workplace due to differences in religious beliefs. Belonging, then, is not only multidimensional, but also encompasses external and subjective influence in the form of determined, chosen or resisted belonging.

Relationships with other people are regarded as central in a sense of belonging, and limited social relationships can therefore result in loneliness or isolation (Renwick et al., 2019). Relationships influence belonging, but they may not always be positive since negative or oppressive relationships can prevent belonging (May, 2013). According to May (2013), one's family is considered an important source for feelings of belonging. The family is the first context of which a person begins to develop a sense of belonging; however, people will vary in their connections to their families, and some who experience their families as negative, may instead opt to find family-like connections in other sources. May (2013) argues that these particularly strong and close ties that one has to family, whether they be biological family or chosen family, are an important source of belonging. Another important relational belonging that May (2013) highlights is with friends. Friends have a varying role in people's lives, at times more important than others, and may be family-like in their nature. Friendships have significant value and contribute to well-being and quality of life (Sigstad, 2016). Friendships and social relationships can have a basis of similarity, meaning that we choose friends based on their similarity to us. Similarity, whether it be in interests or disability, connects people and is a foundation for belonging (Renwick et al., 2019). May (2013) refers to this as the homophily principle, indicating that similar people are likely to come into contact due to similarities in for example ethnicity, class or age. Similarity relates to the foundation of shared experiences, understanding and identities as precursors to belonging (Mahar et al., 2012; Wilson et al., 2017). Mahar et al. (2012) discusses relatedness as a component in forming belonging. The authors discuss that simply having physical or intellectual commonalities does not necessarily automatically determine a sense of belonging, but the element of shared experiences and understanding is the central component. Moreover, shared experiences are important but relationships with others with a similar disability can feel forced if there is no other shared qualities or interests (Renwick et al., 2019). For people who are NEED, having an intellectual disability and a background in

USSID could be a commonality that brings people together but beyond this, the shared understanding and relating to each other can lead to feelings of belonging.

Relationships with others are central in the experience of belonging; however, it also manifests in other contexts. On a broader level, belonging may stem from being part of a wider community. Work is often regarded as providing feelings of purpose, contributing to society and being part of a community, which in turn lead to a sense of belonging (Strnadová et al., 2018; Renwick et al., 2019). Belonging in the workplace is facilitated through being invited, included, accepted, recognized, and developing camaraderie, yet modern day organizations of work such as short-term employment could impose restrictions on developing belonging (McClure & Brown, 2008).

Crisp (2010) distinguishes between belonging and connectedness, which at times are used interchangeably, but according to the author are different concepts. Belonging is subjective, emotional and relates to one's identity; whereas connectedness relates to social participation (Crisp, 2010). The relationship between belonging and connectedness varies - they can co-exist, yet it is possible to experience one and not the other. Crisp (2010) discusses two scenarios that distinguishes these concepts. Firstly, being connected but not belonging occurs when a person has connections to others and in society yet feel they don't belong or don't want to belong to these. Secondly, belonging but not connected refers to, for example, living in new neighbourhoods where one has limited connections but with people where one feels one belongs. Crisp goes on to discuss that not feeling one belongs or is connected are forms of social exclusion.

Aims

The general aim of the thesis is to increase knowledge about young adults with intellectual disability who after upper secondary school are Not in Employment, Education or Daily activity (NEED), by providing deeper understanding and analysis of the target group's characteristics and associations with NEED status, as well as to study the subjective experiences of becoming and being NEED.

The aims for the two studies (register study and interview study) are stated below:

1. To explore and analyze the situation of people with intellectual disability who are NEED. This is achieved through register-based analyses that focuses on background factors, financial support, LSS services and family situation, as well as comparing these factors and their associations with being NEED versus having an occupation of employment, education or daily activity. The aim is also to examine how NEED status changes in relation to time since graduation from upper secondary school. (Articles I and II)
2. To analyze the subjective experiences of the process to becoming and being NEED. To fulfil this the analysis focuses on individual as well as structural factors, and how these are experienced in different arenas in society and in interactions with agencies and institutions. Moreover, in the experiences of the target group, examine social relationships, networks, and living situations as well as explore these relationships and networks as conditions for belonging. (Articles III and IV)

Method

To answer the questions posed in this thesis, different methods have been employed. The research design combines both quantitative and qualitative methods in the form of a register study and an interview study. The combination allows for a complementary approach in studying persons who are NEED. In research, discussions occur on whether combining quantitative and qualitative methods is possible, since there are different opinions on the compatibility of the methods' philosophical paradigms (O'Cathain, 2010).

Critical realism combines the idea that a phenomenon can be viewed from different perspectives, but that this is never a full understanding of reality (Shannon-Baker, 2016). According to Danermark (2008) critical realism views that "reality exists independent of the observer, but at the same time emphasizes that our knowledge of this reality is socially influenced" (p.138 translated). One feature of critical realism is its applicability with quantitative and qualitative approaches, as well as how both approaches are seen as complementary to the other (Craig & Bigby, 2015; Shannon-Baker, 2016). In order to understand a social phenomenon through the lens of critical realism, Craig and Bigby (2015) explain that human agency and structures in society are both influential. Within critical realism, phenomena are often explained through the interaction among various mechanisms and mechanisms in different contexts (Danermark, 2008). Mechanisms are explained as "something that generates something" (Danermark, 2008, p.141), for example what mechanisms generate people with disability as having poor living conditions (Danermark, 2008). It is not easy to study isolated mechanisms, but rather it is more common to provide explanations that consider multiple mechanisms (Danermark, 2008). Craig and Bigby (2015) illustrate some criticisms of critical realism within the field of social work, including difficulties with transferring this to a specific methodology and the limited examples of its application in social work practice.

In this thesis, critical realism is the theory of science departure point for how to view the phenomenon of NEED. As such, NEED status can be viewed as a social construct driven by various mechanisms (at various levels and contexts) that generate people with intellectual disability becoming and being not

involved in an occupation. Critical realism has an aim of explaining and not only describing (Craig & Bigby, 2015), which aids in the focus of this thesis to provide deeper understanding of what contributes to and influences not participating in an occupation. Studying all possible mechanisms at all levels is a large scientific endeavour, therefore researchers often have to limit their focus to a selected few and acknowledge that these are partial explanations (Danermark, 2008). Critical realism fits with Bhaskar and Danermark's (2006) understanding of disability that states disability cannot be reduced to one aspect. The relational model of disability instead is open to which mechanisms are influential and that this can vary from case to case (Bhaskar & Danermark, 2006).

Design

The design of this thesis combines register and interview methods. In article I and II national registers were used to conduct statistical analyses, whereas in article III and IV interviews followed by thematic analysis were conducted. Register studies and interview studies individually have benefits and limitations. Register studies provide national and large data sets illustrating patterns and correlations that pose possibilities of generalizability, while interview studies focus on more in-depth knowledge that provide nuances beyond statistics. Danermark (2008) discusses that quantitative statistical analyses that use regression analyses and dichotomous variables make use of categories as their analytical tools. Yet, as the author points out, these types of statistical analyses tend to reduce complex realities to simplified variables, thereby providing descriptions but not explanations. Understanding complex phenomenon needs a combination of statistical analyses and more in-depth methods (Danermark, 2008). Similarly, other researchers have presented the benefits of combining quantitative and qualitative methods, such as it allows for a comprehensive understanding of the studied topic, increased confidence and validity if both types of methods generate the same findings, opportunity for one method to influence how the other is conducted, and the ability to reach diverse or marginalized participants (Kocman et al., 2018; O'Cathain, 2010). However, there are different typologies and understandings of mixed method or multi method approaches, and at times rationales for their employment in research is neither clear nor anticipated (Bryman, 2006). The rationale for employing both quantitative and qualitative designs in this thesis stems from the limited knowledge about the NEED group; thereby it was important to try and gain a comprehensive understanding through different perspectives. The register study provides national knowledge that describes the target group and

how various variables are associated with NEED status; whereas the interviews give first-hand individual accounts providing detailed nuances to understanding the experiences of not being involved in an occupation. Together the quantitative and qualitative designs complement, as well as furthers and is beneficial to our understanding of the phenomenon.

A summary of the studies and four articles describing population/participants, analysis of the data, and variables is shown in Table 1. Both the register and interview studies have been approved by the Ethical Review Board in Lund, Sweden (Nos. 2011/326; 2011/782; 2014/691; 2016/719).

Table 1: Summary of studies and articles.

	Article	Population/ participants	Analysis	Variables
Register study	Article I	N=12,269; NEED= 2955	Registers used: HURPID, LISA, and LSS. Analyses in SPSS- regres- sion analyses, chi-square and descriptive anal- yses	Occupation, sex, parents' highest education level, parents' country of birth, graduation year, municipality, program type, program specialization, long-term subsidies, labour market involvement subsidies, parental benefits, social assistance, Services under the LSS Act (10).
	Article II	N=12,269; NEED= 2955	Registers used: HURPID, LISA, and LSS. Analyses in SPSS- regres- sion analyses, chi-square and descriptive anal- yses	Occupation, sex, age in 2011, immigrant background, married, common law, single, single parent with a child or children under the age of 18 years old, living at home with one's parents, has children ages 0–3, has children ages 4–6, has children ages 7–10, has children ages 11–15.
Interview study	Article III	N= 10	Framework and thematic analysis (Braun &	

		-education background in USSID -20-31 years old	Clarke, 2006; Bryman, 2015).	
	Article IV	N= 10 -education background in USSID -20-31 years old	Framework and thematic analysis (Braun & Clarke, 2006; Bryman, 2015).	

Register study (article I and II)

The following section presents the register study, which was the basis for articles I and II. Through the use of national registers various statistical analyses were conducted that on the one hand examined background factors, financial support and disability services (article I), and on the other hand examined background factors and family situation (article II). First the Halmstad University Register on Pupils with Intellectual Disability (HURPID) and the other national registers that were used are described. This is followed by presenting the analyses that were conducted in both articles, and a discussion of methodological considerations.

Registers

The register study used the Halmstad University Register on Pupils with Intellectual Disability (HURPID), which is a unique national register providing information of students assessed as having an intellectual disability in the school context and who graduated from USSID in Sweden between 2001 and 2011. A total of 12,269, essentially all, former USSID students who graduated in Sweden between 2001-2011 are included in HURPID. This register is composed of students who attended the old system of USSID, whereas a new system was launched in 2013 (see “background” chapter). The data is based on information collected from final grades and includes social security number, age, sex, graduation year, program type, program specialization and school municipality. Final grades are public documents and are available through requests to municipalities. Each municipality has an obligation to provide these documents (for a more elaborate discussion on the registers, see Arvidsson, 2016). The HURPID register has been linked with the following

Statistics Sweden registers: the Longitudinal Integration Database for Health Insurance and Labour Market Studies (LISA) and the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments register (LSS). The LISA provides data on an individual level and contains variables on demographics, education, occupation and unemployment, income and social insurance, family, and workplace and business³. The data available dates to 1990 and all individuals age 15 years and older who are registered in Sweden on December 31st each year are represented. The LSS register reports services and supports for persons with disability under the Swedish LSS Act⁴. Municipalities in Sweden are obligated to report data on proportions and scope of LSS services for people with disability to the National Board of Health and Welfare in October of every year. This is then compiled into the national LSS register. Individuals have the right to ask for their personal information in the register. Due to strict confidentiality, the LSS register can only be used for research purposes after ethical and confidentiality approval. These three registers, HURPID, LISA, and LSS, were linked using social security numbers. Once this was completed, the social security numbers were removed, and personal identification of individuals was not possible thereby increasing anonymity. The data is accessed and analyzed through Statistic Sweden's external desktop.

The register study was cross-sectional and explored the post-USSID situation of the NEED group in 2011. HURPID consists of 12,269 (men n=7138, 58.2%; women n=5131, 41.8%) former USSID students. Previous research by Arvidsson et al. (2015) described post-school activities and identified four categories: daily activity, employment, education and those not participating in the above occupations ("elsewhere"). Those who were not involved in an occupation made up 24.1% (n=2955) of the total population of former USSID students. The remaining persons who were in an occupation of employment, education or daily activity together made up 75.9% of the population (n=9314).

Analysis

Descriptive analyses, cross tabulations, chi-squared tests, simple and multiple logistic regression analyses were conducted to gain an understanding of the

³ For further information about the LISA register and list of variables see Statistics Sweden (<https://www.scb.se/>)

⁴ For further information about the LSS register and list of variables see the National Board of Health and Welfare (<https://www.socialstyrelsen.se/>)

NEED group and assess relations and correlations between various variables. In article I the regression analyses looked at predicting variables related to background, financial support, and LSS services (independent variables) and their significance to being NEED, as opposed to having an occupation (i.e., combination of employment, education and daily activity) (dependent variable). In article II the regression analyses focused on background variables and family variables (independent variables) and their associations with being NEED as opposed to having an occupation (employment, education or daily activity) (dependent variable). All data was analysed in IBM SPSS Version 20.

Methodological considerations of register study

A major benefit with the register study is the wealth of information and studying a large, in this case national, population. This provides a certain form of knowledge about persons who are NEED and highlights patterns and correlations. HURPID is a total and national sample, and therefore provides sound representativeness.

Building HURPID through the collection of final grades was a comprehensive process and is outlined by Arvidsson (2016). One of the problems early on that Arvidsson (2016) discusses was that municipalities were not consistent in the filing of former students' final grades. This led to a longer process of having to contact various municipalities or ask them to re-send the proper final grades. However, despite these problems, the data collection was concluded after all 290 municipalities in Sweden had responded, either with final grades or stating that they had no USSID in their municipality. Therefore, HURPID is assessed as being a complete representation of students who graduated between 2001-2011. Because the register study in this thesis is based on the population of former students from the years 2001-2011, the generalizability of the empirical findings to later graduating classes can be problematized. This is particularly due to the changes in the format of USSID that occurred after the year 2013, which in turn may influence the population of students in USSID, their post-school occupations and so forth. This emphasizes the importance of developing HURPID further to include graduating classes after 2011 as well. This would not only provide up-to-date data but allow for analyses and comparisons between the old and new system of USSID (see "future research").

Although the registers have many variables and this benefits the data material, they also have limitations. Variables may be overlapping, need to be re-coded to make them manageable, and may be limiting in the type of information that is provided. For example, the registers currently do not have

variables on degree of the disability or if there are any additional behavioural problems or comorbidity present. However, the HURPID variable describing type of program in USSID can be regarded as a proxy variable for degree of disability. National and special-designed programs are intended for people with mild intellectual disability, while individual programs are for people with more severe intellectual disability, although this should be regarded in a broad sense (Arvidsson, 2016).

The design of the register study was cross-sectional, which provides a snapshot of persons who were NEED in 2011. One limitation of cross-sectional studies is that we are not able to understand development or changes over time. This could be complemented with future longitudinal studies that examine transitions, processes and outcomes (Myklebust, 2012). The format of the registers currently does not allow for following individuals across time and would need to be re-structured in order to address this; however, conducting longitudinal analyses would be an added benefit for increasing knowledge about the NEED group. The analyses in the register study were chosen in accordance with the research questions. Regression analyses allow for studying the impact that independent variables have on a dependent variable (Tabachnick & Fidell, 2007). However, while these analyses determine correlations and patterns, they do not determine causality. For example, many in the NEED group had various financial support, but does using financial support cause NEED status or does NEED status lead to having to use financial support? This is important to acknowledge when interpreting the results. Another critical reflection is the use of p-values. Wasserstein and Lazar (2016) describe that the popularity of p-values in the scientific community has led to its misuse. The authors describe that although valuable, p-values alone should not be the sole determinants for inference, claims or truths, but need to also be contextualized and critically evaluated. The analyses in the register study provide a starting point for knowledge and could lead to future elaborate analyses.

Validity refers to how sure we can be about the truth of an inference (Shadish et al., 2002). Validity and reliability of HURPID has been ensured through a systematic approach that controlled for attrition and representativeness (Arvidsson, 2016). A benefit of the register study is that all persons with the criteria of having attended USSID are included in the sample, regardless of degree of the disability, which increases representativeness without excluding people with more severe intellectual disability. The transparency of how HURPID was composed as well as outlining the analysis and procedure of the study increases replication. Context always plays an important role. For example, due to its Swedish context the findings may have limited

generalizability to other countries because of differences in welfare systems, school systems, and definitions of intellectual disability.

Interview study (article III and IV)

In this section the second study in this thesis is presented, namely the interview study. The data that was generated from the interviews was used and analyzed in two separate articles- article III and IV. Article III analyzed the experiences of becoming and being NEED, as well as encounters with agencies and institutions; whereas article IV examined the participants' social relationships and experiences of belonging. The following section describes the design of the interview study, recruitment and description of the participants, how the data was collected, coding and analysis of the data, and concludes with reflections on the interviews and methodological considerations.

Design

The design for the interviews was qualitative and semi structured interviews were conducted with 10 individuals. Interviews aim to understand the individual's perspective and the meaning of their experiences (Kvale & Brinkmann, 2014). It presents the opportunity to study the experience of NEED from the first-person perspective, as well as gain concrete and detailed exemplifications of everyday experiences of being outside of traditional occupations.

