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Mind the gap. Transition to adulthood – youths' with disabilities and their caregivers' perspectives.

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2016

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Mind the gap

Transition to adulthood – youths' with disabilities

and their caregivers' perspectives

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Contents

Abstract

Transition to adulthood, referring to the process of moving from childhood to adulthood, can be a complex period for youths with disabilities who might need special support transitioning into an independent life as adults. Caregivers are significant persons for the youths, which is why their own health and wellbeing is important. Therefore the overall aim of this thesis was to gain a deeper understanding of health and wellbeing, challenges, preferences and needs during the transition from childhood to adulthood in youths with disabilities and their caregivers. The thesis is comprised of two studies, study A focusing on the perspectives of youths with CP (Paper I) and of their caregivers (Paper II) and Study B focusing on the perspectives of immigrant youths with disabilities and caregivers from Middle Eastern countries residing in Sweden (Paper III and IV).

Study A had a qualitative approach and involved focus groups and individual interviews with 12 male and female youths, 17-18 years of age, with CP and various physical and cognitive levels of disabilities (Paper I), as well as 15 mothers and fathers (Paper II). The interviews were analysed using qualitative content analysis. In Study B, a combination of qualitative and quantitative methods was used. Based on structured and semi-structured questionnaires in combination with open ended questions interviews were conducted in Swedish or Arabic with 17 male and female youths, 13-24 years of age with various disabilities and 10 mothers, five fathers and one sibling. The families were all immigrants with Middle Eastern origin and most of them had lived in Sweden for more than five years. The questionnaires Family Need Survey (FNS), Rotterdam Transition Profile (RTP) and Canadian Occupational Performance Measure (COPM) were all translated and adapted to Swedish except for COPM where there already was a Swedish version. The results were analysed using mainly descriptive statistics and based on the framework of International Classification of Functioning, Disability and Health – Children & Youth Version (ICF-CY).

The findings from study A showed that the experiences of youths and caregivers mostly concerned mental health and wellbeing described as both positive and negative experiences. Their family life was experienced as important, secure and convenient, which made the youths feel safe and gave parents a sense of meaningfulness. Youths described participation, socialising and love as being important, but also challenging and worrying. Caregivers experienced sorrow and anger and together with demanding logistics, planning and worrying, their health was affected negatively during their children's transition to adulthood.

The findings from study B showed that youths were dependent on their caregivers for transportations, participating in leisure activities and socialising with friends. They were also

dependent on their caregivers for the demanding of support and health care. The youths had few or no experiences of intimate relationships but felt that they were expected to get married in the future which worried them and their caregivers. Caregivers were uncomfortable with using the term intellectual disability. Caregivers needed help to understand their child's condition and to explain the child's condition to their wives/husbands. A significant difference was found in what problems youths identified with and what their caregivers identified as their youth's problems. The youths experienced problems with handling finances, transportations and seeking employment or daily activities whilst their caregiver thought their youth's primary problems involved self-care.

The overall finding showed that to strengthen health and wellbeing in youths with disabilities and their caregivers and to meet challenges, preferences and needs during transition from childhood to adulthood both youths and caregivers need information and support. Both youths and caregivers expressed a desire for individualised support given by one person who could facilitate the transition period by coordinating information and give support based on individual preferences and needs. During the recruiting process in both studies, great challenges were experienced in finding participants. Collaboration with professionals in schools and leisure activities was found to be the most effective way to get in contact with immigrant youths and thereby also their caregivers.

The findings from this thesis may enable professionals to develop and improve best practice guidelines for support, habilitation and health care in youths' transition. To facilitate for the youth to transfer from services with a family-centred approach to person-centred adult services, their autonomy must be strengthened by involving them in their own transition planning early on. Immigrant youths need special information and support about love and the freedom of choice to get married. The COPM and RTP are suggested to be used as tools in person-centred transition planning given they are used customized and applied with cultural sensibility. To enable those with communication limitations to give their independent voice the use of communication tools is necessary. Furthermore, the transition to person-centred adult support and health care should be flexible and not determined by biological age. However, youths need support by their caregivers who in turn might both need, and want, support for themselves and occasionally hands-on support. Guidance by a specially designated navigator aimed to support the whole family would be an option to meet individual needs. The information and support should be culturally sensitive with respect to various linguistic and cultural experiences. To close the gaps between systems of care collaboration was discussed to be necessary to facilitate the transition between support and health care for children and youths as well as services for adults. The use of ICF-CY as a framework for understanding needs and the standardised terminology in ICF-CY in documentation can facilitate this collaboration.

Abbreviations

AAC	Alternative and Augmentative Communication
AACC	American Association on Intellectual and Developmental Disabilities
COPM	Canadian Occupational Performance Measure
CP	Cerebral Palsy
CRC	Convention on the Right of the Child
FCS	Family-Centred Service
FNS	Family Need Survey
GMFCS-E&R	Gross Motor Function Classification System-Expanded & Revised
HSL	Hälso- och sjukvårdslagen (The Health and Medical Services Act)
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health-Children and Youth
ID	Intellectual Disability
LSS	Lag om Stöd och Service för vissa funktionshindrade (The Swedish Act concerning Support and Service for Persons with Certain Functional Impairments)
PD	Physical Disability
PCS	Person-Centred Service
RTP	The Rotterdam Transition Profile
SoL	Socialtjänstlagen (The Social Services Act)
UN	United Nations
WHO	World Health Organization

Original papers

This doctoral thesis is based on the following papers referred to in the text by their Roman numerals I-IV:

I   Björquist, E., Nordmark, E. & Hallström, I. Living in transition – experiences of health and well-being and the needs of adolescents with cerebral palsy. Child Care Health Dev, 41, no. 2:258-65, 2015.

II   Björquist, E., Nordmark, E., & Hallström, I. Parents' Experiences of Health and Needs When Supporting Their Adolescents With Cerebral Palsy During Transition to Adulthood. Physical & Occupational Therapy in Pediatrics. Early Online:1-13, 2015

III   Björquist, E., Nordmark, E., Almasri, N. & Hallström, I. Immigrant youths with disabilities and caregivers from the Middle-East – Challenges and needs during transition to adulthood. Submitted.

IV   Björquist, E., Nordmark, E., Almasri, N. & Hallström, I. Identified problems during transition of immigrant youth with disabilities from Middle-Eastern countries – youths' and caregivers' priorities. In manuscript.

Paper I and II have been reprinted with the permission of the journals.

Thesis at a glance

Study	Aim	Study population	Methods	Paper	Findings
A	To gain a deeper understanding of how adolescents with CP experience their own health, well-being and needs of support during their transition to adulthood	N=12 youths with CP aged 17-18 years	Focus group and individual interviews Content analysis	I	The youths needed support in order to feel a sense of participation in socialization. Individual support given by a navigator and moving from home step by step may prepare youths with disabilities for transition to adult living. The transition to adult support and health care should be flexible and not be fixed to biological age.
	To gain a deeper understanding of how parents of adolescents with cerebral palsy (CP) experience their own health and wellbeing and their needs for support during the adolescent's transition to adulthood	N=15 caregivers of youths with CP aged 17-18 years	Focus group and individual interviews Content analysis	II	Caregivers' experienced old sorrow, stress and worry in daily life and needed individualized support, preferably by a guide who can provide both guidance and hands-on support to the whole family.
B	To describe challenges and needs of immigrant youths and their caregivers from Arabic speaking countries during the youths' transition to adulthood	N=17 youths with disabilities N=16 caregivers Youths and caregivers were immigrants from Middle Eastern countries	Structured interviews based on questionnaires; RTP, FNS and open-ended questions Descriptive statistics	III	Youths strived to participate in the Swedish society and perceived expectations for future marriage. They wanted to be less dependent on their parents, which stresses the importance of strengthening youth autonomy. Caregivers were unfamiliar with the term intellectual disability, and specific information was

		Content analysis		demanded for immigrant families regarding disabilities and support available in transition to adulthood.
To describe self-identified problems in immigrant youths with disabilities from Middle Eastern countries in Sweden during their transition to adulthood and the problems as identified by caregivers	N=17 youths with disabilities N=16 caregivers Youths and caregivers were immigrants from Middle Eastern countries	Semi-structured interviews based on COPM Coding and categorizing using ICF-CY	IV	Differences were found between the youths' and caregivers' views of what is most important in transition. To optimize planning for the transition for immigrant youths with disabilities is to enable them to identify their own preferences and needs. This should be done in collaboration with caregivers with respect to cultural norms and traditions in terms of collectivistic care.

Introduction

Medical advances have led to most children with disabilities in developed countries living into adulthood and having regular life expectancy, with exception of those with certain, multiple and/or severe conditions (Coppus, 2013; Westbom, Bergstrand, Wagner, & Nordmark, 2011). The transition to adulthood can be a turbulent time for youths in general, however for youths with disabilities the transition to adulthood is a complex and multifaceted process, which can affect their health and wellbeing (Stewart et al., 2010; Young, 2007). Caring and parenting for youths with disabilities in transition require a lot of energy from the caregivers, which can affect their own health and wellbeing (Davis et al., 2010; Kingsnorth, Gall, Beayni, & Rigby, 2011). Youths with disabilities across the lifespan often need habilation and support to manage this transition period. In Sweden, youths with disabilities and their families are entitled to treatment, counselling, technology assistance and support from the Habilitation Services including special support in transition to adulthood (Föreningen Sveriges Habiliteringschefer, 2007; 2015; Karlsson, von Schantz, Ingbrant, & Rudervall, 2011). They can also be entitled to special support with daily living in accordance with Swedish legislation (Proposition 1992/93:159). Knowledge of youths' and their caregivers' perspectives on needs during the transition is therefore of great importance in order to develop the best possible habilitation and support and to design facilitating transition programmes (Stewart et al., 2009; Young, 2007). Sweden has a multicultural population with 16% of the population having been born abroad (Swedish Migration Agency, 2016). Immigrants from Arabic speaking background have been part of a language minority group in Sweden but have increased during recent years. Approximately 150 000 people – with a large number coming from Syria and Iraq – were registered as asylum seekers in November 2015 (Swedish Migration Agency, 2016). However, evidence-based knowledge of needs and challenges for youths with disabilities and their caregivers in this group is generally limited. Overlooking cultural aspects may cause difficulties in the transition planning for youths (Kim & Morningstar 2005). Therefore, this thesis concerns the transition to adulthood for youths with disabilities living in Sweden, which also includes the transition to adult-oriented support and health care. It highlights the perspectives amongst youths and their caregivers' health and wellbeing, as well as the challenges and needs during the youths' transition to adulthood.

Background

Transition to adulthood refers to the life course transition from child- to adult living, such as moving from home and finishing school (Priestley, 2003). For youths with disabilities in need of support and habilitation in various life domains, transition is further defined as the movement from pediatric- to adult-oriented support and healthcare (Blum et al., 1993). Therefore, in this thesis, transition to adulthood involves both the life course transition and the transition between systems of support and healthcare for children and adults with disabilities. This section briefly describes the transition from childhood to adulthood in general and, specifically, the transition for youths with disabilities and their caregivers, focusing on youths' and caregivers' health, wellbeing and needs. Generally, the biological, adoptive or foster parents are responsible for a child's care. However, the term "caregiver" is commonly used, as it further comprises other significant adults who might be responsible for the child as they grow up. Like many other countries in the modern western world, Sweden has a multicultural population in which immigrants make up a portion. The term culture has been described with several different definitions. The Swedish psychologist al-Baldawi (2014), with long experience of encounters with people with diverse cultural and traditional background, defines culture as a lifelong ongoing process of learning. This involves different systems of knowledge, ideas, traditions, norms, values, and religious beliefs. Multiculturalism too, has been defined in several ways, in this thesis it deals with people with diverse cultural and traditional background living in the same society. The Oxford English Dictionary (Stevenson, 2010) defines "immigrant" as "a person who comes to live permanently in a foreign country". This thesis uses the term to refer to an individual or a family who have moved from their country of origin to Sweden for temporary or permanent residence.

To enable the understanding of the context for youths with disabilities and their caregivers living in Sweden, a presentation of the currently available habilitation and support of relevance to the transition period is given. Furthermore, examples of existing transition support used in the transition planning are described. The background includes further definitions of terms used in this thesis.

Transition to adulthood

All transitions in life are developmental stages involving different milestones for the individual (Priestley, 2003). The life-course transition to adulthood refers to the movement from childhood to young adulthood that all youths go through. Age-related stages in a young persons' development during the transition can be understood from several different perspectives e.g. cognitive development and development of identity.

A young individual's cognitive development during adolescence can be understood by using Piaget's theory involving developmental age-related stages based on how the individual thinks, receives, processes and uses information. From approximately age 11 up until adulthood the 'formal operations stage' occur, involving abstract thinking and hypothetical reasoning (Bee & Boyd, 2007). This means that during these years, with respect to individual differences, experiences and environmental demands, the youths become able to make plans for their everyday lives and, when they reach late adolescence, also think about their future. However, not all individuals in all cultures reach this stage; formal operational thinking is more often found among youngsters in industrialised cultures (Arnett, 2004; Bee & Boyd, 2007).

Adolescence comes from the Latin for "growing up". During this period young people also try to find their identity (Erikson, 1968; Marcia, 1966). Bee & Boyd (2007) means that Marcia (1966) focused specifically on adolescent psychological development and identity development during the lifespan, and argues for two important stages during development of identity: crisis and commitment. The former stage involves a period of gradually trying out and making new decisions when old values and choices are to be re-examined. During a period of identity and role confusion the youth develop ideas about who they are and want to become. The latter stage involves a commitment to particular ideologies or roles which is an on-going process throughout life (Bee & Boyd, 2007).

Striving for independence begins early in childhood but it is more pronounced during adolescence. It is also during the adolescence period that puberty begins, involving the development of sexuality, which means a desire to experience love- and sexual relationships (Bee & Boyd, 2007). The development of sexuality is connected to the development of self-confidence. Socialising with peer also plays an important role both in the development of identity, and of self-confidence because friends provide emotional support and confirmations of values (Hwang & Nilsson, 2011).

There is no clear definition of adulthood, but in accordance with the United Nations (UN) Convention on the Rights of the Child (1990) a child is a person under the age of 18 years. In Sweden and many other countries people are adults by law at the age of 18. However, the American psychologist Arnett (2000) coined a new concept called 'emerging adulthood' as the stage after adolescence. He argues that, for young

people in the Western world, it is a period between late adolescence and adulthood, starting after graduation from upper secondary school and lasting until between the ages of 18 and 25. During this period the emerging adults explore the world and examine relationships, education, occupations and places of residence as part of developing who they want to be and become before settling into long-term adult roles. Due to diverse cultural influences, not all emerging adults are able to use this period for independent exploration (Arnett, 2004).

The United Nations (UN) (2006) define adolescents and emerging adults from age 15 to 24 as "youth" and so this term is used in this thesis concerning the movement from childhood to young adulthood/emerging adulthood for youths with disabilities. This period in many ways, involves a process similar to that for youths in general, but conditions and circumstances are individual and the process of transition may last longer and be affected by disability (Beresford, 2004; Gorter & Roebroeck, 2013; May, 2000; Sandström, 2009; Stewart et al. 2010; Young, 2007).

Youths with disabilities

This thesis follows the WHO's definition of disability; hence "disability" is defined as "an umbrella term for impairments, activity limitations and participation restrictions" (WHO, 2015 p. 1). In comparison to WHO's definition, the *International Classification of Functioning, Disability and Health* (ICF) uses neutral terms such as "body functions and structure", "activity" and "participation" (WHO, 2001; 2007) ICF is further described under the paragraph "Conceptual frameworks". Disabilities which often involve limitations in activity, and participation restrictions in daily life during transition to adulthood are for example cerebral palsy (CP) and intellectual disability (ID).

Cerebral Palsy

Among physical disabilities (PD), cerebral palsy (CP) is one of the most common, affecting approximately 2-2.5/1000 children (Rosenbaum et al., 2007; Westbom et al., 2011). Rosenbaum et al. (2007 p. 10) describe CP as "a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain". The degrees of motor function vary greatly among children and youths with CP (Palisano, Rosenbaum, Bartlett, & Livingston, 2007). Clinical prognoses show in a literature review that children with CP in addition to PD often have associated impairments such as intellectual disabilities (ID), communication difficulties, perception and sensation disturbance and epilepsy (Palisano et al.,

2007). One in two children with CP is estimated to have an ID (Novak, Hines, Goldsmith, & Barclay, 2012).

For people with CP, the degrees of motor function are classified using the Gross Motor Function Classification System (GMFCS) which is a five-level system for determining the level that best represents the current abilities and limitations in the gross motor function of a person with CP. It is useful for communicating within health care, clinical decision-making, databases and research. A classification may also be useful in the description of a child or a population when evaluating changes (Rosenbaum & Rosenbloom, 2012). The classification system has been expanded to cover children and youths aged 12-18 years and revised in the sense that the classification is based on the typical activities of this age that are performed in the familiar environments of the home, school and community (GMFCS-E&R). Youths with gross motor performance classified in GMFCS level I move freely in almost all situations. Youths with gross motor performance classified with GMFCS level II walk, run and climb in most settings but may need or choose to use mobility equipment for safety and wheeled mobility for travelling long distances. Youths with gross motor performance classified with GMFCS level III can walk using assistance and self-propelled manual or powered wheelchairs, and those with gross motor performance classified with level IV are capable to walk short distances with assistance but use wheeled mobility in most settings and need physical assistance for transfers. Youths with gross motor performance classified with level V require extensive support in all situations (Palisano et al., 2007).

Intellectual disability

Historically and globally, intellectual disability (ID) has been termed in several different ways. WHO's International Classification of Diseases (ICD-10) uses the term "mental retardation" divided into mild, moderate, severe and profound mental retardation. Youths with mild mental retardation often have learning difficulties in schools but as adults many of them are able to work and have an ordinary social life. Those with moderate mental retardation are generally able to develop some degree of independence concerning self-care and communication and as adults they will need varying degrees of support in living and work. People with severe or profound mental retardation are likely to need extensive support during the whole lifespan (WHO, 2016).