The interviews were conducted with the help of an interview guide where the main research questions were broken down into more concrete themes and questions. The themes of questions asked the participants to describe a typical day, social relationships and belonging, and the process from USSID (See Appendix 4 for interview guide). Lövgren (2013) describes that an interview guide steers the direction of the interview; however, the order of questions can also evolve naturally during the interview process. The interviews were developed and conducted in a way that enabled and stimulated comprehensive narratives from the respondents, while implementing a flexible approach rather than adhering to a strict order of the questions.

During the first 3 interviews extra attention was given to the quality and formulations of the interview questions to test the applicability of the interview guide. Memos were written after each interview to document key points, particular behaviours or feelings that the participants expressed, and my own reflections of the interview situation. The memos along with experiences from the first 3 interviews lead to reflections that repeating questions,

repeating answers back to participants, and formulation of the questions worked differently for the participants, as well as that participants varied in the length of their answers. While some were very talkative, others gave short answers without elaborating. As a result, these reflections and early experiences lead to making adjustments based on the individual. For example, formulating questions in different ways or suggesting breaks for very talkative participants. The design of the interview study and the applicability of the interview guide therefore emphasized flexibility to adapt the situation to best suit the individual.

Participants

The criteria for the participants was to be between 20-30 years old, had attended USSID, and currently were not involved in employment, education or daily activity. The recruitment process led to challenges in finding participants. The criteria were eventually broadened to include those who currently had an occupation but had previously had longer periods of not being involved in employment, education or daily activity. Recruitment of participants took place from March 2017-May 2018. Because people who are NEED are a diverse group, they likely can be found in diverse places. The participants were recruited through various public and private organizations that work with young adults, for example daily activity, leisure activities or employment. Most of the participants were not involved in these organizations, rather gatekeepers had continued contact with them. Participants were also recruited through different sectors within municipalities, habilitation services, online advertisements, and school personnel at USSID.

Thirteen people were asked to participate, but one declined due to not having time, one cancelled, and the third was unreachable. An overview of the final 10 participants (5 females; 5 males) is presented in Table 2 (the same table is provided in article III). The participants were between the ages 21-31 years old, had attended diverse programs in USSID, and lived in various municipalities in Sweden. At the time of the interviews, the majority of the participants did not have an occupation. Four people currently had an occupation but had previously had longer periods of being NEED. Pseudonyms are used for the participants to protect their anonymity.

Table 2: Description of participants.

Name	Age	Program in USSID	Current occupational status
Eric	21	Construction	No occupation

Vincent	31	Handicrafts program; Society and nature program	No occupation
Elliot	30	Does not remember; did not graduate	No occupation
Sofie	22	Food program; Health care and nursing program	Further education
Samuel	24	Arts program	No occupation
Adam	31	Practical program; Hotel and restaurant program	Daily activity
Julia	29	Arts program; Sports program	No occupation
Alice	24	Natural resource	No occupation
Charlotte	29	Arts program	Practicum through daily activity
Emma	28	Art, drama and music program	Practicum through daily activity

Data collection

Gatekeepers were contacted and informed potential participants who fit the criteria. Written and oral information about the study (see Appendix 1 and 2) and their right to decline was conveyed from the gatekeepers. If they expressed interest to participate, they were asked for permission to pass along their contact information to the researcher. In some cases, in order to abide with confidentiality rules, the potential participants were instead given the researcher's contact information so that it was their own choice to make contact if they wanted to participate. During the contact between the researcher and the participants, the study was explained once again highlighting confidentiality and anonymity, as well as discussing any questions. Some participants were firm in their decision to participate and wanted to proceed with planning the interview. In other cases, the participants were given time to think about their decision, and the researcher followed up with another phone call at an agreed upon later date.

Once participation was established, a time and place for the interview was arranged. It was important to plan the interview to make it convenient for the participant. A day or two before, an agreed upon text message was sent to the participants to remind them of the interview. I myself was the researcher that had all contact with the participants and conducted all the interviews. Participants decided the time and place for the interviews to best suit their comforts

and to allow for influence over the interview situation. Interviews took place in the participant's home or in meeting rooms at various locations. "Fika" (Swedish word for having coffee together) was brought along to the interviews. In three interviews, the participants chose to have a support person present. There is an awareness that this could have impacted the interview (see "reflections on interviews and methodological considerations" for further discussion). Before the start of the interview, information about the study was repeated emphasizing participation being voluntary, anonymity, what the results will be used for, timeline to write the articles, how the data will be secured, and the use of pseudonyms. It was important to convey the value of the participants' experiences and their contributions. All participants were given the opportunity to ask questions, once questions were answered the consent forms (Appendix 3) were signed. The theme map (Appendix 5), which shows the different themes of questions for the interview, was explained. In line with Cederborg et al. (2009), during the interviews considerations were made for sufficient time to answer questions, speaking at a comfortable pace, asking one question at a time, and avoiding leading questions. The interviews were recorded on a digital recorder and had an average time of 49 minutes. After the interviews ended, the participant and researcher discussed questions and ensured that the participant felt comfortable. All participants conveyed feeling fine after the interview. Some expressed that they had enjoyed being able to share their stories. Shortly after each interview memos were written. These included summarizing key points from the interviews, if the participants expressed anger or sadness about a certain topic, and methodological considerations such as repeating answers back to the participants to ensure I had understood them correctly.

Coding and analysis

The coding and analysis of the data was done in accordance with framework and thematic analysis (Braun & Clarke, 2006; Bryman, 2015). Braun and Clarke (2006) describe thematic analysis as a flexible approach that can provide rich understandings of patterns and themes in data sets, but has also been criticized as lacking clarity and guidelines. Due to its flexibility and broad applicability, transparency of the research process and analysis is important so to avoid presenting poorly supported findings and interpretations (Braun & Clarke, 2006). The framework approach (Bryman, 2015) was used to complement the thematic analysis (Braun & Clarke, 2006) and together the coding and analysis process took place as follows: The interviews were transcribed verbatim shortly after being conducted. The transcriptions and memos were read several times, in order to become familiar with the material and begin

searching for meanings and patterns. Meaningful units relevant for the aim of the study were extracted and concentrated for each participant in a matrix. During this time initial codes were also noted. These meaningful units were then organized into a matrix across all participants and arranged in categories that related to their codes. For example, all units that had to do with experiences in USSID were organized together, while units that related to daily activity were organized together in a separate category. This meant that sometimes units overlapped and as a result a unit could be organized into more than one category. Once a matrix across all participants was complete, the units and their codes were read multiple times and reviewed, and initial themes and subthemes were generated. During this process of developing themes and subthemes, there was continuous movement and comparison between the data and themes. When reviewing the themes, I along with the other researchers worked with trying to combine, separate or break them down further. The themes were thereby refined and, in the end, given names to identify their main content. An example of the coding and analysis process is shown in Table 3.

The interviews generated data used for both article III and IV. The initial stages of the coding, including extracting meaningful units, writing initial codes and organizing these into matrixes for each participant and across participants was done for both articles at the same time. This was possible since the articles had different aims, therefore the units either were more relevant for one article or the other. However, there was some overlap where perhaps a unit concerning meaningful social relationships was relevant for both articles. The actual analyses of themes and subthemes, including the process of working more closely with units and categories, as well as moving back and forth between the themes and data, was done for each article separately. In other words, the analyses for article III and IV were not conducted simultaneously. All the researchers involved in the project discussed the stages of transcription, coding, and analysis in order to ensure reliability and validity.

Table 3: Example of coding and analysis process.

Transcription	Initial codes	Categories across participants	Subtheme	Theme
“They (the Social Insurance Agency) promised lots of things that they	Was promised help that she never received.	Unfair system/ confusing system	Administrative challenges and injustice	Individual context and encounters with the system

<p>could not keep. That I would get help, that they would fix it so that (pause) they did not offer me anything for 5 years. I sat at home for 5 years.” (Charlotte 1.23).</p>	<p>Without occupation for 5 years.</p>			
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Reflections on interviews and methodological considerations

The researcher carries with them preunderstandings and experiences that influence their research, and in this case the interview situation. My academic background is in psychology and developmental psychology, which inevitably can influence what I notice and do not notice in a given research situation. By not having an academic background within the field of disability studies, I am aware that my preunderstanding is therefore not specific to my thesis. However, as a result, I spent a significant amount of time familiarizing myself with related research and the method and practice of interviewing and working with the target group. This became valuable knowledge that I applied to the interview situation. I also believe that my psychology background coupled with practical real-life experience of working with children with various disabilities and special needs, were beneficial for me in navigating how to interview more vulnerable groups of people.

The recruitment of the participants was diverse, and several challenges emerged. It was difficult to find participants, not only because they are in different places and situations but because they are not in traditional occupations it makes it more likely that they are also outside of or in between systems of supports and services. It became detective work to try and figure out where to find participants and how to contact them. It was at times a long process of trying to establish contact with an organization or finding the right person within the organization to assist with recruitment. Some organizations were quick to convey that they did not know of anyone who fit the criteria, or were not able to assist, whereas others were more helpful or gave further contact information to someone else within the organization or at another organization. Sometimes after long processes of multiple contacts with organizations this still led to no participants in the end. The participants were often found through “someone that knows someone that knows someone”, which entailed

a lot of time and contact with multiple people before even reaching the participants, and personal contacts. For example, gatekeepers who had continued contact with someone they knew years ago, or personnel at USSID that kept in touch personally with former students. The recruitment process therefore did not necessarily always generate multiple participants from one place, but rather they were found one by one. Another reason that could have influenced participation in the study is if people feel ashamed or do not want to associate with a study about intellectual disability. These challenges meant that recruitment was time consuming and even finding 10 participants was difficult. At the beginning of the recruitment process, the plan was to have participants who were currently not involved in an occupation. However, due to the challenges with recruitment the inclusion criteria had to be broadened to also include people who currently had an occupation but previously had longer periods of being NEED. It is important to acknowledge that the final ten participants may be those who are easier to contact and reach, meaning they are closer to the system and could be reached via for example gatekeepers or various organizations. Moreover, are individuals who have the cognitive skills to participate in an interview situation. As such, I acknowledge that there are individuals part of the target group that are not well-represented in the interview study. This is discussed further in the discussion chapter under “limitations and future research”.

Gatekeepers played a central role in the recruitment process. Gatekeepers were often positive, at times expressing they knew several persons that would fit the criteria. However, gatekeepers sometimes at a later point could convey the difficulties in contacting and informing the potential participants or that they were unsure about their occupational status. Some organizations and agencies have privacy and confidentiality issues that made them unable to assist with finding interview persons. Four participants preferred the initial contact or arrangements for the interview to be made through the gatekeeper. The researcher has to rely on the gatekeepers to know the criteria and explain the study well, however in these cases I took extra measures to provide information to the participants myself at multiple times throughout the interview process.

Support persons were present in some of the interviews. Their presence could have influenced what the participants said; however, the participants may not have wanted to be interviewed at all had they not had this third party with them. The experience of the support persons' presence was positive, since they could help clarify the participant's stories if they had a hard time remembering. An interview situation creates an interaction between the interviewer and interview person, where both have an influential role. Even though the interviewer holds certain power, the interview person themselves

have the power to decide over the situation and what they choose to share (Lövgren, 2013). Because it is important that the participant has the opportunity to influence the interview situation, having a support person was a way to ensure that they were comfortable.

Recruiting was time consuming with many logistics and details. This entailed a learning process and adjusting to the individual, where some arrangements were easier than others. Firstly, some people found it repetitive to receive the same information multiple times. It was explained that it was important for the study to provide the information several times. Secondly, planning ahead and scheduling was difficult for some participants. For example, there was confusion about dates, times, and locations. At times there was last minute confusion and misunderstanding even at the scheduled time and location. Planning interviews a few weeks in advance often required several reminders leading up to the day. This also meant that for some participants arrangements had to be made last minute. The importance of clear communication, organization, and flexibility were valuable insights gained from the recruitment and planning process.

The interviews in part consisted of questions asking about the participants experiences in USSID. There is a notion of difficulty acknowledged with retrospective questions. For some participants, they had a hard time remembering their time in school. Some answers included “I can’t remember” “I don’t really know, I don’t remember”. This could relate to cognitive challenges, therefore questions were asked in different ways or more specifically, for example instead of asking how the teachers in USSID were the question was reformulated to if there was someone in school that was supportive? With an intellectual disability, questions should aim to be open and inviting to descriptions, which can be followed by specific questions that lead to clarification or further details (Cederborg et al., 2009). At the same time, formulating open questions are not necessarily easy and encouraging persons who perhaps typically do not talk about their everyday lives at great length to do so can be challenging (Lövgren, 2013). The interview guide acted as a framework, but when some questions were hard to understand they were explained in a different way. Therefore, there is great responsibility for the interviewer to be creative and flexible during the interview process. It is important to mention that the general impressions from the participants was that they enjoyed the interviews. The majority were positive and open to sharing their experiences. It became clear to me that they saw this as an opportunity to share their stories and voice their concerns. At the end of the interview several people expressed that they were glad they participated, and it felt good to share their stories. Feeling that someone is interested in listening to them can lead to positive associations with being interviewed (Lövgren, 2013). For people who

perhaps feel they have been ignored or unheard, the interviews became an important arena for sharing their experiences.

Although concepts of reliability, validity, and generalizability are perhaps more distinct within quantitative studies, Kvale and Brinkmann (2014) state that these concepts are relevant for qualitative research as well; however, can be re-interpreted to better fit qualitative designs. Following Kvale and Brinkmann (2014), reliability is highlighted in the present interview study in terms of me as the interviewer not asking leading questions, which can produce variations in answers, and along with the other researchers discussing and having high agreement on how transcription and coding occurs. Validity can refer to ensuring quality throughout the research process, that the method facilitates studying the phenomena, and that the credibility and skills of the researcher are central (Kvale & Brinkmann, 2014). The results, Kvale and Brinkmann (2014) discuss, do not have to generalize to the whole population and be valid across time, rather qualitative results are contextualized and perhaps allow for generalizations to other relevant and similar situations. This relates to the representativeness of the interview participants in my study, since I acknowledge that they may not necessarily represent all subgroups of NEED.

Another approach to discussing the validity and quality of qualitative research is to focus on trustworthiness. This is discussed in various ways but often center on aspects of credibility, dependability, transferability and confirmability (Graneheim & Lundman, 2004; Lincoln & Guba, 1985 as cited in Nowell et al., 2017). Trustworthiness in research is in part achieved by rigor and transparency, such as clearly describing the analysis process and continually discussing the material and results (Mineur, 2013; Nowell et al., 2017). In line with the criteria of trustworthiness (Graneheim & Lundman, 2004; Nowell et al., 2017), in the present qualitative study, I have aimed to achieve this by outlining the process of the study and analysis, including quotations when presenting the results in the articles to show how the data supports the interpretations, discussing the analysis with co-researchers, devoting ample time to the analysis and developing themes, providing detailed descriptions of the context, participants, data, analysis process, and findings to increase transferability, and discussing the interpretations with various arguments and perspectives.

Reference groups

The research project has two reference groups that have followed along with the process of this thesis. The first reference group consists of representatives

from various agencies and organizations that have relevance for the target group, for example the Swedish Public Employment Service, Swedish National Agency for Education, Social Insurance Agency, The National Board of Health and Welfare, National Agency for Special Needs Education and Schools, and Misa (Misa provides work-oriented daycare activities for people with disabilities). The second reference group consists of individuals who themselves have attended USSID. Meetings with these reference groups have occurred on a regular basis throughout the process of this thesis, during which I have presented and discussed my research and findings. These reference groups have provided a mutual exchange of knowledge and been insightful discussion forums where the representatives have provided feedback, comments, support and input that have greatly contributed to this thesis. The meetings have always ended with the representatives sharing current work the respective agencies or individuals are doing. This has given up-to-date and important context for the thesis and allowed me to spread my research to where it has practical usefulness.

Ethics

The project adheres to research ethics and guidelines. Informed consent should be sought in order to be included in a study (Helsinki Declaration, 1964; Swedish Research Council, 2002). HURPID was created at Halmstad University and the process, challenges and measures to ensure ethical conduct are outlined in the published doctoral thesis by Arvidsson (2016). According to The Personal Data Act (SFS 1998:204), Arvidsson (2016) discusses that persons should be notified when they are included in a register. However, this should only be done when it does not entail a disproportionately large work effort. This issue was discussed with the local personal data representative at Halmstad University and highlighted in the ethics application. These discussions deemed it to be a disproportionately large work effort to notify the almost 13,000 persons who are included in the register and therefore a decision was made that contacting them was not needed.

The raw data of HURPID has been securely locked at Halmstad University where only authorized persons have access. When conducting analyses in the combined registers (HURPID, LSS and LISA) personal identification in the material is not possible. The code key that would enable personal identification is retained by Statistics Sweden. Only the researchers who have been given access can work with the material on the Statistics Sweden desktop.