In this thesis, the term "intellectual disability" is used with similar definitions of mild, moderate and severe ID as in the ICD-10. According to the American Association on Intellectual and Developmental Disabilities (AAIDD) (2015), the term intellectual function refers to general mental capacity such as learning, solving problems and reasoning. The age of onset of the diagnosis is during the developmental period before age 18. However, the AAIDD points out that additional factors must be taken

into account and professionals must consider linguistic diversity as well as cultural differences in how people for example communicate and behave. Because neither the term mental retardation nor ID is universal, the prevalence of ID worldwide is difficult to estimate. However, in developing countries the prevalence is estimated to be higher than in the Western world due to insufficient pre- and perinatal care (Gillberg & Soderstrom, 2003). In the Nordic countries the prevalence of mild ID is estimated at 0.4-1.3/1000 children and moderate and severe ID is estimated to 3/1000 children (Stromme & Valvatne, 1998). In Sweden, pupils in special education due to ID were estimated to comprise 1.5% of the pupils in Swedish schools the year 2005-2006 (Municipal Special Schools: an increase in pupil variation and numbers admitted to the special school, 2006).

Transition for youths with disabilities

The transition to adulthood for youths with disabilities is a multidimensional process, which varies depending on the degree of disability (Gorter and Roebroeck, 2013; Stewart et al., 2010; 2014; Young, 2007). The transition includes things like moving from the parental household to their own home, entering the labour market, leisure activities, livelihood, social relations and sexuality (Donkervoort et al., 2009; Stewart et al., 2010). However, things do not always follow a logical progression; young people might have an income of their own and, for example, manage to arrange transport or to go to a party or the cinema but still stay with their caregivers since they need support in daily living (Donkervoort et al., 2009).

For youths with ID in Sweden, the transition most often includes a transition from special schools to post-secondary special schools or disability day programmes called "daily activities". Furthermore, the transition often involves moving into special accommodation for persons with disabilities known as "housing with special services". This is in accordance with Swedish disability legislation, for example, The Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) (Proposition 1993:387). As youths with disabilities often need support as well as special treatment and habilitation, the transition also involves transitions from child-oriented to adult-oriented support and health care systems, normally organised according to the individual's biological age (Blum et al., 1993; Gorter, Stewart, & Woodbury-Smith, 2011; Young, 2007). These transitions are experienced as challenging and youths and caregivers have described them as a feeling of "falling off a cliff" (Stewart, Law, Rosenbaum, & Willms, 2001 p. 12).

Immigrant youths with disabilities living in Sweden have the same rights to support and habilitation as their peers born in Sweden. Whether or not they actually receive access to services in their host country is a question raised as one literature review showed that evidence-based knowledge is limited concerning if -and how -they obtain service from a multi-cultural perspective (Björngren Cuadra, 2012).

Caregivers' perspectives during their youths' transition

For caregivers in general their youth's transition to adulthood is a tumultuous time, lined with gradual separation involving concerns for the youth's future life as an independent adult (Moore, 1987). When a child reaches adolescence, caregivers are often dealing with their own mid-life transition, which can be a turbulent experience (Todd & Jones, 2005). However, the gradual separation involves changes in how youths and caregivers socialise and caregivers begin to treat their youngsters more like emerging adults (Arnett, 2004).

For caregivers of youths with disabilities the transition has the same meaning but the separation may be different, since being a caregiver of a person with a complex disability not only involves a lifelong commitment but more of lifelong special efforts and support (Bostrom, Broberg, & Hwang, 2010; Raina et al., 2005). It also involves caregivers often having to support and guide their young sons/daughters during transition to adulthood much more than caregivers in general, which requires a lot of energy (Kingsnorth et al., 2011). Caring for a child with disability not only involves extraordinary efforts and involvement, but numerous contacts with and visits to support and health care providers from the time of the birth of their child (Broberg, 2011; Olsson & Hwang, 2003). Caregivers are to be seen, within the support and health care systems as experts on their children's needs (Rosenbaum, King, Law, King, & Evans, 1998). When their children grow older and move from child- to adult-centred support and health care they are supposed to gradually transfer their responsibility to the youths themselves or to other adult carers which entails new challenges (Gorter & Roebroeck, 2013).

Health, wellbeing and needs

The WHO (2003) has since 1948 defined "health" as "a state of physical mental and social wellbeing and not merely the absence of disease or infirmity". A more reasonable definition of health is the ICF's framework for describing health from the perspective of functioning. However, in this thesis also uses the definition suggested by Huber and colleagues (2011 p. 3): "the ability to adapt and to self-manage".

The term "wellbeing" is debated, and Ronen and Rosenbaum (2013) discuss the current view of scholars who suggest that the phrase "complete wellbeing" declares that people with disability should be ill and unhealthy. Dodge, Daly, Huyton, and Sanders (2012 p. 230) however, suggested the definition of wellbeing to be "the balance point between an individual's resource pool and challenges faced", which could be an adequate definition when describing wellbeing in transition to adulthood in youths with disabilities and with their caregivers.

The term "need" refers to individual perceptions of something desired or lacking and is commonly used within support and health care connected to treatments or support (e.g. Bailey & Blasco, 1990).

Health and wellbeing in youths

For youth in general the transition is a turbulent time involving living at home and attending school but preparing for future independent life. During the transition years, the family still play a vital role for health and wellbeing, and participating in school and leisure activities as well as interacting with the youth's peers (*Fokus 13: unga och jämställdhet,* 2013). During the transitioning years between ages 13-24, healthy behaviours involving for example sleep, eating and smoke habits dramatically decline. However, resources such as social support from school, parents and peers have positive effects on the youths' healthy behaviour (Frech, 2012).

A literature review shows that mental health problems affect one in five children and adolescents worldwide and that mental health problems during adulthood often originate early in life (Kieling et al. 2011). A Swedish internet-based survey aiming to investigate self-perceived psychosomatic health in 140,000 young people aged from 10 to 24 between the years 2005-2010 showed that 47% of the female and 29% of the male youths felt they were stressed very often. The survey showed these complaints were more common for youths aged between 16 and 18, in particular females (Friberg, Hagquist, & Osika, 2012). Psychosomatic problems and stress are more common among Swedish female youths than males (*Fokus 13: unga och jämställdhet,* 2013).

For immigrant youths in transition to adulthood, being an immigrant might itself involve health problems. In a Swedish research involving more than 10,000 youths aged 18-29 years from immigrant backgrounds from outside Europe, Swedish researchers found that being an immigrant was associated with poor mental health (Kosidou et al., 2012). For both male and female youths, stress was associated with unemployment and economic problems. In young women distress was associated with parenthood, or not being a parent, and lack of their own housing. Although this thesis concerns youths with disabilities, it is important to have an understanding of youth health in general.

Health, wellbeing and needs in youths with disabilities

For many young people with disabilities, the transition to adulthood is a difficult time that has a general impact on both health and wellbeing. There is of course variation for youths with disabilities partly depending on the degree of physical and intellectual

limitations but also other factors such as personal and environmental (Kraus de Camargo, 2011).

A physical disability such as CP, is often accompanied by other associated impairments (Rosenbaum et al., 2007) and affects health and possibly wellbeing in youths. In a literature overview, Livingston, Rosenbaum, Russell, & Palisano, (2007) describe how youths with CP experience a lower health-related quality of life compared to their peers. A newly published study showed that youths with disabilities such as ID and autism experienced lower physical and psychological wellbeing during transition than their peers without disabilities (Biggs & Carter, 2016). In Sweden, youths with disabilities in general experience more mental health problems and display more stress-related symptoms in their daily lives compared to their peers without disabilities (Swedish National Institute of Public Health, 2012).

Youths with CP and ID are less physically active and have a more sedentary lifestyle than their peers without disabilities. This in turn may result in poorer physical health (Hinckson & Curtis, 2013; Maher, Williams, Olds, & Lane, 2007). Additionally, youths and adults with ID, particularly those with Down's syndrome, are at a higher risk of obesity than their peers without any disability (Krause et al. 2015). A European-wide study showed that pain such as leg pain and headaches, is more common among young people with CP than among those without this disability. Pain was further associated with emotional difficulties and with impaired walking ability (Parkinson, Dickinson, Arnaud, Lyons, & Colver, 2013). From conducting in-depth interviews with youths with CP who were in pain, Castle and colleagues (2007) found that their experiences with pain affected their mental wellbeing. The pain occupied their thoughts and took a lot of their energy, which reduced their opportunities to participate in leisure activities. This resulted in sadness and a feeling of hopelessness. People with CP may develop musculoskeletal problems throughout life and when ageing, these problems change and might increase (Rosenbaum et al., 2007). Adults with CP also experience increasing problems with pain, physical fatigue and muscle stiffness and these changes are often perceived as gradual and may involve a sense of disaffection (Sandström, 2009).

For youths' wellbeing, participation in leisure activities is important but activities may be limited due to motor disorders (Rosenbaum et al., 2007). Youths with CP are found to participate in fewer activities outside the family than younger children with CP and youths with lower gross motor functions participate in fewer activities outside the home than youths with milder motor limitations (Palisano et al., 2009; Palisano et al., 2011). Orlin and colleagues (2010) argue that those who do not require physical assistance or organised activities run a greater risk of acquiring secondary impairments as a consequence of their lack of physical activity. Furthermore, the results from the previously mentioned study by Briggs & Carter (2016) showed that the lowest wellbeing score in transitioning youths with disabilities concerned friends and social support.

Youths with different kinds of disabilities want to participate in activities but often experience barriers associated to environmental factors such as problems with transportation and attitudes in the society (Stewart et al., 2012). In Sweden, it is common for youths with disabilities to feel unsafe in public spaces such as places of entertainment, on public transport and in their own neighbourhoods. Thirty per cent have experienced bullying compared to twelve per cent of their peers without disabilities. Bullying is more common among those with PD (Statens folk-hälsoinstitut, 2012; Ungdomsstyrelsen, 2012).