Conducting research with people with intellectual disability highlights a balance between protecting vulnerable individuals and not excluding them

from participation and sharing their stories in research (Doody, 2018). According to Doody (2018) people with intellectual disability are a diverse group of individuals, therefore it is important to consider that they will vary in understanding, reasoning, and communication in a research situation. Following guidelines from the Swedish Research Council (2002), in the interviews comprehensive oral and written information were provided to the participants with ample time before the interviews were conducted. The consent material and information were adapted to suit the sample in the study, an example was providing reminders during the research process (McDonald & Patka, 2012). The interview situation also needs to be adjusted, for example, this often entails more time and the researcher having the ability, skills and knowledge that are suitable for working with persons with intellectual disability (McDonald & Patka, 2012). Persons with intellectual disability tend to have learned and thereby express increased social desirability and wanting to please others (McDonald & Patka, 2012; Ringsby-Jansson, 2002). This can make the actual interview process challenging and present difficulties in the depth and quality of collected data. To help avoid this, suggestions by Ringsby-Jansson (2002) were followed which included having knowledge about the participants, discussing areas that interested them, and recognizing and validating them as important contributors. The interviews had no physical risks, however there was a possibility that participants could experience feelings of discomfort or inadequacy for example feeling that they are unable to find an occupation. Therefore, it was central to explain that the researcher was not there to judge them nor was there any right or wrong answers, but the interest was in their story and their point of view. The researcher also ensured before, during, and after the interviews that the participants felt comfortable and set aside time to discuss any questions. There was a preparedness to provide the participants with additional and external resources for support, in the case that they were upset or uncomfortable after the interviews. However, this was never needed for any of the interviews.

An important aspect of research that involves persons with intellectual disability is that the individuals have influence over the research process and situation. This was ensured by using a semi-structured interview guide which allows the participants to determine central topics and to adjust the interview situation according to their preferences.

The participants' identities are protected in the qualitative results by using pseudonyms and not providing information that could be used to identify them, for example where they live. All data material including the code list and recordings are locked in separate cabinets at Halmstad University. No unauthorized persons have access to these. In accordance with the Swedish Research Council (2002), prior to the interviews taking place the participants

were informed on principles of participation being voluntary, confidentiality, how the data will be used, and the precautions taken to increase anonymity. The participants were informed that they will have the opportunity to take part of the results once the thesis is complete, in the form of a translated accessible version.

In the ethics application for the interview study, the aim was to explore experiences of becoming and being NEED, as well as the groups' experiences of social relationships and belonging. This is a broad topic and as a result much of the content was dependent upon what the individuals decided to share in the interviews. One topic that came up in a few interviews, was that some participants wanted to bring up aspects that could relate to health, specifically as it related to not participating in an occupation. Specific questions about disease, symptoms or diagnosis were not asked (see interview guide Appendix 4) nor was there a specific interest to study this. The results that emerged are an indication that dimensions of health may be one factor related to the situation of being NEED. Future research is needed to further study this topic, and its relation to having versus not having an occupation for people with intellectual disability.

Results

The four articles in this compilation thesis each have a different focus, but together have the purpose of providing a nuanced understanding of the target group. Below is a summary of the empirical findings for each article.

The aim of the first article was to explore the situation after USSID for persons with intellectual disability who are NEED in terms of background factors, financial support and LSS services, as well as how these various factors are associated with NEED status and how this status changes in relation to time since graduation from upper secondary school. The main results found that this is a heterogeneous group. Within the group it was common to have financial support such as long-term subsidies (65.5%), labour market involvement subsidy (34.2%), parental benefits (7.0%), and social assistance (29.3%), while few made use of LSS disability services (16.5%). Various factors such as sex, municipality, program type in school, financial support, and disability services were significantly associated with not having an occupation as opposed to being in employment, education or daily activity. For example, women were twice as likely not to be involved in traditional occupations compared with men. Incomplete grades increased the likelihood of not being involved in traditional occupations, while special designed programs reduced the likelihood of not being involved in traditional occupations, compared with having attended a national program. In addition, the results showed that time was a central factor. The early years after upper secondary school appear to be an important period for establishing an occupation, as seen in the decrease in the number of individuals who are NEED. This first article gives an initial description of the group, and suggests a multidimensional understanding of the different factors associated with not having an occupation. It indicates that there are various situations where people may be NEED, for example as seen through the use of different subsidies. This means that not being involved in an occupation is complex and consideration has to be made for the diversity of the group.

The aim of the second article was to describe and analyze the family situation for the NEED group and how this relates to not having an occupation as opposed to being in an occupation of employment, education or daily activity. The results found more women in the group were married, common

law, or single parents compared to men. More than half of the men lived with their parents, while the majority of women did not. The older age group of 26 years and older were more often married, common law, single parents, or single. The majority who lived at home with their parents belonged to the younger age group of 18-25 years old. Finally, within the group, larger proportions had immigrated and were married while living at home with one's parents was more prevalent among those with a non-immigrant background. The regression analyses demonstrated that family situation and background factors have significant associations with not having, as opposed to having, an occupation (employment, education, or daily activity), but differ for men and women. For example, partnerships and having children were only significant for women. The conclusions of this study suggest that there are differences between men and women in how family situation and background factors relate to not having an occupation. Moreover, these sex differences, although new findings for the NEED group, are congruent with trends demonstrated in the general population. People with intellectual disability face challenges in establishing an occupation, and the findings from this article suggest that the family situation is another important component in understanding people who are NEED.

The third article aimed to analyze the subjective experiences of becoming and being NEED. To fulfill this the analysis focused on individual as well as structural factors, and how these are experienced in different arenas in society and in interactions with agencies and institutions. Analyses based on qualitative interviews found two themes: *Relating to normality* and *Individual context and encounters with the system*, each with three subthemes. Overall, the process from secondary school to being outside of traditional occupations was not linear, rather most of the individuals had moved in and out of various occupations and NEED status. Individual factors such as desires, abilities, difficulties, and relating to their disability, combined with structural factors of limited or unsuitable post-school occupations and challenges with formal support contribute to understanding the target group. The majority of the participants expressed a strong desire for an occupation such as employment or further studies, while many also found an occupation in daily activity to not be appropriate or suitable for them. The results illustrated that the individual's self-identification was influential, for example seeing themselves as more capable and not identifying with others who have an intellectual disability. It was common to have had negative experiences with formal support and these supports were at times described as inadequate, confusing and unfair. Together this demonstrates that the experience of becoming and being NEED is influenced by the interaction of individual and structural factors. These experiences are underlined with notions of normality and stigmatization that

follows with having an intellectual disability, and the result of being categorized as different leads to a form of social exclusion for the target group.

Finally, the fourth article examined the experiences of social relationships, networks, and living situations for people who are NEED, as well as explored these relationships and networks as conditions for belonging. The results found three main themes of *Informal belonging*, *Organized belonging*, and *Striving for belonging and independence*. The findings showed that participants' social networks consisted of informal relationships and organized settings and activities, and these were central in the experience of belonging. Informal relationships tended to be with family (particularly mothers), friends, partners, and some social relationships occurred online; whereas organized settings and activities focused on relationships with professionals in the support and service system, and with others who engaged in the same activities as the participants. Some of these relationships, for example with mothers and professionals in the support and service system, had a practical function where they provide assistance to the participants. Together these various relationships were often described with positive feelings such as support, comfort, security, assurance, enjoyment, acceptance, and fitting in, which related to a sense of belonging. During this phase in young adulthood, these individuals were seeking greater independence and embarking on markers of adulthood such as desires to live independently, forming partnerships and norms surrounding having children. At times this strive towards increased independence influenced and impeded belonging. For example, the dual need of needing support from family but also wanting to live independently or have a certain occupation could create a clash. The overall conclusions of this article demonstrate the different sources and the diversity in the experiences of belonging for the NEED group. For many, a sense of belonging stemmed from important and meaningful relationships with other people. Furthermore, the strive for independence is an important dimension in the experiences of belonging. This knowledge contributes to a greater, yet complex, understanding of people who are NEED, as well as emphasizes the importance of belonging.

The results are presented and discussed in greater detail in the following discussion chapter.

Discussion

People with an intellectual disability have for a long time been excluded from participating in many of society's arenas. Having a disability often entails a need for added support during the different phases of life and particularly in transition phases, such as between secondary school and adult life. One central marker of adulthood is to work and have a meaningful occupation, and thereby participate in and contribute to society as well as achieve personal standards and conditions. The starting point of this thesis was the surprising proportion that every fourth young adult with an intellectual disability after finishing USSID were not involved in an occupation, as first demonstrated by Arvidsson et al. (2015). This finding elicited questions such as, what are these individuals doing? What happens to them?

The general aim of the thesis is to increase knowledge about young adults with intellectual disability who after upper secondary school are Not in Employment, Education or Daily activity (NEED), by providing deeper understanding and analysis of the target group's characteristics and associations with NEED status, as well as to study the subjective experiences of becoming and being NEED. In the following chapter, the empirical findings are analyzed further by providing different perspectives of understanding NEED status and by implementing the chosen theories, as well as placing the findings in relation to previous research. The chapter begins with summarizing the main findings of the register and interview studies. A discussion on the contribution of the NEED concept and the influential role of employment in society is then presented. This is followed by employing theories to discuss two main aspects of the phenomenon of not being involved in an occupation. Firstly, Bronfenbrenner's ecological theory allows for identifying and organizing characteristics of the individual, characteristics of the environment, and highlighting some of the influential processes and interactions between them. Secondly, social exclusion and belonging are employed to discuss different perspectives of the phenomenon. The chapter concludes with discussing implications, limitations and future research, and final conclusions.

Main findings

The main findings of this thesis demonstrate that the situation of not being involved in an occupation is multidimensional, non-linear and non-static. The complexity of the phenomenon signals that different factors and interactions on various levels, are important in understanding becoming and being NEED.

The major findings from the register study, based on 12,269 people of which 2,955 people were defined as NEED, showed a heterogenous group. This suggests that there are different situations related to not being involved in an occupation. These results illustrated different factors and environments such as the system of formal support (for example financial supports), disability services, school programs, family situation (civil status, having children, living at home etc.) and individual characteristics, had various associations with not being involved in an occupation. These are identified as important environments, systems and characteristics related to NEED status. The findings from the interviews confirmed the same important factors and environments as the register study, yet additionally identified other aspects, for example social networks, barriers in finding an occupation, norms, and attitudes in society to name a few. The interview study, more importantly, also described some of the processes occurring between the environment and the individual or between settings in the environment, told through the experiences of the participants. The first-hand experiences of not having an occupation show how this is a process and accumulation of many different individual and environmental factors. For some it began in USSID, where clear plans after graduation or different supports in planning for an occupation were lacking. Many individuals in the target group found their occupational options undesirable or difficult to attain, and experienced challenges with the system of formal support. There is an underlying notion of being regarded as different by society that in turn leads to challenges for the individual in gaining a meaningful occupation. The individual's own identification also influences their desire and willingness to partake in the care system. Despite the challenges this group faces, the results showed the importance of social networks and relationships. These relationships provided emotional and practical support and were central for a sense of belonging. The experience of belonging for the group was interwoven with a desire for increased independence.

Collectively, the major findings of this thesis are summarized as illustrating the complexity and multidimensionality that is the phenomenon of NEED. It is clear that these individuals, either as a result of poor alternatives or choosing to distance themselves from alternatives, end up outside, falling through or shuffled around society's support systems showing the systems

significant cracks. This highlights the importance of continuing to increase knowledge, awareness and necessary actions.

NEED vs NEET

The specific focus of studying the target group on a national level complemented with first-hand accounts, contributes to the establishment of the concept NEED (Not in Employment, Education, or Daily activity). Some similarities are found when comparing the findings of this thesis with NEET (Not in Employment, Education or Training) research. For example, as the register study illustrated, being NEED has varying associations with incomplete grades, immigrant background, and parenthood, which are factors commonly cited in NEET research as well (Eurofound, 2012; Olofsson, 2014; Olofsson, 2018; Swedish Government Official Reports, 2013:74). However, despite some similarities, this thesis demonstrates challenges and dimensions surrounding having an intellectual disability that lead to additional difficulties with establishing an occupation, and thereby distinguishes NEED from NEET. Moreover, this thesis demonstrates the diversity of the target group in and of itself that is not reflected in the more general concept of NEET. Even though NEED in some respect is a subgroup of NEET, the findings highlight the importance of distinguishing between the two. The concept of NEED therefore provides a more precise definition and concept that is useful to continue to implement. There is acknowledgement that having a concept for the target group can be problematic in terms of labeling or pointing out a specific group; however, the intention has been to make visible a, to some extent, invisible group in order to make their specific situations and needs known.

In line with the critique of the NEET label (Yates & Payne, 2006), the label 'NEED' classifies people by what they are not (not in employment, education or daily activities), which at times has a negative ring to it. People have different life situations and diverse characteristics and abilities, all of which are not seen when they are clustered under one collective label. Some individuals may view not having an occupation as more problematic than others. Likewise, the non-linear and non-static nature of being NEED entails that those who are included in the concept will vary. Therefore, the heterogeneity of the target population must continue to be considered and studied. The findings of this thesis illustrate that, despite the diversity of the group, many who are NEED find this as an undesirable situation. Instead there is a strong desire to have an occupation such as employment, which is considered by many to be an important part of adulthood.

The concept of employment

There exists a societal ideal surrounding the concept of employment. A strong trend of employment permeates throughout society, is highly valued, and provides many positive benefits (Jahoda et al., 2009; Lövgren, 2013; Lövgren et al., 2014). This strong trend was apparent in the findings from the interview study that illustrated having an occupation, most often employment but pursuing further education was also mentioned, was desired by all but one person. There was emphasis on struggles with finding and maintaining a job, including difficulties with structures of working full-time, managing time and schedules. The concept of employment and work varied among the participants as well. At times it was a more traditional concept of work in the regular labour market that was discussed; whereas some referred to their daily activities and practicums as work, others varied in what they described as work, and with some participants it was never clearly stated what type of work they were referring to.

Piippola (2010) discusses the Swedish labor market policies have been strongly influenced by a work-first policy or work principle (“arbetslinjen” in Swedish) that favors active measures such as work, education or practicums that foster employment and contributing to society, rather than receiving subsidies. Over time, the author describes, this emphasized work principle has led to increased responsibility placed on the individual to attain employment. Most people want to do something meaningful in a social context that offers activity and participation. For many, this may mean having employment which provides not only an income that in turn gives financial security and freedom of choice, but also has social significance. Although employment has great value, it is important to acknowledge that it is not ideal for everyone, rather the appropriate and desired type of occupation varies between individuals. Although employment is desirable by many, it is important to question its idealization. The emphasis on employment means that not having employment is regarded as negative, and further amplifies exclusion for those who cannot attain it (Davidsson, 2016). Equally so the type of occupation that one wants to pursue will vary between individuals who have an intellectual disability, which means that there needs to not only be different occupational options available, but these have to match with the individual’s desires and abilities. According to Wilson (2003), the emphasis of a “real/normal job” is problematic in the sense that this construction is centered on people without a disability. Wilson (2003) argues that this creates, at times, an impossible standard for people with intellectual difficulties to achieve even with substantial support. For some of the NEED participants who had tried jobs or work related activities with support, it was still difficult to maintain

these occupations. Tideman (2000) discusses employment in the labour market as a notion of normalization, however it presents a dichotomy where employment leads to benefits but also poses a risk of enhancing feelings of inadequacy for people with intellectual disability. The meaning and construction of employment as it relates to people with disabilities needs to be problematized. For those who find alternative occupations such as daily activity as fulfilling and meaningful should not be considered as socially excluded simply because they are not participating in traditional employment. Equating employment with inclusion is an insufficient measure, and again reinforces a standard not necessarily attainable for everyone (Hall, 2010; Renwick et al., 2019). Non-paid work can also provide value and contribute to belonging (Renwick et al., 2019). Rather than viewing employment as the main ideal, different types of occupations should hold value and recognition in society as well. Arvidsson (2016) discusses that the unpaid (or disproportionately low paid) nature of daily activity sends a message that this work is not valued by society. Additionally, this furthers the economic marginalization and social injustice that people with intellectual disability face (Arvidsson, 2016).

The varying meanings and concepts of work that were present among the participants in the interview study, emphasizes the individual's own understanding as well as the individual's different intrinsic and instrumental value of work as outlined by Ferrari et al. (2008). These findings suggests that the conceptualization of employment could be expanded to include a wider range of activities, but it is the benefits that are central to the individual. With the idealization of employment in society it continues to both highlight the exclusion for people with intellectual disability who struggle with establishment in the labour market, as well as reduce value from any other alternative types of occupation. For those individuals who desire employment this should be supported. However, a wider concept of employment that more so emphasizes its varying meaning for the individual is also needed.

The interaction of individual and environmental factors

In order to understand the situation of becoming and being NEED, there must be a focus on the individual and society, and more importantly the interactions and encounters between them. Critical realism's emphasis on various mechanisms and interactions aiding in explaining phenomena (Danermark, 2008), points to the need for a closer examination of what generates people with intellectual disability not participating in an occupation. People with intellectual disability have varying individual difficulties and may be in need of everyday supports. However, the importance is not only about challenges

with the intellectual disability itself but also the surrounding environment. Rather than only focusing on the long tradition of the individual as the problem, there needs to be equal, or more, focus on the environment as contributing to people with intellectual disability and their occupational status or lack thereof (Lövgren & Hamreby, 2011). More so, it is the interaction between the individual and the environment that together contribute to our understanding of NEED status. This is in line with the relational model of disability, since the individual is not isolated but rather exists in a context in society that influences their experiences. The interplay between the individual with impairment and the environment creates disability when the adaptations fail.

Applying Bronfenbrenner's ecological theory (Bronfenbrenner, 1979, 1992, 1994; Bronfenbrenner & Ceci, 1993; Bronfenbrenner & Morris, 1998, 2006) to understanding NEED status, allows for a framework to organize, identify and discuss the individual and the environment as well as some of the interactions and processes between them. The studies in this thesis do not have a longitudinal design, as such the element of time is not specifically measured. However, the interviews in part portray experiences over time that highlight important and continued interactions with different systems and settings in the environment; therefore, the processes discussed are based on those which the participants have shared from their experiences. Bronfenbrenner's model is used as a support and structure to discuss my results, as such, it is acknowledged that this discussion is the beginning of addressing the complexity of NEED, rather than presenting the whole picture. The following sections discuss characteristics of the environment and characteristics of the individual, and how these contribute to becoming and being NEED. The discussion focuses on time, barriers in the labour market, formal support, special school systems, post-school options and individual factors. In line with Bronfenbrenner (1992), the aim is also to shed light on some of the interactions and processes that are occurring.

The influence of time

Time is an important element that influences various levels in Bronfenbrenner's model, and includes changes occurring over time in both the individual and the environment (Bronfenbrenner, 1994; Bronfenbrenner & Morris, 1998). The aspect of time is relevant for understanding the NEED group. The register study was cross-sectional and provided a snapshot of the target group in 2011. However, examining proportions of NEED over time illustrated that these vary, for example initial proportions who are not involved in an occupation right after USSID have changed over time, as well as the first few years

after school appear as an important period in establishing an occupation. The interview study provides further understanding to the changing nature of NEED status. The interviews showed that the process from USSID to not being involved in an occupation was non-linear. After finishing USSID, it was more common for people in the target group to move in and out of various types of occupations, combined with periods of not having an occupation. These back-and forth movements highlight that NEED status is not necessarily static, but rather a dynamic state. In the interviews, participants discussed processes and experiences from secondary school to present day. These experiences show that individuals spend various amounts of time not participating in an occupation; some shorter, some longer, and others with multiple periods. Therefore, this situation is temporary for some individuals, although it is not ruled out that it can be a long-term problem for others. This also means that many have had occupations or eventually find some form of occupation. Regardless of the amount of time spent without an occupation, most of the participants in the interviews conveyed that this time was negative and undesirable. This suggests that despite the existence of a range in time spent without an occupation, the consequences for the individual tend to be negative. The implications of NEED being a non-static category suggest that proportions will vary and change over time, as well as that there are different subgroups of NEED. It suggests that even though early intervention and prevention is favorable, the dynamic state presents multiple opportunities in time for providing support to better assist people with intellectual disability to gain an occupation.

As Olofsson (2014) states, many young people have longer and individualized transition periods between secondary school and establishing an occupation. People with intellectual disability who finish USSID can, in some respect, be considered to have a transition period like that of young people in general. However, even if there are periods of instability or movements between occupations, people with intellectual disability have further and additional disadvantages compared to young people in general that continue to affect their occupational status (some of which are discussed in following sections). These are additional layers to consider when confronted with proportions of people with intellectual disability who do not have an occupation. Bronfenbrenner (1994) discusses how changes in the individual's life such as their family, socioeconomic status, where they live, and everyday routines will influence their development. Yet the historical time in which an individual lives, and current patterns and ideals in society have an impact as well (Bronfenbrenner & Morris, 1998). The aspect of time contributes to understanding and contextualizing the nature of NEED, suggesting that it is

regarded as a dynamic and evolving construct influenced by ongoing changes in the individual, their environment and society.

Barriers in the labour market

A central structural aspect that influences the situation of not participating in an occupation is the labour market. In line with Bronfenbrenner (1979, 1994), the structures and demands of the labour market, including the attitudes towards people with an intellectual disability, may be regarded as part of the micro, exo and/or macrosystem depending on the extent of the individual's direct/indirect interactions. The empirical findings of this thesis showed the difficulties that people who are NEED experienced when trying to enter and establish themselves in the labour market. They expressed they lacked qualifications, applied to jobs without success, did not know where to even apply, and for those who had work experience some shared they were not able to maintain these due to demands of the job. Increased unemployment rates for young adults and a demand for higher education, coupled with a shortage of suitable jobs due to high requirements (Germundsson & Runesson, 2014; Kocman et al., 2018) make participation in the labour market challenging, particularly for marginalized groups. The increased demand for qualifications and higher education becomes problematic for individuals from USSID, since this school form limits qualifications for studying at post-secondary school institutions (Germundsson & Runesson, 2014). This applies to people who are NEED, who then are an especially vulnerable group in relation to changes in the labour market.

Another element in the labour market are attitudes towards people with a disability as exemplified in employer's attitudes. If employers are hesitant to hire people with an intellectual disability (Andersson et al., 2015; Kocman et al., 2018) or view people with a disability as less skilled or capable to do the job (Kaye et al., 2011; Kocman et al., 2018), this attitude trickles down the chain and directly affects individuals' opportunities for employment. This potentially helps explain one aspect that makes finding employment difficult, and as a result why more individuals find themselves without an occupation. The relational model of disability, apart from acknowledging the role of the individual, places emphasis on the influence of negative or stigmatizing attitudes in the environment as central to understanding how a disability is created (Lindqvist, 2009). As the interviews showed, there continues to be a lack of seeing individuals with intellectual disability as capable, which in turn falls in line with the medical model that views disability as stemming from illness or injury and focuses on the individual's shortcomings. The combination of changes and demands in the labour market as well as negative attitudes,

illustrates how the meeting between the individual and labour market environment leads to barriers in establishing employment.

Systems of formal support

The system of formal support presents a setting that some individuals directly interact with, but also a broader setting where governing legislations and organizations of formal supports impact the individual. Both the register and interview studies confirmed that formal supports were an important setting in the environment for understanding NEED status. The register study showed that many had different types of financial support, but few used disability services under the LSS Act. To further understand what occurs in the interactions between the individual and the system of formal support and services, this was in part explained in the interviews as a disconnect between the individual and this system. Individuals' desires and expectations of occupational options and various supports were not met by agencies. These individuals tended to fall between different agencies or get shuffled around and as a result gained no support, and had poor experiences in their encounters with agencies. Moreover, the individual's view of themselves did not match that of the formal support system since they did not necessarily identify with a disability and the care system, which led to distancing themselves. In other words, some individuals were choosing to not use these services meant to support them.

The rights of people with intellectual disability are outlined in various international and national legislation. The UN Convention on the Rights of Persons with Disabilities aims "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (United Nations, 2006, Article 1). The national LSS Act (LSS 1993: 387), coupled with formal support provided by various agencies (for example Swedish Public Employment Service, Social Insurance Agency, Social Services, and the Health Care System) are in place to help people with intellectual disability, such as to have equal opportunities and rights as the general population. However, if individuals, such as those in the target group, do not use these formal supports it defeats the purpose of these services. This process occurring between individuals and formal support systems contribute to why services and supports are not used or are not working as intended. Below two different aspects of formal support are specifically discussed, the first showing the linkage between family and formal support, and the second discussing coordination and cooperation. Again, these settings and the linkages between them could be considered part of the mesosystem, exosystem and/or

macrosystem depending on the involvement of the individual (Bronfenbrenner, 1979, 1994).

Interaction between family and systems of support

The findings from the interview study showed that people who are NEED often expressed their experiences with formal support as challenging filled with feelings of mistreatment, not being heard or understood, and poor quality in the support. Moreover, the participants shared that they experience the system of formal support as confusing and unfair. The results illustrated that families and parents have an important role in assisting with and navigating the system of formal support. The participants shared that their mothers in particular were often the ones to “fight” with agencies on their behalf, fill out paperwork for different supports, and partake in meetings and discussions with agencies. The important and supportive role of family members, such as parents, that was found in the NEED group has been demonstrated in other research as well (for example Björquist, 2016; Petner-Arrey et al., 2016). In accordance with the ecological approach (Bronfenbrenner, 1979, 1994), this could be an example of the interaction between microsystems of family and formal support constituting a mesosystem that influences not participating in an occupation. In other words, how well-resourced and able a parent is to advocate and navigate the system of support could in part lead to different outcomes for the individual with intellectual disability.

Today’s society is marked by a welfare of negotiating (Tideman & Strandberg, 2018). Individuals must know their rights, be able to present their needs, negotiate with administrators at different agencies and so forth in order to have their rights and needs met. This is particularly important for people who perhaps need support throughout the life course, such as people with intellectual disability. As Tideman and Strandberg (2018) describe, this negotiating role may be challenging for individuals with cognitive difficulties, who then are at risk of not receiving support or help at all and instead are dependent on others, for example family members, to advocate for them. The link between parents and the system of formal support is found in other research stating the impacts and benefits of having resourceful parents (Arvidsson et al., 2016; Nowak et al., 2013). For some of the individuals who are NEED the assistance of their parents, mainly mothers, was a great help with obtaining and maintaining supports and services. This is not to say that not being involved in an occupation is the fault of parents, but it presents a more systematic and unjust issue where one *must* have well-resourced parents to attain any type of proper support (financial, occupational etc.). It problematizes the scenarios where individuals or their families are not able to advocate and “fight” for

services. If they are not, in other words are not able to negotiate or are well-resourced, these individuals likely have a disadvantage.

In this thesis, family members have not been directly asked about their experiences with formal support, but previous research shows that from the family's perspective it is a stressful and complicated process (Leonard et al., 2016; Nowak et al., 2013; Olsson & Hwang, 2003). The complicated process of attaining formal support, Olsson and Hwang (2003) relate this to differences in service allocation and delivery when it concerns individuals with disability:

Since the other privileges available to all parents in Sweden (i.e. the child allowance and the parental leave) do not include an application and evaluation process, but come automatically, why should the support to families with children with disabilities be different?. (Olsson & Hwang, 2003, p. 339)

Another related perspective is that family members may risk being overly involved. This can cause dilemmas and question the individual's capacity (Leonard et al., 2016). The interaction between individuals with intellectual disability/their families and the system of formal support and service, highlights that the exchange between them can be either facilitators for or hinder obtaining proper support. Services that are inaccessible and difficult to navigate and obtain could contribute to the NEED situation. Similarly, if one has experienced poor treatment from formal support in combination with the ability to advocate for their rights, this interaction could also add to NEED status.

Coordination and cooperation among formal support

A challenge with the system of formal support is the coordination and cooperation among various actors in the social safety net. Due to young people commonly having diverse needs that require support from multiple agencies, this requires coordination among different sections of formal support such as labour market initiatives and financial support but also the health care system (Swedish Government Official Reports, 2013:74). The NEED group is an example of where coordination and cooperation among services are lacking. The interview study showed that participants had experiences with multiple and different agencies, yet felt they were shuffled around between agencies without receiving aid, or felt confused and frustrated by involvement of different agencies. One participant, Emma, shared how the Social Insurance Agency and the Public Employment Service had different evaluations of her work abilities, therefore she was caught in the middle and without an occupation. Research shows that cooperation is not easy (see e.g. Germundsson

& Danermark, 2012). Increased specialization and fragmentation within different welfare agencies, along with agencies having difficulties fitting their own initiatives with that of others are some possible explanations for individuals being shuffled around the system (Swedish Government Official Reports, 2013:74). Additionally, individuals may be shuffled around when they fall between different agencies areas of responsibility (Ståhl & Anderzén, 2016). This poses a larger problem with how services are organized and work together, which when this fails impacts the individual. There is therefore a need for improvement in how services and agencies work together, to ensure that individual's various needs for support are being met as well prevent people from falling through the cracks of the system.

The effects of a background in USSID

It is reasonable to begin to understand the process of becoming NEED as starting in USSID. Young people spend a considerable amount of time in secondary school, and as such this constitutes an important microsystem. The actual setting or operation of USSID has not been specifically studied, but in the interview study, participants' experiences of their time in school was central and continued to impact their paths after graduation. Many of the experiences tended to be negative in nature. The participants were aware that a background in USSID limits future opportunities. They struggled with pursuing higher secondary education and encountered barriers with preconceived notions and stigmatization. One feature that emerged in the interviews was many participants did not have set plans after secondary school. Although some had ideas of what they would like to do, it was common to not have concrete plans.

USSID as a school form is meant to provide students with an adapted education that is a foundation for professions and continued studies, as well as personal development and active participation in society (SFS 2010:800). An adapted school form can be regarded as providing better opportunities to prepare students with intellectual disability for adulthood. Additionally, society has a responsibility to ensure the continued support for individuals after finishing USSID. As the interview study demonstrated, the stigmatization and stereotypes associated with this school form presents problems for some individuals in their pursuits of post-school occupations. This is supported by other research findings, where experiences of special schools include exclusion and an awareness that special schools and those who attend it are viewed as different (Mineur, 2013; Szönyi, 2005). These difficulties found in the target group are likely amplified by the previously mentioned limitations that a background in USSID has with pursuing further education. Collectively this

suggests the negative consequences that a background in USSID has for some individuals with intellectual disability, and contributes to becoming NEED. It is worthy to note that since the 2013 reforms, students now have the option of attending either USSID or individual programs in mainstream secondary school (Swedish National Agency for Education, 2016). With this expansion of choice, The Swedish National Agency for Education (2016) found that more individuals with mild intellectual disability are choosing to not attend USSID, perhaps more so due to the stigma surrounding this school form rather than actually seeking individual programs for their content.

From the interviews, a sense of being unprepared for life after USSID was expressed such as not having clear plans. This could relate to organizational issues raised by the Swedish National Agency for Education (2016), that although schools aim to increase the link to the labour market, many struggle with implementation, cooperation with employers and agencies, and still foresee difficulties with students' establishment in the labour market. Research also finds variation in how secondary schools work together with relevant agencies (Lövgren et al., 2014). It seems reasonable to state that if students are better prepared for the time after secondary school, it could assist in minimizing the likelihood of being without an occupation.

Limited post-school occupations

The available post-USSID options are another component in the surrounding environment that affects our understanding of NEED. These options generally consist of daily activity, employment or further education (although not at higher post-secondary institutions). Why are people who are NEED not participating in these occupations and instead are without an occupation? A collective understanding from the interviews indicated that the post-school occupational options are either undesirable or unattainable. Many participants did not see daily activity as a suitable option, whereas challenges with gaining employment or pursuing further education were present.

Daily activity is an unpaid occupation and complex since it may be enjoyable and regarded as work, but not necessarily fostering productivity or opportunity for an income (Engeset et al., 2015), and potentially has a lock-in effect (Tideman et al., 2017). A general view has been that daily activity is the main post-school option which is shown in the tendency to train students to directly go from USSID into daily activity, and at times this direct path is the result of poor and lacking investigations (Lövgren et al., 2014). This thesis does not have the aim of portraying daily activity in a negative light, but rather uses the first-hand experiences of daily activity to problematize its use and implementation as it occurs for some individuals. Daily activity may be

a suitable option for some people with intellectual disability, but the problem arises when this becomes the main and encouraged occupation for everyone. It may not be suitable for those who do not identify with a diagnosis, see themselves as more capable, or wish to have a job. The notion of seeing oneself as more capable and normal compared to others who have a disability or are in daily activity is not uncommon. This self-presentation and comparison are also seen among students in USSID (Szönyi, 2005). If daily activity is not appropriate, employment or further education may instead be an option. In the interviews, 9 out of 10 participants expressed a desire to work. At the same time, difficulties with employment and further education for people with intellectual disability are well-established (for example, Lövgren et al., 2014; Statistics Sweden, 2017:2; Tideman et al., 2017) and have been illustrated several times in this thesis. If on the one hand some occupations are not suitable or desirable, and on the other hand some occupations are not attainable the result perhaps is to not have an occupation at all i.e. NEED status. For some individuals, these limited or undesired post-school occupations are a contributing factor that influences becoming NEED. Subsequently, it also has a continuous effect in the experience of being NEED that includes being limited and not developing in the direction they themselves desire.

The individual and their characteristics

There may be individual reasons that temporarily or long-term influence not having an occupation. As the register and interview studies showed various individual characteristics are associated or present among the NEED group. For example, sex, age, program type in USSID, where one lives, civil status, as well as varying abilities and desires for different types of occupations. In the interviews, it was also demonstrated that how individuals view and identify themselves in relation to having an intellectual disability plays a significant role for their occupational status. These individual characteristics are important factors for understanding NEED and show the group's diversity. However, in accordance with the ecological approach as well as the relational model of disability, individuals interact with environments and it is more so these interactions, not the individual per se, that lead to difficulties in participating in an occupation.

An intellectual disability itself can entail diverse difficulties or challenges in everyday life. Common for all individuals who have attended USSID is that they have been diagnosed with having an intellectual disability. However, the majority go on to find an occupation in daily activity, further education or employment (Arvidsson et al., 2015) - meaning not all become NEED after they finish secondary school. This means that having an

intellectual disability is not a sufficient explanation for becoming NEED. I want to emphasize that although a diagnosis of intellectual disability itself can lead to difficulties, it is more so how society (including employers, agencies, formal supports etc.) views the diagnosis and the categorization that occurs from this diagnosis, that also leads to consequences for the individual. The discussion in this thesis thus far, based on the empirical findings, has illustrated various environments and barriers that are not accommodating to people with intellectual disability and subsequently influences not having an occupation.