Having friends is also important for the wellbeing of youth but in Sweden, youths with moderate or severe disabilities were found to spend less time with friends compared to those without disabilities (Statens folkhälsoinstitut, 2012). It is almost three times as common for young people with disabilities in Sweden to be dissatisfied with relationships with friends compared to young people without disabilities (Ungdomsstyrelsen, 2012). Kang et al. (2012) showed that the way in which a young person perceives him or herself as a friend was important for their interaction with others and that those who perceived themselves as having good social competence spent more time with friends.

Other important issues in youths' lives are romantic relationships, dating and sexuality. In the period between young adolescence and the age of 25 these are essential elements of sexual development. This period in life involves physical changes for the youths, and masturbation and intimate relationships become important for the development of sexual identity (Wiegerink & Roebroeck, 2013). Youths with disabilities in Sweden reported sexuality as being important and associated with social life (Brunnberg, Boström, & Berglund, 2009). However, youths 18-22 years of age with CP were found to have fewer sexual experiences than their peers without disabilities (Wiegerink, Roebroeck, van der Slot, Stam, & Cohen-Kettenis, 2010). Youths and young adults with ID find few possibilities to meet others of the opposite sex without having caregivers or staff around (Löfgren-Mårtensson, 2004). Young adults with CP were also found to experience problems with both emotional and physical sexuality (Wiegerink, Roebroeck, Bender, Stam, & Cohen-Kettenis, 2011).

Depending on type and level of disability, youths commonly need support to do things that other youths do, participating in age- appropriate activities; socialising and experiencing love and sexuality (Gorter and Roebroeck, 2013). Support with socialising and participating in activities concerns individual support but also transportation and access to appropriate activities. Nowadays as the internet is a common arena for socialising, youths with ID often need support in how to deal with the internet and social media (Molin et al. 2014). In order to have opportunities to experience love and sexuality, young people need education, counselling and sometimes practical support (Murphy, Lincoln, Meredith, Cross, & Rintell, 2015).

Another essential life course transition related to quality of life is that of finishing school and entering the labour market. A Swedish study aimed to examine life after school for young people with ID showed that nearly half (47%) of those who graduated from special secondary schools during the years 2001 to 2011, participated in 'daily activities' (LSS) in 2011. Almost 25% of the young adults did not participate in any 'daily activities', education or employment (Arvidsson, Widén, & Tideman, 2015).

Health, wellbeing and needs in caregivers of children and youths with disabilities

Caring for a child with a disability is both demanding and challenging and has a profound impact on caregivers' quality of life with consequences for both their physical and mental wellbeing (Brehaut et al., 2009; Byrne, Hurley, Daly, & Cunningham, 2010; Davis et al., 2010). Caregivers' independence and financial stability can also be affected, which might have an impact on their mental health (Davis et al., 2010; Statens folkhälsoinstitut, 2012). Disabilities as CP and ID imply that caring for the youth continues throughout the years of growing up and even in adult life (Raina et al., 2005; Rosenbaum & Rosenbloom, 2012). Many families cope well, despite the added challenges but demands connected to caring for a child with disability can explain that the health status of caregivers with and without children with disabilities is different (Brehaut et al., 2004; 2009; Broberg, Nowak, Norlin, & Starke, 2014; Svedberg, Englund, Malker, & Stener-Victorin, 2010).

Stress in caregivers of children with disabilities often causes physical health problems and may cause disorders such as headaches and back problems (Brehaut et al., 2004). Caregivers may also show signs of depression due to caring for their children (Sawyer et al., 2011). Byrne and colleagues (2010) showed that male caregivers of children with lifespan disabilities from Ireland had better physical and mental health than female caregivers. This is due to the fact that the mothers were responsible for a greater extent of the care than the fathers. There is limited research concerning the health and wellbeing of Middle Eastern caregivers as most literature originates from Anglo-Saxon countries. However, there seems to be a consensus concerning the link between caring for a child with disabilities and health problems in caregivers. Al-Krenawi, Graham, and Al Gharaibeh (2011) reported that Bedouin-Arab caregivers of children and youths with ID and without PD residing in Israel experienced more stress and caregiver burden, less marriage satisfaction and sense of coherence compared to those not caring for disabled children and youths. Higher rates of depression were found amongst mothers of children with disabilities in Saudi Arabia and Lebanon than in the mothers of children without disabilities (Al-Eithan et al. 2013; Azar & Kurdahi Dadr, 2006). Caregivers in the United Arab Emirates

also reported a high level of stress that was associated with the severity of the child's disability (Khamis, 2007).

In a study of health in caregivers of youths with disabilities in the Nordic countries, caregivers were found to be in poorer health than those of children and youths without disabilities. They had more health problems in terms of stress-related symptoms such as stomach problems, headaches and sleep problems. Forty per cent of caregivers reported having headaches each or every other week and a quarter reported stomach problems to the same extent. These problems were more common among caregivers of youths with moderate or severe disabilities and were associated with low levels of education, work and economy (Statens folkhälsoinstitut, 2012).

Caregivers of children with disabilities often feel negative emotions when they are informed of their child's diagnosis and may also experience feelings of grief for several years and sometimes even lifelong sorrow (Bostrom, Broberg & Hwang, 2010; Broberg, 2011; Whittingham, Wee, Sanders, & Boyd, 2013). However, a Dutch study showed that a large majority of caregivers overcome their initial reactions to the diagnosis as the child gets older – even if this varies depending on the youth's level of disability (Schuengel et al., 2009). Facing their youth's transition, caregivers often worry and are concerned about their youth's future as an adult (Antle, Mills, Steele, Kalnins, & Rossen, 2008).

Livingston and colleagues (2007) argue that there is a lack of research concerning experiences of health and wellbeing in caregivers that relates specifically to youths, yet this is important since they appear to have different life issues compared to those of children. Since caregivers are the major constant in their sons' and daughters' lives, they play a primary role in advocating through transition (Leiter & Waugh, 2009), their health and wellbeing is also important. It is therefore of great interest to increase knowledge of caregivers' own experiences of health and wellbeing in the youth's transition to adulthood.

Immigrant youths with disabilities and their caregivers from Middle Eastern countries

Little has been written about Middle Eastern immigrant youths with disabilities in transition. However, to get a picture of immigrant families with youths with disabilities from the Middle Eastern countries, certain things are mentioned. For immigrants from a non-western country, language difficulties and varying systems of cultural beliefs can cause misunderstandings between a client and a service provider and families might be unaware of services aimed for support and habilitation for their child in their new host country (Hasnain, Rooshey et al., 2008; Leavitt, 2002; 2003). In a survey, Broberg and colleagues (2014) found that immigrant caregivers of

children with disabilities in Sweden were less aware of adequate and available support for their children when compared to Swedish caregivers.

Immigrants from non-western countries, with respect to great individual variations, might have different beliefs, expectations and perceptions related to health and disability. Among the many barriers an immigrant might perceive is the terminology used in information materials, application forms and conversations, for example different terms for medical [disability] diagnoses, sometimes used without clarification (Hasnain, Rooshey et al., 2008). In a literature review examining perceptions of disability among caregivers from Middle Eastern background, common perceptions were found among different cultural groups that included seeing children with disabilities as developing normally but more slowly or viewing the child's condition as temporary (Diken, 2012). Leavitt (2002; 2003) discusses that the term "disability" does not exist in all cultures. Having a PD or visual or hearing impairment might be more accepted in the society than having an intellectual disability, which is rather seen as being "slow" or "mentally retarded". Furthermore, mental retardation is stigmatised in many cultures (Azar & Kurdahi Badr 2006; Crabtree, 2006; Hasnain, Rooshey et al., 2008: Raman et al. 2010; Scior, Addai-Davis, Kenyon, & Sheridan, 2013).

Immigrants settling down in a new country may have to deal with cultural norms that are different from their countries of origin. This refers to the concept of acculturation which is an ongoing process of cultural and psychological change that takes place over time. With longer residence in a new environment, people are more likely to adapt to the culture in their new host country (Sam & Berry, 2010). How immigrants deal with the process of acculturation depends on several factors. One factor of importance is possibilities to participate in the new society of settlement. al-Baldawi (2014) highlights that immigrants more often hold on to traditions from their countries of origin as a coping strategy to feel secure in their new environment. Berry, Phinney, Sam, and Vedder (2006) have focused on the acculturation process of youths and argue that it is a matter of living in and between two cultures. On the one hand, they live with their family including caregivers, siblings and sometimes other relatives. On the other hand, they spend their daily lives for example in school socializing with teachers and peers. Berry and colleagues (2006) highlight that it is of great importance that immigrant youths are encouraged to retain their own cultural identity but also establishing close ties with the new society of settlement.

During youths' transition to adulthood, one area of particular relevance is the contrast between the individualistic cultures of many Western countries and the collectivistic culture more common to non-western countries such as those in the Middle East (Armstrong & Anger, 2005; Leake, Black, & Roberts, 2004). Al-Baldawi (2014) argues that with an individualistic approach such as the one that dominates in Sweden, the individual's autonomy and integrity is considered obvious and important. With a collectivistic approach, however, the individual is considered as being part of a group consisting of the family, the extended family, religious

affiliation or links to earlier national memberships. An individual is assumed to born as a member of a group and is expected to exist by continuing to belong to it. Development of independence and autonomy might therefore not be seen as necessary in youths' transition to adulthood (Leake, Black, & Roberts, 2004). Additionally, in line with collectivistic worldview, collectivistic caretaking is common in many Middle Eastern countries where people have strong cultural responsibility to care for family members throughout their lives (Armstrong & Ager, 2004; Crabtree, 2006; Hasnain, Rooshey et al., 2008). Not only does the responsibility concern the closest family members, i.e., parents and siblings, it also includes the extended family such as cousins and aunts.