There are various factors that relate to not participating in an occupation. Sex is an example of such a factor that showed clear differences in the register study. The register study found differences between men and women in regard to NEED status. For example, women had higher odds of not participating in an occupation, the majority of women in the NEED group did not live with their parents, and more women than men in the NEED group received parental benefits, had partners, were single parents, and had children. This suggests that there are varying circumstances and situations to consider for women vs. men who are not participating in an occupation. On a broader level, this highlights intersects between sex, intellectual disability, and occupational status demonstrating the importance of considering multiple dimensions in order to understand the diversity of the target group. One perspective is that the intersect between being female and having an intellectual disability produces, what research terms, a double disadvantage (Brown & Moloney, 2019) or accumulated disadvantage (Maroto et al., 2019). There is a need to incorporate intersectional analyses that focus on how various categories and power structures influence each other (Mattsson, 2010), which in turn provide a holistic understanding of people's situations and lives (Söder & Grönvik, 2008).

As shown in the register study, many of those who are not involved in an occupation have attended national programs in USSID. National and special-designed programs are assumed to be for people with mild intellectual disability and therefore can be regarded as a proxy for the degree of disability (Arvidsson, 2016). If many in the NEED group have a background in national programs, it suggests that with a mild or moderate disability they perhaps are more able to obtain and maintain an occupation. As was demonstrated in the interview study, it was common to not fully identify with an intellectual disability or present themselves as not as deviant as others with a disability. If people feel they were misplaced in USSID, do not identify with a disability or with the care system meant for people with intellectual disability, then perhaps their alternative is to distance themselves. The findings of this thesis suggest that being caught between their own identification and the diagnosis

and perceptions that have been placed on them may result in NEED status. In a similar notion, Olin and Ringsby-Jansson (2009b) describe that when the individual and the formal support system have contrasting views of the person with disability, the result may be to resist support so not to jeopardize the individual's self-identity. For a subset of people in the NEED group who are more so on the border of having an intellectual disability, their self-identification and how this is met by the surrounding environments plays an important role in not having an occupation.

The interview study found that some individuals mentioned their health or well-being as affecting their occupational status. These were at times reasons for not participating in an occupation. However, this topic was not examined in-depth in the interview study and instead points to directions for future research where the connections and causality between NEED status and health should be further studied.

An ecological theory facilitates an understanding that not participating in an occupation is a multidimensional phenomenon consisting of individual and environmental factors, and interactions between them. One consequence of this is that there are different situations, circumstances and experiences that relate to NEED status. As such, the findings of this thesis suggest several subgroups: long-term vs. short-term NEEDs, those who have vs. do not have formal support, those who identify with having an intellectual disability vs. those who do not, women who are taking care of children, individuals in partnerships, men with immigrant background, individuals who live with their parents, younger vs. older NEEDs and those individuals who are much further removed from society. The complexity of the target group presents the need for continued research, but also demonstrates multiple areas where interventions and resources can be provided and highlights the need for a holistic and individualized approach to better support individuals.

Social exclusion and belonging as intertwined experiences

In the following section, theories of social exclusion and belonging are employed to provide different perspectives of the target group and their experiences that in turn allow for addressing the phenomenon's complexity. Even though these theories in part are viewed as separate they are also viewed in relation to each other. Social exclusion and belonging are not just opposite states, rather they are intertwined producing a complex experience. Incorporating Taket et al. (2009) and May (2013), I view and discuss social exclusion

and belonging as being on a continuum, where it is possible to experience varying degrees of both and depends on contexts, situations and characteristics. Additionally, within social exclusion and belonging there is an aspect of choice which I discuss in relation to the NEED group as manifesting in resistance to categorization.

Social exclusion is being denied rights and opportunities leading to the lack of participation in society (Taket et al., 2009). One perspective of people who are NEED is that they are regarded and categorized as deviant due to having an intellectual disability, having attended USSID, and their lack of an occupation, all of which differ from notions of normality and results in social exclusion. In line with Taket et al. (2009), for people who are NEED this form of social exclusion is involuntary and based on having a disability. Not having an occupation for people with intellectual disability is considered a form of social exclusion since it limits individuals to participate and engage in an occupation, form social relationships, have an income, and maintain desirable living conditions. However, idealizing employment and seeing the lack of employment as a measure of social exclusion is problematic (Davidsson, 2016). This highlights that not all those who are without employment should be regarded as socially excluded.

Social exclusion for people with intellectual disability not involved in an occupation is not restricted to one arena, but rather exists in and across various dimensions. As the findings of this thesis demonstrated, people who are NEED are excluded from participating in the labour market or studying in higher education institutions, but as a result are also restricted from expanding their social networks or having an income to finance living independently. Exclusion from an occupation therefore leads to further exclusion in other areas. Studying social exclusion from both objective and subjective perspectives (Mathieson et al., 2008; Nicholson & Cooper, 2013) is implemented in the present thesis. In the register study, objective measures of social exclusion are studied through the individual not having an occupation. The register study examined how indicators of background and various other factors relate to this form of social exclusion. Meanwhile, the interview study gave first-hand accounts of experiences of exclusion and exclusionary practices. For example, with barriers in the labour market or in contact with formal support and services. Combining objective and subjective approaches is beneficial since together they capture different aspects and measures of social exclusion. The findings from both the register and interview studies provide nuances to the experience of social exclusion, validating the notion by Taket et al. (2009) that individuals can feel and experience various degrees of exclusion and inclusion.

There is in general a tendency to focus on the individual with intellectual disability and their shortcomings, for example not having the skills or capability to perform a job, as reasons for their exclusion from the labour force. For people who are NEED their situation could be explained by individual factors, however this presents a weak version of social exclusion (Davidsson & Petersson, 2016). The strong version of social exclusion targets societal structures and agents that lead to people becoming excluded (Davidsson & Petersson, 2016), and would instead focus on school forms, limited or unsuitable post-school options, inadequate support, labour market requirements and demands, and attitudes toward disability, which all hinder people with an intellectual disability in their pursuits of an occupation and consequently contributes to being socially excluded.

The opposite of social exclusion in this discussion is belonging. Belonging focuses on the interactions with others, and experiences and feelings of where and with whom we belong that contribute to our sense of identity (May, 2013). Relationships with other people is one important aspect of belonging. The results from the register study, presented in article II, indicated small proportions in the NEED group that were married, common law or had children, although these proportions were slightly larger in the target group compared to people who have an occupation. Also, partnerships and having children related to women not being involved in an occupation, but this was not found for men. Although the register study showed small proportions of the target group that had partnerships or children, it showed that family situation is an important aspect of being NEED. The interviews extended this knowledge further by suggesting, in the results of article IV, that one way belonging manifests on an individual level was in informal relationships (family, friends, and partners) and organized relationships (with professionals in the support and service system as well as through organized activities and settings). The majority of participants expressed positive feelings towards these relationships and emphasized their emotional, supportive, and practical importance. Despite enduring other challenges in their daily lives, these close relationships acted as a safe place where many of the participants could be themselves and found enjoyment and support. Family, friends and partners were at times regarded as the most significant people in their lives, which is in accordance with previous research demonstrating the important value of these relationships (for example Kamstra et al., 2015; May, 2013; Sigstad, 2016). Moreover, these relationships provide the individuals with a sense of identification, which according to May (2013) is central to belonging. The experience of belonging for people who are NEED centered on their relationships with other people. Even when recreational activities or organized settings were discussed as part of their social networks, it was the relationships

with other people within these that were emphasized. May (2013) describes this as relational belonging.

Another way to view belonging on a societal level for the NEED group is belonging in a community, in different areas like the labour market, leisure activities etc. Previous research shows a dimension of belonging is to feel that one contributes to society and is a valued part of a community, for example through work (Renwick et al., 2019; Strnadová et al., 2018). Given the value that an occupation such as work has for belonging, it presents restrictions for people who are NEED. As a result of being excluded from an occupation, it leads to limited opportunities to develop and experience belonging in this type of community. Although this does not eliminate that a sense of belonging can stem from other types of communities, for example in leisure activities, living accommodations etc. But belonging in the particular community that comes with being employed or having an occupation, is one that is more so limited for the target group. For many people in general, who spend much of their time at a job, the relationships and friendships that are created in the workplace with colleagues are valuable. As such, by not having a workplace the prospect of developing these relationships are limited among people in the target group. Belonging in the NEED group therefore varies in different contexts, where individuals may experience belonging in social relationships or activities but not in an occupation.

Social exclusion and belonging are not total or static states. They are characterized as changing, stemming from multiple sources, and can be experienced in varying degrees (May, 2013; Taket et al., 2009). Previous research demonstrates multiple aspects of where people with intellectual disability are disadvantaged or socially excluded (e.g., Hall, 2005; Hubert & Hollins, 2010; Wang, 2013). Similarly, NEED status presents another way in which people with intellectual disability are socially excluded. However, through the accumulated findings of the studies and articles in this thesis, I propose that it is more complex than this, and social exclusion and belonging are much more entangled. The experiences of being NEED showed that individuals feel socially excluded in some respects such as from having an occupation or having appropriate formal support, yet in other arenas of their close relationships they felt a sense of belonging. This is not necessarily different from what most people experience, varying degrees of exclusion and belonging depending on our characteristics, settings and contexts. Yet, it becomes important to highlight that for people who are often regarded as socially excluded, and this is central to address in order to increase participation in society for people with intellectual disability, they also experience a sense of belonging. A belonging that provides positive feelings and experiences for them. This provides a multifaceted understanding of NEED status, where knowledge of the

varying sources, processes, and experiences of social exclusion and belonging can help in developing resources and action.

Resistance to categorization

The interview study illustrated a sense of agency or active choice among some of the individuals. This manifests in varying degrees of opposing the categorization of an intellectual disability and the care system meant to support them. By rejecting this categorization, some individuals are exerting a conscious choice of where one wants to be included versus excluded and belong versus not belong. In the NEED group there are two different examples of how this manifests. In the first, are those individuals who more so acknowledge having difficulties, but see themselves as not as deviant as others with a disability. Even though these individuals seem to understand that they need support, they find that alternatives such as daily activity are not suitable for them. They do not want to belong in this arena. Distancing themselves from daily activity instead leads to not having an occupation and being socially excluded. In the second group, are those individuals who do not identify with a disability identity. This means they do not identify themselves as having an intellectual disability and/or oppose the identification of people with intellectual disability. These individuals are more vocal about feeling misplaced in USSID. Subsequently, they take a stronger stance against the options, resources and settings intended for people with intellectual disability. These are examples of being connected to the formal system of support and settings associated with having a disability, but not feeling they belong, which fall in line with Crisp's (2010) distinction between connectedness and belonging. Both subgroups show resistance to the categorization of an intellectual disability but to different degrees.

Within the literature of social exclusion and belonging, both concepts highlight an element of active choice. Chosen social exclusion is when individuals actively choose to not participate in society (Taket et al., 2009). Simultaneously, belonging can be chosen or resisted but also bounded by where one is permitted to belong (Mahar et al., 2012; May, 2013). This suggest that for some individuals in the NEED group, social exclusion and belonging are not merely something that is determined for them and passively accepted. Rather, individuals are also exerting their own choices. Szönyi (2005) describes a strategy for dealing with the categorization of having an intellectual disability or having attended USSID, can be to seek a sense of being regarded as normal. For people who are NEED, this may translate to distancing themselves from the care system and supports, and instead seeking "normal" occupations and lifestyles. As such they are resisting the categorization that

comes with a diagnosis or background in USSID, and the associated ideas and views that society has of people with intellectual disability. However, because they still face the challenges with gaining an occupation after USSID they are caught in the middle of this categorization and their own identification, in turn resulting in social exclusion. This is problematized further by reflecting on whether rejecting the care system and a disability identity is an actual active choice of social exclusion. Are individuals who resist categorization actively choosing to not partake in society or belong in certain arenas, or are individuals left with little choice and influence and as a result remove themselves from society?

Choosing where and with whom one wants to belong can be seen in the varying relationships that people who are NEED have with other people with and without disability. As expressed in the interviews, some participants felt a stronger sense of belonging with others with an intellectual disability or who have also attended USSID. This highlights the aspects of similarity or shared experiences as a basis for meaningful relationship and belonging (Mahar et al., 2012; May, 2013; Renwick et al., 2019; Wilson et al., 2017). However, other participants refuted these sources of belonging and instead experienced greater belonging with people who do not have a disability. This may perhaps be more common for those individuals in the target group who do not identify with an intellectual disability. This is in line with May (2013), where non-identification can lead to resistance in belonging with people who have a disability. Other research supports these findings, and have illustrated that the way an individual views their disability identity and relates to the stigma surrounding disability, will in turn influence their experiences of belonging (Olin & Ringsby-Jansson, 2009b; Strnadová et al., 2018). It does not necessarily have to be one or the other, meaning that one can experience belonging with others who have and don't have a disability at the same time. For some people in the NEED group, they are choosing to not belong with the care system and resources meant for people with intellectual disability, including daily activity. The result is a form of social exclusion from participating in society, i.e. not being involved in an occupation. These individuals tend to experience other arenas for belonging such as with their families, friends, partners or in recreational activities. Together it illustrates that social exclusion and belonging take different forms, but a key underlining notion in these experiences is individuals' relation to identifying with and/or resisting the categorization of an intellectual disability.

Implications

This thesis shows that the time after USSID is filled with diverse challenges and difficulties for a substantial group of young adults with intellectual disability. Perhaps more so for those who have a mild intellectual disability or see themselves as capable of having a more typical form of occupation. The contribution of this thesis to research and practice is thus twofold. Firstly, to present knowledge about a group of people that previously have been unknown and under researched, thereby providing a starting point for continued future research. Secondly, by employing both national comprehensive register-based and subjective first-hand approaches generate an increased understanding that NEED status is multidimensional.

Based on my thesis, the findings are translated to concrete efforts and implications within four areas: individual, school, support systems, and the labour market. The NEED group is diverse, which highlights that efforts need to be tailored to the individual and based on their conditions, abilities and desires. The necessary efforts for women with small children may be very different from that of men with immigrant background. Where one group may need assistance with their family life, the other might require practical support with language barriers or navigating available occupations. Similarly, young adults living at home with their parents may need support in gaining independence, whereas women living on their own with children perhaps need support in terms of balancing childcare with having an occupation. Another example is individuals who are closer versus further from the labour market. People who are participating in labour market policy programs perhaps need support to successfully transition into employment; whereas individuals who are not involved in any supports or services are much further from the labour market. Therefore, the aimed support needs to have different focuses that long-term will result in a meaningful and valuable occupation that individuals both desire and are able to maintain.

In the context of the school setting, there is a need for improvement in preparing students for life after USSID, including planning and preparing for having an occupation as well as follow-up after secondary school. Implementing early interventions, either in USSID or during the time shortly after graduation, is paramount for ensuring that young adults with intellectual disability have the right support as early as possible. In turn, this may benefit some people not becoming NEED right after they finish secondary school.

An overarching understanding from the NEED group is that there should be better options and opportunities for post-school occupations. Moreover, understanding the heterogeneity of the group entails that there will be diversity in the types of occupations that they wish to pursue. The findings

emphasize the importance of being well-resourced and able to advocate and negotiate in order to navigate systems of support. This is problematic for individuals with intellectual disability and highlights the importance of their family and close network to assist them. In sum, the systems must not only improve in accessibility and understanding, but on a broader level provide better occupational opportunities and support individuals in attaining them. A few concrete examples include, that since many people who are NEED have activity compensation there should be better and accurate follow-up that they also have activity that prepares them for employment. Activity compensation provides income support, but there has to be assurance that it is implemented and functioning as intended to increase successful transition to an occupation. Another example is that the transition from daily activity to employment for those who desire it improves in order to avoid a lock-in effect. Additionally, the social security net and options after USSID should not exclusively encourage daily activity but promote vocational activities and preparations if the individual desires it. Finally, support should be offered in navigating the system, as well as consider simplifying the system through better cooperation between agencies. The NEED group is a clear example that people with intellectual disability encounter a society that is not able to prevent that individuals fall through welfare society's cracks and creates disability. Because there are multiple systems of support and resources for people with intellectual disability, coordination and cooperation is central. To help prevent people getting lost in the system or being shuffled around without appropriate support, agencies and relevant actors have to improve how they coordinate their services. If one agency's evaluation is that an individual is capable to work and another agency's evaluation is the opposite, it should not fall on the individual to resolve this conflict. The need for research that analyzes the systems limitations and consequences is of great importance.

Finally, in the labour market, the focus should be to increase opportunities and lower the barriers in attaining paid employment. An example is for greater involvement and collaboration between actors in the labour market and USSID, so that individuals with intellectual disability early on gain experiences and contacts. Another example is that the available wage subsidies should be better used in regard to the target group, in order to facilitate more work opportunities as well as influence employer's attitudes. For those who wish to have a job there needs to also be increased and ongoing individual support in gaining and maintaining employment.