System for habilitation and support

The Swedish welfare system is based on freedom of choice and autonomy, with the principal of the equal value and equal rights of all being the cornerstone of Swedish disability policy. National, regional and local governments share the responsibility of ensuring good health and financial security for people with disabilities and this includes the boosting of each individual's prospect of living an independent life (The National Board of Health and Welfare, 2009). Sweden has ratified the UN's Convention on the Rights of Persons with Disabilities (United Nations Human Rights, 2006). This means special consideration to that people with disabilities should be involved in decision making and have freedom to make their own choices. Today this is highlighted in all disability services.

The following sections describe habilitation, support and benefits available for people with disabilities in their Swedish context. Special focus is placed on the target population of this thesis, namely transitioning youths with disabilities and their caregivers.

Habilitation Services

Habilitation is defined by The Swedish National Board of Health and Welfare as any initiative that will benefit a person with congenital or early-acquired disabilities, and that is based on this person's needs and requirements (The National Board of Health and Welfare, 2010). Habilitation is aimed to develop and retain the best possible capabilities and to create favourable conditions for independent living and active participation in social life.

There are no national guidelines for habilitation services in Sweden but The Swedish Association of Habilitation Managers has established policies for habilitation in Sweden that are aimed as a basis for planning and development of habilitation

services for all organisations. The policy was adopted in 2006 and revised in 2014. Habilitation, support and advice should be given based on the individual's needs and circumstances and involves counselling that requires expert knowledge relating to problems and conditions including medical, pedagogical, social and psychological expertise (Föreningen Sveriges Habiliteringschefer, 2014).

Habilitation, counselling and support for children and youths with disabilities are based on the UN's international policy documents such as the Standard Rules on the 'equalization of opportunities for persons with disabilities' (1993) and the UNs 'Convention on the Rights of the Child' (CRC) and Swedish national legislation such as the Health and Medical Services Act (HSL) and LSS (Föreningen Sveriges Habiliteringschefer, 2014).

Habilitation and support for people with disabilities and their families are provided through habilitation services offered by the municipalities or the regions of residency. Habilitation services for children and youths are usually run by the regions (Föreningen Sveriges Habiliteringschefer, 2014; The National Board of Health and Welfare, 2009). One of the aims of the habilitation services is to support youths in their transition to adulthood in accordance with the National Habilitation Programme with an important part of this being youth involvement. The activities offered should be comprehensible, manageable and meaningful for both young people and caregivers (Föreningen Sveriges Habiliteringschefer, 2014).

Across Sweden, there are differences in age at which youths leave the child and youth habilitation services and are offered their habilitation, elsewhere such as from the region's adult rehabilitation. In most regions the transition occurs at age 18. Habilitation services for adults offer similar kinds of counselling and habilitation as the child and youth habilitation services ("Habilitation and Assistive Technology Services – a brief presentation", 2011).

Service and support according to LSS

Regulated by Swedish laws, citizens are entitled to support based on a needs assessment and support should be granted if and when the individuals themselves request it. The individuals should also have the opportunity to influence the support and service. In addition, there are special paragraphs regulating support for people with disabilities. The LSS is an entitlement law intended as a complement to other legislation (Proposition 1992/93:159). The aim of this special legislation is to remove barriers in daily living and guarantee good living conditions for people with extensive and long-term functional impairments (The National Board of Health and Welfare, 2009). The child's best interest is clearly regulated in LSS assessments, which involve taking into account both the best interest of the child and the child's own perspective (The National Board of Health and Welfare, 2014).

Not everyone with disabilities is entitled to support according to LSS but those with "intellectual disabilities and/or autism or who have other lasting physical impairments that are substantial and cause considerable difficulties in daily life and, consequently, have an extensive need for support and service", are entitled to the support it if they have the need (LSS §1) (The National Board of Health and Welfare, 2009). The support in LSS is regulated by specific measures (§9:1-10) and is most often provided by the municipality of residence, with the exception of "Advising and personal support". One of the measures is personal assistance and assistance benefit regulated in LSS (Proposition 1992/93:159) or in Chapter 51 of the Swedish Social Insurance Code (2010:110). Personal assistance is intended for persons with major functional impairments and who have an extensive need of support in their daily lives. The purpose with personal assistance is to make it financially possible to appoint one or more personal assistants. This measure enables caregivers to themselves be the assistants for their child with remuneration, either as a full-time job or, for example, during the evenings and nights (The National Board of Health and Welfare, 2009).

Additional LSS measures include the possibility for youths to be entitled to a "companion service" or a "contact person" aimed to provide support with social life and leisure activities. This can lead to reduced social isolation or help the youth participate in leisure and social activities (Proposition1993:387). Youths are also able to spend short stays away from home at weekends or during school vacations. This is a useful step for preparing to move away from home and can also be seen as a respite for the caregivers. When the youths become of working age they can be entitled to participate in "daily activities" organised by their municipality, which are an alternative to work on the labour market. However, people with disabilities but without ID or autism are not entitled to this measure. Furthermore, anyone in receipt of a measure according to LSS shall be offered an Individual Plan (§10), meaning that approved and planned measures are to be drawn up in consultation with the youth with or without support from caregivers (The National Board of Health and Welfare, 2014; Proposition 1992/93:159; The National Board of Health and Welfare, 2009). This provides a useful tool for transition planning.

Parental leave and benefits for caregivers

Swedish parents have the right to parental leave with an allowance up until the child is 15 years old, if their child needs special care or treatment. If the child has a disability, this right continues until the youth turns 19. If a young person is covered by LSS, these rights can apply until the youth turns 21. Caregivers may also receive an additional allowance aimed to cover health care costs and other expenses related to a child's special needs (Swedish Social Insurance Agency, 2013).

Support in transition to adulthood

Over the past two decades, attention has been drawn to the special needs of young people with disabilities during their transition to adulthood, with particular focus on the transition between child and adult-centred support and health care systems (Blum et al., 1993). Gorter and Roebroeck (2013) argue for the importance of empowering youths and preparing them for dealings with the individualised adult health care system as well as providing them with the opportunity to meet health care providers without the presence of their caregiver. However, these authors maintain that caregivers are the experts and that they both can, and should, engage in their youth's transition process from early on, when their youths are at the start of their adolescence. Cooperation with caregivers is also found to be essential, in particular for immigrant youth (Kim & Morningstar, 2005). Furthermore, collaboration between systems of care, service and education has been shown to facilitate the transition for both youths and their caregivers (Stewart et al. 2014). Nowadays, various methods and programmes are used with the aim of providing support in the youth transition process.

Examples of transition programmes

The Rotterdam Transition Profile

The Transition Research Group South West Netherlands developed the 'Rotterdam Transition Profile' (RTP) intended as a tool to monitor and summarize the transition process for both adolescents with CP in their transition to adulthood and for young adults with disabilities in the beginning of early adulthood. RTP is based on developmental theories claiming that there are three developmental phases involved in the process of transition to adulthood. During phase one, the youths are dependent on the adults around them, who are primarily their caregivers but also others such as [health care] personnel. During phase two, the youths are guided on their road to a life that is more independent. This involves experimenting and orientating towards the future in order to help them experience self-confidence. Finally, phase three is the phase in life when young adults are supposed to manage their autonomy in the sense that they are as independent as possible (Donkervoort et al., 2009).

Best Journey to Adult Life

A predecessor, in terms of guidelines, is the compilation of best practice guidelines for transition to adulthood known as the 'Best Journey to Adult Life' (BJA) (Stewart et al., 2009). This was identified and developed by the CanChild Centre, and intended for young people with disabilities. It is a model representing the dynamic and ever-changing developmental process of a young person's life course with the transition to adulthood described as a journey. BJA summarises the following six

themes: 1) Collaborative initiatives and policies are necessary to support the transition; 2) Building the individual's capacity will facilitate the transition process; 3) A 'navigator' can facilitate the building of the individual's capacity; 4) Resources and information should be available during the transition process; 5) Education is a critical component of any transition strategy; 6) (Stewart et al., 2009). Ongoing research and evaluation provides the evidence needed for a successful transition (Stewart et al., 2010).

Within each theme, guidelines are provided for three key phases of the transition: 'the preparation', 'the journey' and 'the landing'. The preparation phase takes place during a youth's late childhood, the journey during the transition itself, and the landing in early adulthood (Stewart et al., 2009). The CanChild Centre has developed a tool called 'The Youth Kit' which has two versions, one intended for caregivers and one intended for youths, helping them to set their own goals and find the right support as well as to organise information during their transition (Freeman et al., 2015; Stewart et al., 2006). The 'Youth Kit' has recently been evaluated for use with youths with disabilities aged 12-25 and was found to be a valuable tool for transition into adulthood (Freeman et al., 2015). The 'Youth Kit' is available on the CanChild Centre's website (www.canchild.ca) and has both a written kit and videos.

Transition programmes and projects in Sweden

Inspired by the results of the BJA, the Association of Swedish Habilitation Managers introduced a programme for support the transition from childhood to adulthood in 2007 that was revised in 2015 (Föreningen Sveriges Habiliteringschefer, 2007; 2015). This programme was intended for use in activities within the habilitation services in Sweden and adapted to fit in a local context. It proposes three stages of the transition process similar to those of the BJA: *getting started*, *on the move* and *almost completed*. The individual process depends on the degree of autonomy and goal preferences and might be different for each individual. The differences partly depend on the amount of support the youth currently needs and might need in the future but they also depend on areas of life such as living conditions, education/work and leisure activities. The programme includes providing the youths with tools and information to enable them to take action on their own paths to greater independence. It also includes collaboration with caregivers as well as collaboration between professionals and systems of support. In 2011, the Association of Swedish Habilitation Managers introduced a similar programme aimed at supporting young adults at the beginning of their adulthood (Karlsson et al., 2011).

It is important for professionals working with youths in transition to have operating models. Several habilitation units around Sweden have developed different kinds of models and programmes for interventions. Among these models and programmes is a project that took place in 2013, which aimed to develop a model for communication and exchange of information between different health care systems responsible for care for people aged 16-20 with disabilities. One intention was to implement the ICF

into all documentation and to exchange information between habilitation services for children and youths and the adult services (Mannberg, Gustafsson, Gustafsson, & Wetterholm, 2013).

Conceptual frameworks

In 2001 the World Health Organization (WHO) developed the universal classification system, *International Classification of Functioning, Disability and Health (ICF)* (World Health Organization, 2001). The overall aim according to WHO (2001, p 3) is "to provide a unified and standard language and framework for the description of health and health-related states". The ICF or its equivalent for children and youths – the ICF-CY – is recommended for use within support and habilitation services as a theoretical health-related model for wellbeing and functioning based on a bio-psychosocial approach. It is also a classification system for the planning of interventions to facilitate activity and participation in daily living for children and youths with disabilities, and in transition planning (Gorter & Roebroeck, 2013; Rosenbaum & Gorter, 2012). Family Centred Support (FCS) and Person Centred Services (PCS) are philosophies and approaches recognised as best practice in service delivery for children, youths and adults with disabilities and their caregivers (King, Baldwin, Currie, & Evans, 2005; Rosenbaum, King, Law, King, & Evans, 1998). Developed from for example FCS, culturally sensitive service is recommended in support and habilitation for language minorities (King, Desmarais, Lindsay, Piérert, & Tétreault, 2014). These concepts are used and discussed in this thesis.

Health and wellbeing related to ICF/ICF-CY

ICF is developed from the International Classification of Impairments, Disabilities and Handicaps (ICIDH), which has a biomedical perspective on impairment and health (WHO, 1980). It has its focus on curing and normalizing persons with disabilities. In contrast ICF has a wider psychosocial perspective emphasizing social and physical environments, as factors potentially producing barriers that may result in disability (WHO, 2001). The ICF provides globally accepted terminology for the definition and measure of health and disability in various disciplines such as education, support and health care services, and across several different countries and cultures. The ICF has a holistic approach meaning the language is a starting point for what does function rather than what does not, and provide a broad and more meaningful picture of the health of people or populations (WHO, 2001).

ICF-CY

As a response to the need for a version for children and youth, in 2007 the WHO developed the International Classification of Functioning, Disability and Health – Children & Youth version (ICF-CY). ICF-CY is based on ICF but has been adapted for use when describing the functioning of children and youth in the environment of a child's or young person's ordinary life and with a special focus on health and development (WHO, 2007).

The ICF-CY (ICF) has two parts, each with two components that are linked to one another, which can be expressed in both positive and negative terms. One part deals with *functioning and disability* with the components of *body function and structures* and *activity and participation*. The other part involves contextual factors with the components of *environmental factors* and *personal factors* (WHO, 2001; 2007). In the ICF/ICF-CY model the arrows illustrate the interaction between the components (Figure 1).
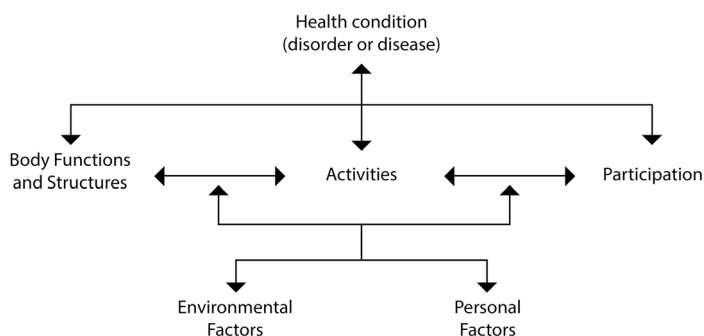
Figure 1: "Interaction between the components of ICF/ICF-CY" (WHO, 2007 p. 17) © World Health Organization

The components *Body functions and Structures*, *Activity and Participation* and *Environmental Factors* includes five to nine chapters consisting of categories divided into several levels. All categories have a code consisting of a letter and combination of numbers. An example of a code is d4103, d stands for chapter 4, "Mobility", d410 for level "changes body position" and specific d4103 for "sitting" (WHO, 2007). In ICF-CY, *Body functions* involve a child's or a youth's psychological and physiological functions, the term body refers to the human organism as a whole. This includes the brain meaning mental/psychological functions are listed under body functions. *Body structures* are the structural or anatomical parts of the body, meaning that impairments are problems in body functions or structures and deemed to be a significant deviation or loss. *Activities* involve a youth's action or the execution of a task meaning that activity limitation refers to the difficulties he/she may have in

executing activities. *Participation* is involvement in life situations meaning that participation restrictions are the problems a youth may experience in involvement in life situations. In the ICF-CY, the chapter *learning and applying knowledge* has been included within the component *activity and participation* (WHO, 2007). Examples of life situations related to the transition period are leaving home, finishing school and starting a job as well as participating in leisure activities and seeing friends (Donkervoort et al., 2009). *Environmental factors* include the physical or social environment in which a young person lives, for example family or school, as well as attitudes in society (WHO, 2007). The environment around a young person primarily involves the family; it is within the family that he/she can develop and achieve wellbeing. It is therefore important to focus the support on both youths and their caregivers (Rosenbaum and Gorter, 2011; Rosenbaum and Stewart, 2004). *Personal factors* are contextual factors, not specifically classified, that relate to the individual, such as; age, gender, social background and life style (ICF/ICF-CY, 2001; 2007). Although all other components of the ICF have codes, personal factors do not have any taxonomy of codes due to their large social and cultural variance (Simeonsson et al., 2014).

When assisting a youth with disabilities during their transition to adulthood it is important to include the youth him/herself in the planning. The ICF-CY can be useful as a model of thinking and when making up transition plans, taking into special consideration activities and participation as well as the environmental factors within which the youths are present and belong (Kraus de Camargo, 2011). Important environmental factors that have significant impact for transitioning youths – besides the family – are post-school options and access to transportation (Foley, Dyke, Girdler, Bourke, & Leonard, 2012).

There is a risk that ICF/ICF-CY can be misused as a classification of persons (Simeonsson et al., 2014). In spite of the lack of taxonomy in *personal factors* the component is included in the ICF model as contextual factors (WHO, 2001; 2007). Simeonsson et al. (2014) and the Functioning and Disability Reference Group of the WHO-FIC (Leonardi et al., 2015) argue that lack of taxonomy and definition of inclusion and exclusion criteria can lead to a misuse of documenting personal attributes described as personal factors. In addition, there are no guidelines for how to document personal factors. The authors argue that this might result in blaming the individual for having a disability due to for example his/hers age, gender, social status or experiences in life.

Ibragimova, Granlund, & Bjorck-Akesson (2009) argue for the need of comprehensive guidelines for using the ICF-CY as a common language across for example social- and health care services. Rosenbaum & Gorter (2012) highlight the importance to have in mind what is important for children and youths and have developed the 'F-words' as an idea for a more natural framework for use in services for children and youths. The 'F-words' contains the terms *fitness*, *function*, *friendships,*

family factors and *fun* to be used in a more popular way. In addition, the 'F-words' contains the term *future*, with the argument that future is what child development is about.

Family-Centred Service

Family-Centred Service (FCS) is a philosophy and an approach aimed for service delivery where the family is at the centre (Rosenbaum et al., 1998). Before the 1960s, institutional placement for people with disabilities was recommended and caregivers were viewed as incapable of raising their child (Rosenbaum et al., 1998; Strock-Lynskey & Keller, 2007). This involved a top-down paternalistic medical model of care where the professionals were the experts. According to Rosenbaum and colleagues (1998) the concept of family-centred service began in the mid-1960s. Due to deinstitutionalization, the independent living movement, and the movement of consumer advocacy professionals began to realise caregivers had tremendous competence regarding their child (Rosenbaum et al., 1998; Strock-Lynskey & Keller, 2007). The development of FCS aims therefore to strive for a balance between caregivers' knowledge about the child and the expertise on conditions and treatments from health care professionals (Rosenbaum et al., 1998). By using FCS, the caregivers are supported in making their own decisions about the services for their child and service providers should respect and support families and provide tailored information. This means that service providers should listen to, believe in and trust the families as experts on their children's needs by developing collaborative relationships where both parents and their child are engaged as equal partners (Rosenbaum et al., 1998; King et al., 2004). Using FCS suggests that information and guidance should be provided so that each family can make their own well-founded decisions (Rosenbaum et al., 1998).