Limitations and future research

This thesis is a starting point for studying young adults with intellectual disability who are not involved in traditional occupations and presents many paths for future research. It is important to continue to study and further define the subgroups of NEED. As has been demonstrated, this is a diverse group and it is problematic to assume all individuals under one, negative, label. Therefore, future research should continue to expand our understanding of the group's diversity and complexity. A limitation of the interview study that has been highlighted (see "reflections on interviews and methodological considerations") is the representativeness of the participants. These ten participants may be those who are closer to systems and supports, whereas individuals who are further removed from society or who have more severe disability may not be well-represented. There could also be individuals who do not disclose their background in USSID or that they have an intellectual disability to their family, partners or friends, which would make participation in the interview study problematic. This points to the importance in conducting more interview studies that include people in different situations related to not participating in an occupation. Some subgroups that have been mentioned as important to study include women who have children, those with varying degrees of or no formal support, long term NEEDs vs temporary NEEDs, and individuals who are much further removed from society to name a few. A potential subgroup that was mentioned several times during recruitment for the interview study and in conversations with various practitioners, was women with an intellectual disability who have a foreign background. The suggestion was that some women would get married and this was a reason for not having an occupation. For some they would not disclose having an intellectual disability or having attended USSID to their partner and families. As a result, they were not involved in supports and services meant for people with intellectual disability. Another potential subgroup to study would be young men who live in their parents' home, as seen in the results from the register study. A part of studying subgroups would also be to continue to examine the mechanisms, processes, and factors that influence why some individuals are not or ever will be NEED, are NEED for much longer periods, or move in and out of NEED status frequently. And finally, which individuals are outside the system and which are more so between the cracks or under the radar? By studying different subgroups, it is additionally important for future research to study effective supports that prevent or make the time spent not having an occupation as short as possible. As shown above, there are many directions for future research. With the findings that this thesis has generated it could perhaps lead to further analyses that show clearer typologies, if

possible, in the group as well as closer examination of varying factors and experiences that relate to these subgroups.

The discussion of NEED status as understood through systems theory raises another concept of interest - namely resilience. How can we understand resilience in the target group? If not participating in an occupation is influenced by individual and environmental factors (and the interactions between them), how can these instead be used in the opposite sense for fostering resilience? The display of resistance to categorization among the target group, is this a form of resilience? These questions would help in shifting focus to how best to promote or encourage resiliency.

An important element for future research is to continue to employ methods that highlight the individual's own experiences. This gives individuals, who perhaps often feel that they are not heard or acknowledged, an opportunity to share their stories and is a valuable source of knowledge for researchers and practitioners. An example would be to more in-depth study the relation between health and not participating in an occupation from the individual's perspective. The interviews themselves generated a wealth of knowledge, but in addition the actual process of conducting the interviews including the logistics and methodological aspects also resulted in important knowledge. Conducting interviews required preparation, skills and knowledge of the group. This became one of the most valuable experiences and knowledge that I have gained.

The thesis has focused on studying the target group. In order to give a more complete picture of a complex phenomenon the experiences of other related actors would be needed, for example employers, government representatives, family, relatives and friends. It would be particularly beneficial to investigate the perspective of practitioners and agencies who meet and work with this group. During this research process I met many practitioners in this field. They would often eagerly share their experiences or versions of the situation and conditions surrounding the NEED group. By including the practitioners' side it could enrich our knowledge and provide complementary understanding of the difficulties they encounter and the tools and skills important for working with this group. With continued focus on not only the target group itself, but the systems and supports in their surrounding environment, it would allow for greater knowledge on what schools, agencies, families and other important systems can do to better prepare and assist individuals who are at risk of or are currently not participating in an occupation.

As was mentioned in the method discussion, future research should address the element of time and the new format of USSID. Firstly, a limitation with the cross-sectional design of the register study is that time and changes over time were not specifically examined. This points to the need for future

research with longitudinal designs. Questions for future research include: How does NEED status change over time? How do individuals move in and out of an occupation over time? This thesis has focused on what contributes to becoming NEED; however, it is equally valuable to examine what factors contribute to exiting NEED. Are there factors that help people move from not having to gaining an occupation? Secondly, the data in HURPID is currently based on the old USSID school system and reforms were made in 2013. It is important to compare the old and new school systems, as well as follow up on the reforms to investigate if there have been any changes and how this affects the outcomes for young adults with intellectual disability. Currently a new doctoral thesis has begun at Halmstad University that will expand HURPID to include those students who graduated after 2011, and thereby allow for comparisons between the old and new school system. HURPID is a valuable and unique resource that offers a wealth of information and can generate further analyses. It holds the possibility of being linked with other national registers to study many different areas.

The essence of future research needs to continue to study particularly marginalized groups such as people with intellectual disability, at the individual, group and societal level. This knowledge can then be translated into practical action. It is of utmost importance that people receive support, help and opportunities to live what they deem to be a good life with good conditions.

Conclusion

The main conclusions of the thesis highlight that NEED status is composed of multiple factors and dimensions. That beyond just the individual's characteristics, it is the interaction and processes between the individual and the surrounding environments and society that together helps us understand not participating in an occupation. Individual characteristics such as background factors and consequences of the disability have an important role, but they do not explain the situation of becoming and being NEED sufficiently. Structural problems and barriers in different environments including in the labour market, USSID's preparations for adult life, and challenges with formal support (navigating and obtaining support, negative experiences with support, and lack of coordination among agencies) add further explanations. The situation of not participating in an occupation is regarded as non-linear and non-static, suggesting its dynamic nature. Not having an occupation leads to social exclusion and poses consequences in various areas of life. Individuals in the target group are not given the opportunity to have a meaningful occupation, participate in society, attain financial stability, or develop expanded social

networks. At the same time, social exclusion and a sense of belonging are intertwined experiences in this group and generate an understanding of the complexity and variation that exists in being NEED.

There has been a general notion of security that society takes care of and ensures the well-being and occupational status of people with intellectual disability after USSID. However, the target group illustrates that many, against their will and wishes, are without an occupation and without appropriate support. People with an intellectual disability who are not participating in an occupation can be regarded as having the utmost unfavourable situation. Meaning, that firstly they have been categorized by having an intellectual disability and attending USSID, which entails diverse challenges for finding an occupation. When they then finish secondary school they are not able to find a meaningful occupation, and when trying to navigate their occupational options and appropriate support they instead fall through the cracks of the social support system.

The existence of this target group, that one in four young adults are not involved in an occupation after USSID, showcases the shortcomings and the cracks of the welfare society. Where the meetings between the individual and society's systems present difficulties and barriers that at times hinder rather than help. Society has an inherent responsibility to care and provide for its most marginalized individuals, and this includes people with intellectual disability. Aside from having an intellectual disability that can entail challenges on its own, the lack of action and support from society leads to additional difficulties for the individual. As such, this presents a challenging, yet imperative issue that society must address. It illustrates the need for continued research as well as political initiatives and actions, to better support and prevent future young adults from becoming NEED.

På lättare svenska

Den här boken handlar om unga vuxna med intellektuell funktionsnedsättning som varken arbetar, studerar eller har daglig verksamhet (dom har inget att göra på dagarna, de saknar sysselsättning) efter att de har gått ut gymnasieskolan. Jag heter Renee Luthra och under 5 år har jag jobbat på Högskolan i Halmstad och forskat om den här gruppen. Den här boken är min doktorsavhandling. I boken skriver jag om hur jag har gjort för att studera gruppen och vilka resultat jag har hittat i min forskning.

En av fyra av de som har gått i gymnasieskolan saknar sysselsättning efter skolan. Jag kallar gruppen unga vuxna med intellektuell funktionsnedsättning som inte har något sysselsättning för "NEED". På engelska står detta för "Not in Employment, Education or Daily activity", vilket på svenska betyder "Inte i arbete, studier eller daglig verksamhet".

Vi vet inte så mycket om gruppen

Inom forskningen och i samhället vet vi väldigt lite om denna grupp personer. Men vi vet att det är viktigt för alla att ha en sysselsättning och att man mår bra av det. Många personer med intellektuell funktionsnedsättning har svårt att hitta jobb. Därför behöver vi veta mer om vad det är som gör att de, även om de vill arbeta, inte har någon sysselsättning efter gymnasieskolan.

För att veta mer om detta har jag gjort två studier:

1. En registerstudie
2. En intervjustudie

Registerstudien

I min forskning har jag använt tre register som innehåller olika sorters information om personer som har gått gymnasieskolan. Med hjälp av registren har jag kunnat få svar på några frågor som: Hur många kvinnor och män med intellektuell funktionsnedsättning saknar sysselsättning efter att dom slutat skolan? Får de några pengar att leva på? Har dom en partner eller barn? Spelar det någon roll att vara kvinna eller

man, vilket program personen gick i skolan och om personen har en familj?

Det ser väldigt olika ut för olika personer inom gruppen. Det betyder att det finns olika anledningar till att man inte har en sysselsättning. Till exempel var det vanligt att personerna i gruppen hade aktivitetsersättning, men inte någon sysselsättning. Det var inte många i gruppen som hade något LSS-stöd. Ett annat resultat var att det fanns skillnader mellan män och kvinnor. Det var vanligare att kvinnorna saknade sysselsättning om de hade en partner eller barn. Samma sak gällde inte för männen.

Intervjustudien

Jag har också gjort intervjuer. Jag har intervjuat 10 personer med intellektuell funktionsnedsättning som saknar sysselsättning. Jag har ställt frågor om hur deras vardag ser ut, hur tiden efter gymnasiesärskolan fram till idag har sett ut, om vilket stöd de får och om deras sociala relationer.

Det fanns många olika saker som påverkar att man inte har en sysselsättning. Det handlade om individen och olika saker som man vill eller inte vill göra. Det handlade också om

miljön runtomkring dem. Det var vanligt att känna att det var svårt att få hjälp från olika myndigheter. Det var också vanligt att daglig verksamhet inte var något man vill vara på. Istället ville personerna i gruppen ha ett vanligt jobb eller studera.

Jag frågade också om personernas familj och vänner. Personerna berättade att de har familj, vänner och partners som betyder mycket för dem. Några berättade att de har bra relationer med personal där de bor eller med andra personer som de träffar under fritidsaktiviteter. De fick stöd och kärlek, och kände tillhörighet i sina nära relationer. Personerna som jag har intervjuat önskade ofta att de skulle vara mer självständiga.

Diskussion

Mina studier visar att det finns många olika faktorer som bidrar till att var fjärde ung vuxen med intellektuell funktionsnedsättning saknar sysselsättning efter gymnasieskolan. Det handlar om olika svårigheter och problem när individen möter miljön runtomkring.

Personer med intellektuell funktionsnedsättning som saknar sysselsättning har inte möjlighet att delta i samhället som alla andra. Man kan säga att de hamnar utanför samhället och inte får den hjälp de behöver. Mina studier visar att personerna samtidigt också känner tillhörighet. De har bra och nära relationer med personer som betyder mycket för dem. Dessa relationer hjälper dem och ger dem stöd. Man kan känna sig utanför samtidigt som man känner tillhörighet.

Det finns också personer i gruppen som känner att de inte hör ihop med andra som har en intellektuell funktionsnedsättning.

Varför är detta viktigt?

Den här boken är viktig för den ger kunskap om unga vuxna med intellektuell funktionsnedsättning som saknar sysselsättning. Innan har man inte vetat så mycket om detta. Jag hoppas att mina resultat kan hjälpa att personer med intellektuell funktionsnedsättning får bättre stöd och hjälp, så att alla ska få möjligheter och få ha en sysselsättning som de vill och önskar.

Sammanfattning på Svenska

För unga vuxna präglas tiden efter gymnasieskolan av olika förändringar och vuxenmarkörer. Dessa kan exempelvis handla om att hitta ett jobb, studera vidare eller flytta hemifrån. Forskning om unga vuxna generellt visar att tiden efter gymnasiet för en grupp kännetecknas av att inte ha en sysselsättning. I forskningen benämns dessa individer ofta som Not in Employment, Education or Training (NEET) eller Unga som Varken Arbetar eller Studerar (UVAS) (Eurofound, 2012; Swedish Government Official Reports, 2017:9; Swedish Government Official Reports, 2013:74). Det finns dock begränsad kunskap och forskning om unga vuxna med intellektuell funktionsnedsättning som efter gymnasiesärskolan saknar sysselsättning. En tidigare studie (Arvidsson et al., 2015) identifierade en betydande grupp (24.1%) av före detta gymnasiesärskolelever som varken arbetar, studerar eller har sysselsättning i daglig verksamhet. Detta är en viktig grupp att studera eftersom personer med en intellektuell funktionsnedsättning med en bakgrund i gymnasiesärskolan ofta har stora svårigheter att etablera sig på arbetsmarknaden eller hitta en sysselsättning. I denna avhandling benämns dessa individer som Not in Employment, Education or Daily activity (NEED). Syftet med denna avhandling är att öka kunskapen om unga vuxna med intellektuell funktionsnedsättning som efter gymnasiesärskolan inte har sin sysselsättning i arbete, studier eller daglig verksamhet (NEED), genom att ge djupare förståelse och analys av gruppens karakteristik och samband med att vara NEED samt att studera de subjektiva erfarenheter av att bli och vara NEED. Sammanläggningsavhandlingen består av två delstudier (en registerstudie och en intervjustudie) vilka presenteras i fyra artiklar, samt en ramberättelse (kappa).

Tidigare forskning

Eftersom forskningen om NEED-gruppen är begränsad, samt att fenomenet är relaterat till olika forskningsområden, är det viktigt att ta hänsyn till tidigare forskning som spänner över flera områden. En sammanfattning av tidigare forskning visar att övergången från skola till vuxenliv ofta är svår för individer med intellektuell funktionsnedsättning. Att finna en sysselsättning kan

vara en del av svårigheten, eftersom personer med intellektuell funktionsnedsättning möter utmaningar med att komma in på arbetsmarknaden på grund av höga prestationskrav, efterfrågan på högre utbildning eller negativa attityder (Andersson et al., 2015; Germundsson & Runesson, 2014; Kocman et al., 2018; Lövgren et al., 2014; Statistics Sweden, 2019:2). Personer från gymnasiesärskolan är inte behöriga att studera på universitet (men däremot exempelvis på folkhögskola) vilket begränsar deras möjligheter till vidare studier. Det vanligaste sysselsättningsalternativet är att delta i daglig verksamhet. Dock har daglig verksamhet, som är en obetald sysselsättning, en inlåsnings-effekt eftersom det är mycket ovanligt med övergång från daglig verksamhet till arbete (Migliore et al., 2008; National Board of Health and Welfare, 2008; Tideman et al., 2017).

Personer med intellektuell funktionsnedsättning kan behöva olika grader och typer av stöd i sin vardag. Behovet varierar beroende på omfattning av funktionsnedsättningen och individens olika behov samt hinder och barriärer i omgivningen. Därför är stödsystemet, d.v.s. de olika aktörer och myndigheter som ska ge stöd och service, ofta centrala för personer med intellektuell funktionsnedsättning och deras livsvillkor. Det finns olika former av stöd (ekonomiskt stöd, LSS-stöd, stöd genom hälso- och sjukvården, med mera) och därför är samverkan mellan myndigheter en viktig del för att personer ska kunna få sina behov tillgodosedda (Danermark & Germundsson, 2016; Swedish Government Official Reports, 2013:74; Östlund & Johansson, 2018). Det är också viktigt att ta hänsyn till att det finns olika erfarenheter av stöd, dessa kan upplevas som stigmatiserande eller att man pekats ut som anorlunda genom att använda dem (Olin & Ringsby-Jansson, 2009a).

I övergången från gymnasiesärskolan till vuxenlivet är familjen och sociala nätverk betydelsefulla. Forskning visar att familjen fyller en viktig funktion genom att stödja personen under olika livsfaser (Dyke et al., 2013; Pallisera et al., 2016; Pérez et al., 2015; Petner-Arrey et al., 2016; Ringsby-Jansson & Olsson, 2006; van Asselt-Goverts et al., 2015). Forskning visar dock att personer med intellektuell funktionsnedsättning har färre sociala relationer och nätverk än andra (Pallisera et al., 2016; van Asselt-Goverts et al., 2015; Velsvik Bele & Kvalsund, 2016). Ofta består dessa relationer av familjemedlemmar, personal, eller andra i aktiviteter eller program man deltar i (Dyke et al., 2013; Forrester-Jones et al., 2006; Kamstra et al., 2015; Schneider & Hattie, 2016; van Asselt-Goverts et al., 2015).

Kunskapen om personer med intellektuell funktionsnedsättning som inte har en sysselsättning är ytterst begränsad. Det finns mer forskning om unga vuxna i befolkningen generellt som är utan sysselsättning (NEET). Det som blir tydligt i NEET-forskningen är att det finns flera undergrupper och att olika riskfaktorer som exempelvis låg utbildning, invandrarbakgrund, ohälsa,

funktionsnedsättning och kön påverkar situationen (Celikaksoy & Wadensjö, 2018; Engdahl & Forslund, 2015; Eurofound, 2012; Olofsson, 2014; Olofsson, 2018; SEU rapport, 1999; Swedish Government Official Reports, 2013:74; Tamesberger et al., 2014).