Today, FCS is considered as best practice in pediatric rehabilitation and is widely used as an approach in the Western world (Arcuri et al., 2016; Dunst, Trivette, & Hamby, 2007; King et al., 2004; Rosenbaum et al., 1998). The CanChild Centre for Childhood Disability Research in Canada has developed a best practice approach for using FCS to guide professionals in paediatric rehabilitation and within social work practices to support children with disabilities and their families (King et al., 2004). Within the Swedish child and youth habilitation services, the FCS approach involves treating a family with dignity and respect and viewing both the child and the caregivers as partners to the professionals (Broberg et al., 2010).

In a recently published Canadian article (Arcuri et al., 2016) satisfaction of FCS in rehabilitation services was evaluated. It showed an overall satisfaction from both professionals and caregivers of young children with disabilities, including caregivers from language minorities. Nevertheless, the study also showed the complexity of its

successful implementation. From the caregivers' perspective, their psychosocial needs were met by service providers using FCS but they identified limited access to general information such as assistance, respite care and dating and sexuality. This was explained to be due to institutional barriers such as limited time and resources. Another important finding was that caregivers were unfamiliar with the medical terminology used by health care professionals and wished for more understandable terms to be used (Arcuri et al., 2016).

Person-centred Service

Person-Centred Service (PCS) within support and health care for adults, in contrast to FCS, has the client him/herself in focus, meaning that the young adult is to be viewed as the partner to the professional (Ekman et al., 2011; Ekman, Hedman, Swedberg, & Wallengren, 2015; King, Baldwin, Currie, & Evans, 2005). The partnership involves the young person and the professional sharing discussions and decision making for support and treatments. However, many youths with intellectual disabilities need support from others, such as caregivers in this partnership, even if the youths are to be treated as individual persons.

According to King et al. (2005) and Ekman et al. (2011), PCS is rooted in a client-centred approach. The client-centred approach has a holistic perspective and deals with the fit between the individual and the environment. King and colleagues (2005) describe PCS as an approach for youths with disabilities in person centred transition planning. The approach focuses on the provision of emotional support to the youth and information to assist him/her in adapting to various environmental settings. This involves the importance of providing support and guidance aimed for the youth to make a successful transition into adult life. All planning stresses the importance of customising information and support to respond to the individual's needs (King et al., 2005). Customised services involve guidance, goal setting and coaching, meaning that services should be responsive and informative to support the individual's options and decision making – in particular they should be respectful to the individual youth's readiness for self-determination (Gorter & Roebroek, 2013). Self-development is an ongoing process during the lifespan, hence services should continue over time (Gorter & Roebroek, 2013; Rosenbaum et al., 1998).

Culturally sensitive service

Culturally sensitive services have been found to be essential for support and service delivery for children and youths with disabilities and their caregivers from diverse cultural and linguistic backgrounds (King et al. 2014; Lindsay, King, Klassen,

Esses, & Strachel, 2012; Nochajski, Matteliano, & Stone, 2008). Person centred-planning has been recognised to have a positive impact in transition for linguistically and culturally diverse youth in vocational rehabilitation services (Hasnain & Sotnic, 2003).

Cultural competence in professionals is the key concept in delivering culturally sensitive service. Campinha-Bacote (2002) developed a model for cultural competence in health care. Campinha-Bacote (2002) argues that cultural competence in professionals is an ongoing process and involves integration of five elements; *cultural awareness, cultural knowledge, cultural skill, cultural encounters* and *cultural desire*. Based on this model, the Center for International Rehabilitation Research Information and Exchange (CIRRIE) has developed a guide aimed to provide a resource for including and strengthening cultural competence in education. This concerns education for various types of professionals working in schools, social services and health care with people with disabilities and their families (Nochajski et al., 2008). The Campinha-Bacote model (2002) is briefly described below. To be understood in the context of service delivery for youths with disabilities, the elements have been inspired by the CIRRIE guide (Nochajski et al., 2008).

1) *Cultural awareness* involves awareness of the professional's own cultural and professional background including assumptions about individuals who are perceived as 'different' and one's own biases and prejudices.

2) *Cultural knowledge* means to obtain general knowledge about various cultures including worldviews, traditions, religion, education, health and disability practices and how people perceive disability.

3) *Cultural skill* involves assessment of youths and caregivers from diverse cultures meaning to determine their problems and needs within the context of their culture. Furthermore, it involves assessment of the youth's/caregiver's linguistic needs.

4) *Cultural encounters* involve the professionals being interested in and having the possibility to engage in cross-cultural interactions with families from culturally diverse backgrounds.

5) *Cultural desire* involves, in short, the motivation for the professional to empathise and care for youths and caregivers irrespective of cultural background.

Rationale for the research

According to the background as presented earlier in this thesis, the transition to adulthood is a complex and multifaceted process for all involved. Despite a range of on-going national and international activities, within support and health care services to facilitate the transition to adulthood for all those involved in the process, there is still a gap of knowledge, especially knowledge about youths' and caregivers' own opinions about preferences, challenges and needs when living through transition.

Aims

The overall aim of this thesis was to gain a deeper understanding of health and wellbeing, challenges, preferences and needs during the transition from childhood to adulthood in youths with disabilities and their caregivers. The thesis is based on four papers; two of which focus on the perspectives of youths with CP and of their caregivers and two papers focus specifically on the preferences and needs of immigrant youths with disabilities and caregivers from Middle Eastern countries residing in Sweden.

Paper I: The aim was to gain a deeper understanding of how adolescents with CP experience their own health, well-being and needs of support during their transition to adulthood.

Paper II: The aim was to gain a deeper understanding of how parents of adolescents with cerebral palsy (CP) experience their own health and wellbeing and their needs for support during the adolescent's transition to adulthood.

Paper III: The aim was to describe challenges and needs of immigrant youths' with disabilities and their caregivers' from Arabic speaking countries during the youths' transition to adulthood.

Paper VI: The aim was to describe self-identified problems in immigrant youths with disabilities from Middle Eastern countries in Sweden during their transition to adulthood and the problems as identified by caregivers.

Methods

This thesis includes two studies and four papers. Study A led to papers I and II and Study B to papers III and IV. An overview of the papers and their respective aims, methods and findings is provided in 'Thesis at a glance'.

Design

A combination of qualitative and quantitative methods was used for this thesis. Study A used an inductive qualitative design. Focus group interviews and individual interviews were conducted for data collection for youths and their caregivers (Krueger & Casey, 2009; Kvale & Brinkmann, 2009). The data was analysed using manifest and latent content analysis in the way Graneheim & Lundman (2004) recommend.

In study B structured and semi-structured interviews based on questionnaires in both Swedish and Arabic was conducted for data collection in combination with open-ended questions. The data was analysed differently depending on the questionnaires used. The data in paper III was analysed using mainly descriptive statistics (Björk, 2011) and a manifest content analysis (Graneheim and Lundman, 2004). In paper IV, a deductive approach was used to analyse the data, using ICF-CY as a framework for organizing the data (WHO, 2007).

Context of the study

Study A was carried out between October 2011 and May 2013. This period included participant recruitment and data collection. The inclusion criteria were youths with CP aged between 17 and 18 and their caregivers who lived in Skåne in Sweden. The Skåne region consists of 33 municipalities and has approximately 1.2 million inhabitants (Statistics Sweden, 2012). An estimated 63 youths with CP aged between 17 and 18 lived in this region during the study's period.

Study B took place between May 2014 and February 2015 and included participant recruitment and data collection. The inclusion criteria were youths with any kind of disabilities aged between 13 and 25 and their caregivers from Arabic speaking

countries, living in three counties in the southern and western part of Sweden; Skåne, Blekinge and one municipality in the Västra Götaland (VG) region. Blekinge consists of 150 000 inhabitants and the municipality in the VG region has approximately 55,000 inhabitants (Statistics Sweden, 2012). There was no data for the numbers of immigrant youths with disabilities living in these regions.

Procedure

Preparations for the data collection

In study A, an interview setup consisting of basic topics for youths and one for caregivers, and a questionnaire for background characteristics aimed only for caregivers, were prepared. The development of the topic guides was based on knowledge from previous literature. A pilot interview for youths (Paper I) was conducted in October 2011 with a young person with CP aged 17 living in another region of Sweden. The pilot interview involved testing both topics and layout of the interviews. As the layout used youth-friendly images and pictogram images, the author also tested and discussed their use with the youth. A pictogram is a functional visual language intended to support people with ID and/or speech difficulties. They are commonly used in special education and within child and youth habilitation services in Sweden (National Agency for special needs Education and Schools, 2010). Examples of these images are provided in Figure 2. The setup and the use of images worked well and the youth stated that those who were used to visiting a habilitation unit were familiar with pictogram images. The pilot interview resulted in minor adjustments such as changing the setup to include more open-ended follow-up questions.

In order to develop the setup for the interviews with the caregivers (Paper II), an open-ended interview was performed with a mother of a young adult with CP. During the interview, issues that were important for the mother when her young adult was in the transitioning years were discussed.
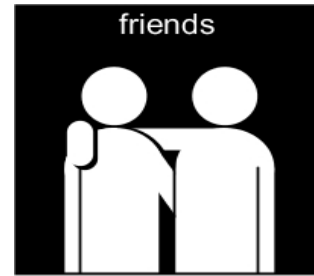
Figure 2. The image and the pictogram image used in the interviews with youths aimed to illustrate the topic 'friends' (Paper I). The Pictogram Image has been printed with permission from the Swedish National Agency for Special Needs Education and Schools.