Teoretiskt ramverk

I avhandlingen används systemteori samt teori om social exkludering och tillhörighet för att analysera och diskutera de empiriska resultaten. Bronfenbrenners systemteori fokuserar på betydelsen av individens och olika miljöers karakteristik (vissa miljöer som är närmare och andra längre ifrån individen), och fokuserar särskilt på interaktioner mellan dessa som påverkar utveckling (Bronfenbrenner, 1979, 1992, 1994; Bronfenbrenner & Ceci, 1993; Bronfenbrenner & Morris, 1998, 2006). Systemteori används i avhandlingen för att organisera, identifiera och diskutera olika miljöer/system och individuella egenskaper och hur interaktionen mellan dem bidrar till att vissa som gått i gymnasiesärskolan blir NEED. Begreppen social exkludering och tillhörighet används för att diskutera olika perspektiv och erfarenheter av att vara NEED. Social exkludering innebär att nekas möjligheter och tillträde till arenor vilket leder till att individer och grupper inte fullt ut kan delta i samhället (Millar, 2007; Taket et al., 2009). Tillhörighet fokuserar på hur man identifierar sig med, anknyter till och känner samhörighet med människor, kulturer och platser (May, 2013).

Metod

För att öka kunskapen om NEED-gruppen har två delstudier genomförts – en registerstudie och en intervjustudie. Registerstudien använder det nationella registret Halmstad University Register on Pupils with Intellectual Disability (HURPID). HURPID bygger på slutbetygen från i princip samtliga studenter (N=12,269) som gick ut gymnasiesärskolan i Sverige mellan 2001 och 2011. HURPID har sedan samkörts med Socialstyrelsens LSS-register som innehåller information om personers insatser via LSS-lagen och med Statistiska Centralbyråns LISA-register, vilket bidrar med uppgifter om arbete, ersättningar m.m. Med dessa register har olika statistiska analyser gjorts för att dels beskriva NEED-gruppen, dels undersöka olika samband och mönster. Intervjustudien bygger på intervjuer med tio personer från målgruppen. Rekruteringsprocessen till intervjustudien var komplicerad, vilket delvis kan förklaras av att dessa individer är svåra att hitta eller nå då de inte deltar i en

sysselsättning och kan sakna formellt stöd. Till slut var det tio personer, mellan 21-31 år, från olika kommuner som deltog i studien. Alla intervjupersoner hade en bakgrund i gymnasiesärskolan och majoriteten var vid intervjutillfället utan en sysselsättning. På grund av svårigheter att rekrytera breddades inklusionskriterierna och personer som för tillfället hade en sysselsättning men tidigare haft en lång period av att vara NEED inkluderades i studien. Intervjuerna analyserades genom en tematisk analys. Både registerstudien och intervjustudien har godkänts av Etiknämnden i Lund (Dnr. 2011/326; 2011/782; 2014/691; 2016/719).

Resultat från artiklarna (I-IV)

Resultaten från de två studierna presenteras i fyra artiklar. Artikel I undersökte situationen efter gymnasiesärskolan för NEED-gruppen utifrån bakgrundsfaktorer, ekonomiskt stöd och LSS-insatser. Resultaten visade att NEED är en heterogen grupp. Olika faktorer som kön, kommun, programtyp i skolan, ekonomiskt stöd och LSS-insatser hade signifikanta samband med att inte ha en känd sysselsättning. Till exempel hade kvinnor större sannolikhet att vara utan sysselsättning jämfört med män. Ofullständiga betyg visade ökad sannolikhet för att inte ha en sysselsättning, medan specialutformade program minskade sannolikheten för att vara NEED, jämfört med att ha gått ett nationellt program. Dessutom visade resultaten att tid var en betydelsefull faktor. Exempelvis var de första åren efter gymnasiesärskolan en viktig tid för att hitta en sysselsättning. Den här första artikeln visar att en förståelse av NEED innebär olika dimensioner, faktorer och situationer. Det betyder att det är ett komplext fenomen och att man måste ta hänsyn till gruppens heterogenitet.

Artikel II beskrev och analyserade gruppens familjesituation och hur denna relaterar till att vara NEED. Familjesituationen i målgruppen varierade beroende på kön, ålder och invandrarbakgrund. Exempelvis visade resultaten att fler kvinnor i gruppen var gifta, sambo eller ensamstående föräldrar jämfört med män. Mer än hälften av männen bodde hos sina föräldrar, medan majoriteten av kvinnorna inte gjorde det. Regressionsanalyserna visade att familjesituationen och bakgrundsfaktorer hade signifikanta samband med att inte ha en sysselsättning, men att det skiljer sig mellan män och kvinnor. Partnerskap och att ha barn t.ex. var signifikanta faktorer för att vara NEED för kvinnor, men inte för män. Resultaten av denna studie visar att det finns könsskillnader i hur familjesituationen och bakgrundsfaktorer relaterar till att vara NEED. Denna könsskillnad liknar på ett sätt mönster som finns i den allmänna befolkningen när det gäller kön och sysselsättning. Människor med

intellektuell funktionsnedsättning står inför utmaningar när det gäller att etablera sig och hitta en sysselsättning, och avhandlingens resultat tyder på att familjesituationen är en betydelsefull komponent för att förstå målgruppen.

Artikel III bygger på intervjupersonernas erfarenheter av att bli och vara NEED, samt deras möten med olika myndigheter och institutioner. Analyserna resulterade i två teman: att relatera till normalitet och individuella sammanhang och möten med systemet. Sammantaget visade resultaten att processen från gymnasiesärskolan till att vara utan sysselsättning inte var linjär, utan de flesta individerna hade rört sig in och ut ur olika sysselsättningar och haft perioder som NEED. Upplevelsen av att inte ha en sysselsättning påverkas båda av individ- och miljöfaktorer. Individuella faktorer som olika önskemål, förmågor, svårigheter och hur man identifierar sig med en funktionsnedsättning spelar roll, i kombination med strukturella faktorer som sysselsättningsalternativ och utmaningar med att få formellt stöd. Sammantaget bidrar detta till förståelse för hur personer med intellektuell funktionsnedsättning upplever att bli och vara NEED. Dessa upplevelser påverkas av föreställningar om normalitet och stigmatisering som följer med att ha en intellektuell funktionsnedsättning. Resultatet av att kategoriseras som anorlunda kan leda till social exkludering.

Artikel IV undersökte NEED-gruppens sociala relationer, nätverk, livssituation och upplevelser av tillhörighet. Analyserna resulterade i tre huvudteman: informell tillhörighet, organiserad tillhörighet och strävan efter tillhörighet och självständighet. Deltagarnas sociala nätverk bestod av både informella relationer och organiserade miljöer och aktiviteter, och båda var centrala i erfarenheten av tillhörighet. Informella relationer bestod framförallt av familj (särskilt mödrar), vänner, partners och därutöver vissa sociala relationer online. Organiserade miljöer och aktiviteter fokuserade på relationer med personal i stödsystemet och med andra som deltog i samma aktiviteter som deltagarna. Några av dessa relationer, till exempel med mödrar och personal, hade en praktisk funktion där de hjälpte deltagarna med olika uppgifter. Personernas sociala relationer beskrevs ofta med positiva känslor och var centrala för intervjupersonernas känsla av tillhörighet. Under denna livsfas, som unga vuxna, sökte dessa individer samtidigt efter större självständighet, såsom önsknningar att leva på egen hand, träffa partners och för en del att bilda familj. Denna strävan efter ökad självständighet kunde ibland påverka och hindra upplevelsen av tillhörighet. Till exempel kunde det dubbla behovet av att behöva stöd från familjen och samtidigt vilja leva självständigt eller ha ett visst yrke kollidera.

De samlade empiriska resultaten visar att vara NEED är ett komplext och multidimensionellt fenomen. Både registerstudien och intervjustudien

demonstrerar och bekräftar att faktorer på olika nivåer, miljöer och processer är viktiga för att förstå vad som bidrar till att bli och vara NEED.

Diskussion

I diskussionen lyfts några centrala aspekter som relaterar till att förstå NEED. Tidigare forskning om relaterade grupper, NEET, saknar särskilt fokus på personer med intellektuell funktionsnedsättning. Därför finns det skäl till att använda begreppet NEED, för att mer tydligt identifiera, synliggöra och diskutera villkoren för personer med intellektuell funktionsnedsättning som inte har en sysselsättning i arbete, studier eller daglig verksamhet. Resultaten visar på likheter mellan NEED och NEET (Eurofound, 2012; Olofsson, 2014; Olofsson, 2018; Swedish Government Official Reports, 2013:74) men samtidigt innebär en intellektuell funktionsnedsättning specifika villkor, svårigheter och utmaningar, vilket gör det motiverat att urskilja NEED som en specifik undergrupp till NEET.

En underliggande aspekt som är relevant för denna avhandling handlar om synen på och normer om arbete. Vårt samhälle präglas av ett ideal där arbete är centralt för vuxenlivet och därmed framställs som viktigt och önskvärt med flera fördelar (Jahoda et al., 2009; Lövgren, 2013; Lövgren et al., 2014), och majoriteten av personerna i intervjustudien önskade sig ett arbete. Samtidigt är det viktigt att problematisera vad detta arbetsideal har för konsekvenser. I linje med, Tideman (2000) och Wilson (2003), skapar detta ett ideal som blir svårt för alla att uppnå, och särskilt utmanande för vissa personer med intellektuell funktionsnedsättning. Därför kan det behövas en ökad ansträngning för att stödja personer med intellektuell funktionsnedsättning till betalt arbete. Men också en utökad conceptualisering av arbete som tar hänsyn till olika sorters meningsfulla sysselsättningar, som är värdefulla för individen och samhället.

Med hjälp av Bronfenbrenners systemteori (Bronfenbrenner, 1979,1992, 1994; Bronfenbrenner & Ceci, 1993; Bronfenbrenner & Morris, 1998, 2006) lyfts några centrala faktorer hos individen, miljön och interaktionen dem emellan: tid, barriärer på arbetsmarknaden, stödsystemet (särskilt interaktionen mellan familjer och stödsystemet, samt vikten av samverkan), utbildningsbakgrund i särskolan, begränsade sysselsättningsalternativ och individens situation och villkor. Sammanfattningsvis understryker diskussionen att NEED som fenomen består och skapas av flera olika faktorer vilket gör det komplext. Det handlar inte bara om individens karakteristik, även om den också är viktig, utan det handlar mycket om olika miljöer som i interaktionen med individen ibland hjälper och ibland försvårar när det gäller att hitta en

sysselsättning. Några exempel är brist på tillräckliga förberedelser i gymnasiesärskolan, svårigheter att navigera i stödsystemet och få det stöd man önskar och behöver. Samt negativa attityder och förutfattade meningar som personer med intellektuell funktionsnedsättning möter på arbetsmarknaden och på samhällets olika arenor.

Att vara NEED är inte ett statiskt tillstånd, vilket betyder att det finns en dynamisk aspekt där personer rör sig in och ut mellan sysselsättningar och perioder av NEED. Hur lång tid man är utan sysselsättning varierar. I linje med detta, och gruppens heterogenitet, finns det flera undergrupper av NEED som behöver uppmärksammas i framtida forskning. Exempelvis långvariga/kortvariga NEED:s, de som har kontra inte har formellt stöd, kvinnor som tar hand om barn, individer i partnerskap, män med invandrarbakgrund, individer som bor hemma hos sina föräldrar och yngre/ äldre NEED:s.

För att fördjupa och nyansera perspektiven av vad det innebär att vara NEED används teorier om social exkludering och tillhörighet (t.ex. May, 2013; Taket et al., 2009). Social exkludering och tillhörighet finns på ett kontinuum där individer i målgruppen upplever olika grader av båda beroende på kontext och situation. Å ena sidan är individer i målgruppen socialt exkluderade för att de inte har en sysselsättning och därav inte deltar fullt ut i samhället. De exkluderas också genom att inte få de möjligheter och det stöd som de önskar och behöver. Å andra sidan visar resultaten att personerna samtidigt, i vissa kontexter, upplever en känsla av tillhörighet. Detta förekommer främst i olika relationer de har. Både när det gäller social exkludering och tillhörighet har personer med intellektuell funktionsnedsättning ett visst mått av eget aktivt val. En del individer värjer sig mot kategoriseringen som avvikande genom att välja att inte delta på arenor eller i stödsystem som förknippas med en intellektuell funktionsnedsättning. Inom NEED-gruppen finns två olika exempel på detta. I det första handlar det om individer som erkänner att de har svårigheter, men inte ser sig själva som lika avvikande som andra med funktionsnedsättning. Även om dessa individer förstår att de behöver stöd i vissa sammanhang, anser de att alternativ som daglig verksamhet inte är lämpliga för dem. De vill inte tillhöra denna arena/sammanhang. Att distansera sig från daglig verksamhet kan då leda till att de inte har någon sysselsättning alls. I det andra exemplet finns de personer som inte identifierar sig med att ha en funktionsnedsättning. Dessa individer uttrycker en stark uppfattning om att de var felplacerade i gymnasiesärskolan. De tar avstånd från de resurser och insatser som är avsedda för personer med intellektuell funktionsnedsättning. Genom att värja sig mot kategoriseringen som personer med intellektuell funktionsnedsättning väljer således en del var man vill inkluderas/exkluderas samt tillhöra/inte tillhöra.

Implikationer och framtida forskning

Resultaten i avhandlingen bidrar med kunskaper som har implikationer på fyra områden: individ, skola, stödsystem och arbetsmarknaden. På individnivå handlar det om att förstå målgruppens heterogenitet. Denna heterogenitet innebär att det finns olika situationer och individuella förutsättningar som relaterar till att vara NEED, därmed behöver stödet vara mer individuellt anpassat. Inom skolan behövs det förstärkning av förberedelserna för sysselsättning efter skolan. Det behöver finnas tydliga individuella planer, fler uppföljningar och tidiga insatser för att säkerställa att personer inte står utan sysselsättning. För stödsystemet handlar det om att det behöver finnas fler och bättre möjligheter till sysselsättning, så att daglig verksamhet inte är det enda alternativ som uppmanas. Tillgänglighet och möjligheten att navigera inom stödsystemet behöver också förbättras för att personer ska kunna erhålla det stöd de behöver och har rätt till. Därmed blir bättre samverkan mellan olika aktörer betydelsefullt, men även att se över hur olika insatser fungerar (t.ex. aktivitetsersättning, daglig verksamhet) för att undvika potentiella inläsnings-effekter. På arbetsmarknaden handlar det om att öka möjligheterna och sänka barriärer för att få ett betalt arbete. Ett exempel är att bättre utnyttja de lönesubventioner som finns och påverka arbetsgivares attityder.

Utifrån resultaten, men också utifrån begränsningar i avhandlingens forskningsdesign och metodval, väcks förslag på framtida forskning. Resultaten i avhandlingen indikerar att det finns flera olika undergrupper av NEED (exempelvis långvariga/tillfälliga NEED:s, de som identifierar sig med eller inte identifiera sig med att ha en intellektuell funktionsnedsättning, de personer som är mycket längre ifrån samhällets stödsystem m.m.). Det är därför viktigt att fortsätta studera målgruppen för att urskilja olika villkor och behov hos undergrupperna. De tio personer som var med i intervjustudien är inte nödvändigtvis representativa för alla undergrupper i NEED, det finns troligen personer som är ännu längre ifrån arbetslivet och samhället och därav svårare att nå och framtida forskning bör försöka även inkludera dessa personer i studier. Det ligger också i linje med behovet av att fortsätta forska om individers egna upplevelser, eftersom det är viktigt att personerna själva får komma till tals och dela med sig av sina erfarenheter.

Fokus i denna avhandling har varit att studera målgruppen och deras erfarenheter, men det hade också varit intressant att studera detta från andra perspektiv, särskilt kanske stödsystemens. Genom att undersöka erfarenheter hos de handläggare och praktiker i stödsystemets olika delar som möter gruppen finns det möjlighet att få mer kompletterande underlag för vad som behövs för att förhindra att fler blir NEED och stödja de som är NEED till meningsfull sysselsättning. Ytterligare ett förslag på framtida forskning handlar om

att tydligare fokusera på tidsaspekten i forskningsdesignen. Hur ändras NEED-status över tid och hur rör sig individer mellan olika sysselsättningar? I denna avhandling har registerdatan varit baserad på dem som gick ut gymnasiesärskolan mellan 2001 och 2011. Det är angeläget att undersöka hur sysselsättningsmönster och NEED-gruppen har förändrats över tid för dem men också för senare årskullar och i eventuella förändringar i samband med reformeringen 2013 av gymnasiesärskolan. En uppdatering av HURPID-registret med senare årgångar sker nu på Högskolan i Halmstad för att möjliggöra en del av detta.

Avslutning

En slutsats i denna avhandling är att situationen för unga vuxna med intellektuell funktionsnedsättning som inte har en känd sysselsättning är ett komplext fenomen. För att förstå detta mer ingående måste många olika faktorer på olika nivåer, interaktioner och erfarenheter beaktas. Det finns ett stort behov av att utveckla resurser och stöd till NEED-gruppen utifrån en helhetssyn – både på individ, grupp, organisations- och samhällsnivå – för att främja ökat deltagande och förhindra att individer faller mellan stolarna. Det har funnits en allmän uppfattning om och tro på att samhället tar hand om och säkerställer sysselsättning för personer med intellektuell funktionsnedsättning efter gymnasiesärskolan. Avhandlingen illustrerar dock att var fjärde saknar sysselsättning och adekvat stöd. Unga vuxna med intellektuell funktionsnedsättning som inte har en känd sysselsättning kan betraktas som den grupp som har den mest ogynnsamma situationen. De har kategoriserats att ha en intellektuell funktionsnedsättning och därmed fått sin utbildning i gymnasiesärskolan. När de avslutar skolan har de uppenbara svårigheter att hitta en meningsfull sysselsättning och får inte adekvat stöd av samhället, istället faller de mellan stolarna.

Att en av fyra unga vuxna med bakgrund i gymnasiesärskolan saknar sysselsättning efter gymnasiesärskolan visar på samhällets brister. Möten mellan individen och samhällets system medför utmaningar och barriärer som ibland hindrar snarare än hjälper. Samhället har särskilt ansvar att stötta och försörja de mest utsatta individerna, inkluderat människor med intellektuell funktionsnedsättning. Bortsett från att ha en intellektuell funktionsnedsättning som kan medföra utmaningar, leder brister på handling och stöd från samhället till ytterligare svårigheter för individen. Detta illustrerar behovet av fortsatt forskningsbaserad kunskap såväl som politiska initiativ och praktiska åtgärder för att bättre stödja och förhindra att framtida unga vuxna att bli NEED.

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Appendix 1: Information letter to gatekeepers

Till verksamheter som möter unga vuxna som saknar sysselsättning

Information om intervjustudie i forskningsprojektet ” Unga vuxna med intellektuell funktionsnedsättning som varken arbetar, studerar eller har daglig verksamhet”.

Bakgrund och syfte

Det finns begränsad kunskap om unga vuxna med intellektuell funktionsnedsättning (utvecklingsstörning) och deras sysselsättning efter gymnasiesärskolan. Aktuell forskning har visat att en oväntat stor grupp, 24 %, (2955 personer av totalt 12269) av f.d. elever inte har någon känd sysselsättning, d.v.s. inte finns i arbete, studier eller i daglig verksamhet. Detta väcker frågor om vad dessa personer gör och hur deras situation ser ut. Ett forskningsprojekt vid Högskolan ska de närmaste åren studera denna grupps upplevelser och erfarenheter av att vara utan sysselsättning (inte i arbete, studier eller daglig verksamhet).

Information om studien

I ditt arbete möter du troligen unga vuxna med intellektuell funktionsnedsättning som saknar sysselsättning och har kännedom om och kontakt med några av dessa individer. Vi vill be dig hjälpa oss med att få kontakt med några av dessa unga vuxna. Syftet är att genom att intervjua ett antal unga vuxna med intellektuell funktionsnedsättning få kunskaper och en djupare förståelse för individernas egna upplevelser och erfarenheter när det gäller deras sysselsättningssituation, livschanser och livsvillkor.

Om du känner till personer som har gått i gymnasiesärskolan, i åldern 20-30 år, och som i dagsläget inte arbetar, studerar eller har daglig verksamhet och som du tror skulle vara intresserad av att bli intervjuade vill vi be dig om följande: fråga personen/erna om de skulle vara intresserade av att bli intervjuade om sina erfarenheter av forskare vid två tillfällen. Betona att deltagande är frivilligt. Om intresse finns be om att få vidarebefordra namn och kontaktuppgifter till forskarna och informera om att forskaren kommer att ta kontakt och berätta mer om intervjuerna innan de måste bestämma sig om medverkan. Skicka sedan deras kontaktuppgifter till Renee Luthra (renee.luthra@hh.se).

Om personerna vill delta kommer vi att kontakta dom för att ge mer information och om de därefter vill bestämma vi tid för att träffas för att få skriftligt samtycke och genomföra intervjuerna.

Ansvarig

Forskningshuvudman för projektet är Högskolan i Halmstad och vetenskapligt ansvarig är Docent Sara Högdin. Ansvarig för genomförandet av intervjuerna är doktorand Renee Luthra.

För ytterligare information

Om du vill ha mer information om studien är du välkommen att kontakta:

Renee Luthra, doktorand i Hälsa & livsstil, inriktning handikappvetenskap
Telefon: 035-167672 E-post: renee.luthra@hh.se

Sara Högdin, docent i socialt arbete
Telefon: 035-167182 E-post: sara.hogdin@hh.se

Appendix 2: Information letter to participants

Information om forskningsprojektet: *Sysselsättning och vardagsliv efter gymnasiesärskolan*

Hej!

Jag heter Renee Luthra och är forskare på Högskolan i Halmstad. Under de närmaste åren ska jag ta reda på mer om vad personer som gått gymnasiesärskolan gör efter att de slutat skolan. Jag vill särskilt veta mer om deras sysselsättningsituation och vardagsliv.

Jag vill fråga dig om du vill vara med i den här forskningsstudien och berätta om dina erfarenheter. Jag skulle vilja träffa dig och prata om hur din vardag ser ut. Jag vill också fråga dig om hur du tycker att du får stöd av olika myndigheter och av din familj och dina vänner.

Om du vill vara med i forskningsstudien så hörs vi av och bestämmer var och när vi kan träffas. Jag kommer sedan till dig och intervjuar dig. Sen bestämmer vi tid för en träff till. Om det är OK för dig så vill jag gärna spela in vårt samtal under intervjun.

Att vara med i en forskningsstudie är frivilligt och du har rätt att säga nej. Även om du bestämmer dig för att du vill vara med och säger ja så kan du säga nej senare om du ändrar dig. Du behöver inte berätta varför du inte vill vara med.

Det som jag får veta när jag har intervjuat dig kommer jag att skriva om på engelska i artiklar. Jag kommer att veta vem som har sagt vad, men när jag skriver kommer jag att ändra ditt namn så att de som läser inte kan veta vem du är.

Det kommer ta ungefär två år tills studien är klar och när den är det så kommer du som har varit med om du vill få reda på resultaten.

Om du vill fråga om något innan du bestämmer dig för om du vill bli intervjuad eller inte får du gärna ringa eller skicka e-post till mig eller projektledaren för studien, Docent Sara Högdin.

Om du kan tänka dig att bli intervjuad så ring eller skicka ett mail till Renee (telefonnummer och mailadress ser du här nedanför)

Med Vänliga Hälsningar

Renee Luthra

Telefon: 035-167672

E-post: renee.luthra@hh.se

Sara Högdin

Telefon: 035-167182

E-post: sara.hogdin@hh.se

Appendix 3: Consent forms

Samtycke till deltagande i forskningsprojektet: *Sysselsättning och vardagsliv efter gymnasiesärskolan.*

Jag har fått muntligt och skriftlig information om forskningsstudien: *Sysselsättning och vardagsliv efter gymnasiesärskolan.* Jag har fått tillfälle att ställa frågor och fått svar så att jag förstår vad det innebär att medverka i studien.

Jag vet om att deltagandet i studien är helt frivilligt och att jag när som helst och utan att behöva förklara kan avbryta deltagandet.

Sätt kryss i rutan:

Jag säger JA till deltagande i forskningsstudien

Ort och datum

Deltagarens namnunderskrift

Namnförtydligande

Ort och datum

Forskarens namnunderskrift

Namnförtydligande

Appendix 4: Interview guide

- Jag är intresserad av din berättelse eftersom du har gått i gymnasiesärskolan och jag vill veta vad som har hänt efter det; inte här för att bedöma dig
- Alla svar är bra, finns inga rätt eller fel
- Jag kommer ställa följdfrågor så att vi är överens om vad du menar
- Säg till om du vill ta en rast
- Jag kommer spela in intervjun och sedan skriva ner vad du har sagt
- Träffas nu, och (kanske) träffas en gång till om det behövs
- Uppmuntra att de ska ge exempel

Berätta om samtycke/anonymitet- hur resultaten ska användas, anonymitet med namn, använda bandspelare, 2 kopior att skriva på (en till intervjupersonen, en till mig).

Berätta om Temakarta- om vilka ämnen jag tänker ta upp idag

Frågor?

Starta inspelningen

Bakgrund

Ålder

Kommun/skolkommun

Vilket program de gick på gymnasiesärskolan

Tema 1: En vanlig dag

- Hur ser en vanlig dag ut i ditt liv?
- Vad gör du? (när går du upp? Vad gör du sen? vad gör du efter det? Hur gör du med mat? vilka träffar du?)
- Nu har du berättat om din dag, hur nöjd är du med vad du gör under en dag?
- Finns det saker du vill göra under din dag men som du inte gör? Kan du ge exempel?

Tema 2: Tillhörighet och sociala relationer

- Du berättade om en vanlig dag innan, vilka personer träffar du vanligtvis då?

Familj

- Vilka personer finns i din familj (föräldrar, syskon, släkt)?
- Gör du saker ihop med din familj? Vilka personer? Vad gör ni när ni träffas?
- Hur känns det när du är med din familj? Vad är det som gör att du känner så?
- När du är med din familj finns det situationer när du mår riktigt bra? Vad gör du då?
- Vilka i din familj känner du dig trygg med?
- Är du nöjd med dina relationer med din familj idag? Skulle du vilja att det såg ut på ett annat sätt?
- (Vad betyder ordet familj för dig?)

Vänner

- Har du andra personer förutom din familj, som du träffar? Vänner kanske? Om ja, vilka är de, hur träffades ni och vad gör ni när ni träffas? Om nej, är det något som du vill ha?
- Hur känns det när du är med dessa personer? Vad är det som gör att du känner så?
- När du är med dessa personer finns det situationer när du mår riktigt bra? Vad gör du då?
- Vilka av personerna känner du dig trygg med?
- Är du nöjd med dessa relationer idag? Skulle du vilja att det såg ut på ett annat sätt?
- (Vad betyder ordet vänner för dig?)

Partner/barn

- Har du en flickvän/pojkvän/man/fru? Om ja, hur träffades ni? Om nej, är det något som du vill ha?
- Har du barn? Om ja, kan du berätta lite mer om dem? Om nej, är det något som du vill ha?
- Vad gör ni tillsammans med er partner/barn?
- Hur känns det när du är med din partner/barn? Vad är det som gör att du känner så?
- När du är med dessa personer finns det situationer när du mår riktigt bra? Vad gör du då?
- Är du nöjd med dessa relationer idag? Skulle du vilja att det såg ut på ett annat sätt?
- (Vad betyder det att ha en partner? vad betyder det att ha barn?)

Övriga frågor om tillhörighet

- Finns det någon annan situation eller med andra personer (tex förening, husdjur, platser mm) som du mår bra av att vara i/träffa? Vad eller vilka då? Vad gör ni då? (kopplat till Mays teori om tillhörighet) Vad är det som gör att du känner så?
- Använder du sociala medier (tex facebook)? Har du vänner eller kontakter på nätet?

Val och motstånd av tillhörighet

- Var/hur bor du?
 - Om du bor själv, hur länge har du gjort det och har du valt detta själv? varför?
 - Om du bor hemma, har du valt detta själv? skulle du vilja bo på ett annat sätt? Varför?
- Hur har du träffat dina vänner? har ni saker gemensamt?
- Vad gör dina vänner på dagarna? Vad gör din partner på dagarna?

-Bland dina vänner eller partner, är det andra personer som är i samma situation som du? T.ex. har gått i gymnasiesärskolan? Vad gör de på dagarna?

-Om de inte har vänner eller partner, hur känns det? Känner du dig ensam då?

Tema 3: Processen från gymnasiesärskolan

Tid i skolan

- Hur upplevde du din tid i skolan? Kan du ge exempel på vad som var bra och dåligt?
- Fanns det särskilda personer i skolan som var viktiga för dig?
- När du slutade skolan, vilka planer fanns då? Vad ville du göra då? Exempel?
- Vem bestämde dessa planer? Fanns det andra personer som hjälpte till?

Arbete

- När du slutade skolan ville du börja arbeta? Varför ville du det eller inte?
- Sen du slutade skolan har du provat på ett arbete? Exempel? Om nej, varför inte?

Daglig verksamhet

- När du slutade skolan hade du tankar på att börja på daglig verksamhet efteråt? Varför ja eller nej?
- Sen du slutade skolan har du provat på daglig verksamhet? Exempel? Om nej, varför inte?

Studier

- När du slutade skolan ville du studera vidare? Varför ja eller nej?
- Sen du slutade skolan har du provat på studier? Exempel? Om nej, varför inte?

Stöd och myndigheter

- Vad fick du för stöd efter gymnasiesärskolan? Vilka personer gav dig stöd?
- Sen du slutade skolan har du haft kontakt med myndigheter eller organisationer?
- exempelvis arbetsförmedlingen, försäkringskassan eller liknande? och i så fall på vilket sätt?
-vilka personer på dessa ställen har varit viktiga för dig?
- Hur upplevde du denna kontakt och stödet du fick?
- Finns det något som du har saknat i stöd?

Exkludering och delaktighet

- Har du velat ha stöd eller hjälp efter du slutade skolan men inte fått det?
- Har du sökt till daglig verksamhet, studier eller arbete men inte fått det?
- Om du har fått möjlighet till daglig verksamhet, studier eller arbete, varför gör du inte det idag?

- Upplever du att du har blivit nekat arbete, studier eller daglig verksamhet?
 - Om ja, vad tror du detta beror på? kan du ge exempel eller förklara mer?
- Vad är det bästa i ditt liv? Finns det saker som du verkligen vill göra? Om ja, är det något som du kan göra ?

Avslutande frågor

- Vad skulle du vilja göra i framtiden? Vad har du för drömmar? Vad skulle du behöva för att nå dem?
- Från det du har berättat finns det något du vill tillägga? Något som varit oklart? Undrar du något om studien?

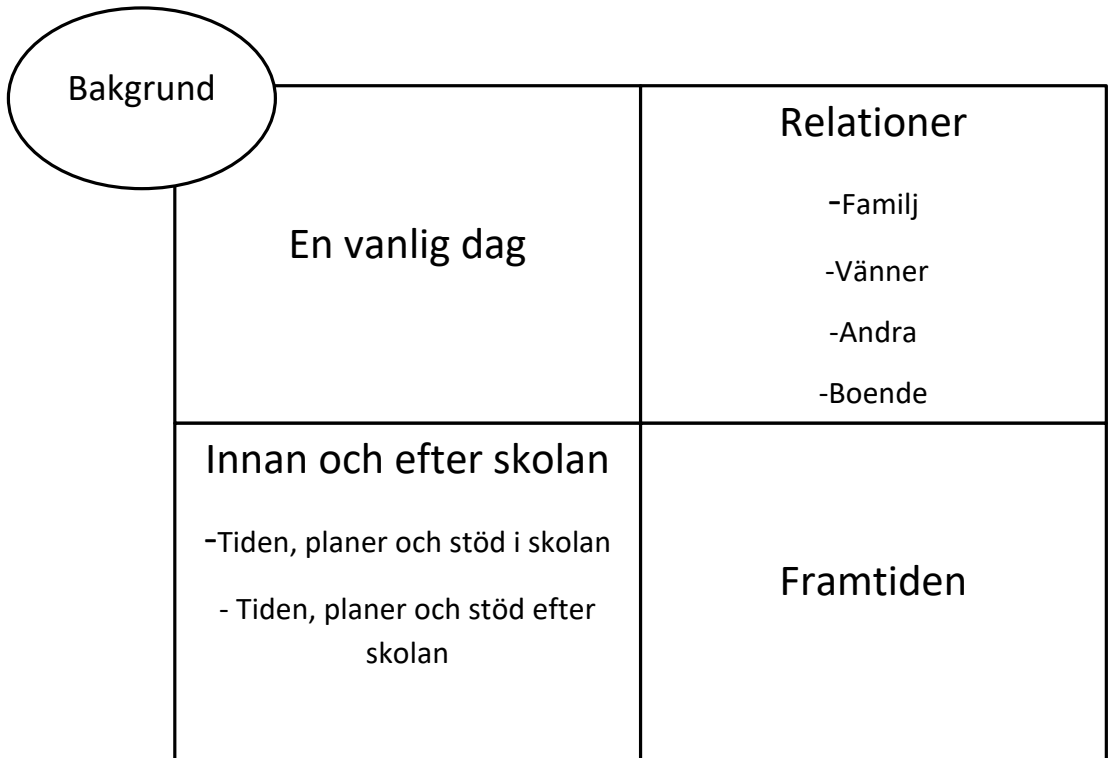
Avsluta inspelningen

Hur känns det efteråt? Frågor?

Om vi ska träffas igen, kan bestämma dag/tid. Alternativt att vi håller det öppet om det skulle behövas ytterligare frågor.

Tack!

Appendix 5: Theme map





Renee Luthra

Renee Luthra has a BA and MSc in psychology. This is her doctoral thesis in the field of health and lifestyle with a specialization in disability studies conducted at Halmstad University.

The thesis focuses on young adults with intellectual disability who after secondary school are Not involved in Employment, Education or Daily activity (NEED). The thesis consists of a register study and an interview study. Using national registers, the register study analyzes the target group's characteristics, situations and various factors associated with being NEED. The interview study, consisting of interviews with ten participants from the target group, analyzes first-hand experiences of becoming and being NEED.

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