In study B, structured and semi-structured questionnaires were used. Their preparations, translations and adaptions were carried out by a team involved in all or different parts of the preparations. In addition to the author of this thesis, the team consisted of two Swedish researchers from varying health care backgrounds and a native Arabic-speaking researcher, experienced in rehabilitation for persons with disabilities in Jordan. The team also included one native-Arabic speaking project assistant who was fluent in Swedish (henceforth referred to as PA) and a medical doctor and health care researcher. For support with back-translations, two additional health care researchers and an authorised translator were involved. The questionnaires used and the translation process - including pre-testing - are described below.

Questionnaires and the process of translation (Study B)

Study specific questionnaires for background characteristics were prepared in Swedish and translated into Arabic. One aimed at the youths described gender, age, country of birth, their parents' country of birth, education/employment, living arrangements and type of disability. One for caregivers described gender, age, country of birth, length of residence in Sweden, marital status, educational background and employment status and relation to, and the characteristics of, their youth. Both questionnaires asked about the youths' current support as per LSS and their contacts with habilitation services. Questions about experiences and preferences of information about transition to adult support and habilitation services were also included. Finally, the questionnaires contained two open-ended questions: "What do you experience as challenging in your transition/the youth's transition to adulthood?" and "What kind of support do you think could be helpful to you?"

The Rotterdam Transition Profile (0.2) (RTP) (Wiegerink, Donkervoort and Roebroeck, 2007) is a tool comprising seven domains of participation and three parts of health care for use in interviews with youths in transition to adulthood. RTP was

developed by the Transition Research Group South West Netherlands and tested for validity in 81 young adults with CP (47 males and 34 females) and normal intelligence age range 18-22 years (Donkervoort et al., 2009). RTP was found valid as a tool for use in clinical practice and research to identify individual stages for youths with CP in their transition to adulthood at both individual and group level. The stages are defined as: 1) Dependent on parents 2) Experimenting and orientating with the future 3) Independent life. Participation involves education and employment, finance, housing, leisure and social activities, intimate relationships, sexuality and transportation. Healthcare involves care demand and service, aids and rehabilitation services. The original version of RTP was translated into English with this version being translated and adapted for Swedish (Appendix 1) and Arabic.

Family Needs Survey (FNS) is a parent-report questionnaire, containing 35 statements grouped into six types of needs of caregivers of children with disabilities (Bailey & Simeonsson, 1988). The types of needs are defined as; a) information, b) support, c) explaining to others, d) community services, e) financial needs and f) family functioning. Caregivers are able to choose from the answers, 'definitely do not need help', 'not sure' or 'definitely need help'. FNS has been tested for stability of responses. The test-rest scores were 0.67 for mothers (p<0.001). The most stable subscales for mothers were: need for support (r=0.71), explaining to others (r=0.53), financial (r=0.65) and family functioning (r=0.62). The most stable subscales for fathers were: need for support (r= 0.79), community services (r=0.54), and financial needs (r=0.78) (Bailey & Simeonsson, 1988). The FNS has also been adapted to cover the needs of caregivers of both children and youths up to age 21, by including additional statements related to transition (Palisano et al., 2010). FNS has previously been translated and adapted to Swedish and used with parents of children with disabilities (Granlund & Roll-Pettersson, 2001). In this study the original version of the FNS was used translated and adapted for Swedish and Arabic (Baily & Simeonsson 1988).

COPM (Law et al., 2005) is an individualized five-step outcome measure for semi-structured interviews with a client and/or caregiver, aimed to identify individual perceptions of problems with activities such as: a) self-care, b) productivity and c) leisure and social activities. COPM focuses on the activities a client wants, needs, or is expected to do. Importance, performance and satisfaction are ranked on a Visual Analogue Scale (VAS) 1-10 using scoring cards. The COPM has been shown to be a valid tool. In a research and clinical literature review Carswell et al. (2004) showed that in relation to psychometric properties including 19 papers and/ or 33 practice research outcomes, the COPM is a valid, reliable, clinically useful and responsive outcome measure acceptable for use by clinicians and researchers. COPM has been used in several studies with children or/and youths mainly with physical disabilities (e.g., Chiarello et al., 2010; Cusick, Lannin, and Lowe 2007; Lauruschkus, 2015; Law, Anaby, Imms, Teplicky, & Turner, 2015). There is a 4th edition of the Swedish version of the COPM (Law, 2006), which is based on the original version 4th edition

(Law et al. 2005). The translation into Arabic version was based on the original English version.

All translations were done in agreement with the original authors and in accordance with the WHOs international guidelines for translations of measurements including forward and back-translations. All translations emphasized conceptual rather than literal translation using natural and relevant language for the target group. This involved discussing and adjusting terms in order to customise the questionnaires to fit a Swedish context (WHO, 2013). The Swedish versions of background characteristics and all questionnaires were pre-tested and validated with five Swedish-speaking youths aged 16-21 years with various types of disabilities and with five caregivers. The questionnaires in Arabic were pre-tested with five youths without disabilities and with five caregivers. A validation of the Arabic version of COPM for use with youths and caregivers is ongoing. All translations served well and only minor adjustments of terms were made after the pre-testing. The test interviews were not included in the results.

Recruitment of participants

The recruitment of participants was comprehensive and time consuming, involving several stages including invitations (studies A and B), announcements (study B), and the use of 'snowball technique' (studies A and B) as described by Taylor & Bogdan (1998).

In study A, invitations to participate were sent in October 2011, by an administrative assistant at the Child and Youth Habilitation to 20 youths with CP born between January and June 1994. The invitation included an information letter with an application form to register interest and a youth-friendly and easy to read version. At the same time, a copy of the information letter was sent to their caregivers. One reminder was sent. One youth agreed to participate. A new invitation including the same content was sent in January 2012 to 71 households with youths with CP born between 1994 and 1995. Furthermore, an invitation was sent to the caregivers with an invitation to participate in interviews themselves. Divorced caregivers received letters containing copies of the youths' invitation separately. One reminder was sent. In addition, invitations were sent to four youths living in school residences connected to 'Riksgymnasiet' and to their caregivers. Riksgymnasiet is a school with accommodation and habilitation for youths with severe physical disabilities. In total, 75 youths and their caregivers were invited. Nineteen youths and 22 caregivers answered and those who were interested in participating were contacted and given further information. They were also asked whether they wanted to participate in a focus group interview or an individual interview and whether or not the youth needed a proxy or special equipment during the interview. These contacts resulted in one additional youth and two caregivers showing interest in participating.

In study B, the habilitation units in the two counties, in the municipality and two schools with access to habilitation services in one of the counties were asked to assist with issuing invitations to participate in the study. The schools, the habilitation units in one of the counties and the habilitation units in the municipality accepted and identified 33 youths that were invited by post. The invitation included an information letter with an interest application form and a youth-friendly and easy to read version written in both Swedish and Arabic. No reminder was sent.

Meanwhile, information about the study and the possibility to participate were announced and distributed by approximately 200 posters (Appendix 2 and 3), one in Swedish and one in Arabic in different facilities and on websites. Habilitation units for children and youths and for adults, mainstream schools and facilities for community based programmes for youths with disabilities made announcements. The posters were also set up and explored on web sites at associations for people with disabilities and for immigrants, churches, mosques and other facilities that were assumed to be places that immigrants would visit for example non-governmental organisations, language cafes, libraries and facilities for 'Swedish For Immigrants' (SFI). Before placing advertisements for the study, contact was made with the facilities where they were to be displayed, either by post, telephone, email and/or pre-arranged or spontaneous visits. Once permission had been received from those in charge of the facilities, the advertisements were displayed and continued to be so throughout the entire study period. Together with the invitations, advertising resulted in contact with two youths and four caregivers.

Three months after the first invitations were sent and advertising began, approximately 130 people were contacted and asked to assist with recruiting participants. School personnel, LSS administrators, social worker, counsellors, companies for personal assistance and directors of local social services and leisure activities assisted. This resulted in contact with 20 youths and 45 caregivers.

In connection with the interviews, participating youths mediated contacts with peers and caregivers and this resulted in participation from two additional youths and two additional caregivers.

Participants

In total, 12 youths and 15 caregivers participated in study A and 17 youths and 16 caregivers participated in study B. Characteristics of the participating caregivers are presented in Table 1.

In study A, nine male and three female youths aged 17-18 participated. Fifteen caregivers, of whom eight mothers and seven fathers, to 10 of these youths participated. The youths and caregivers lived in urban or rural areas in Skåne except for two caregivers who were living outside Skåne or abroad. The descriptions of the

youths' backgrounds were based on their own stories or on information provided by their caregivers. One youth had been adopted from another country while all the others had been born in Sweden. All caregivers, except one, had been born in Sweden. All of the youths were living in their parental homes. However, three of them lived in school residences during their study periods. Six of the youths had personal assistants in accordance with LSS or LASS. The youths had CP and were at various cognitive levels. Based on personal information or information from their caregivers, the group included all five gross motor function levels according to GFMCS-E&R (Palisano et al., 2007) (Table 2).

In study B, nine males and eight female youths aged 13-24 participated. Sixteen caregivers participated, of whom 10 were mothers, five were fathers and one was a sibling. Two were caregivers of youths not participating in the study for youths. The families lived in the regions Skåne, Blekinge and one municipality in the VG region. All were immigrants from Middle Eastern countries, except for the caregivers of one of the participating youths; these caregivers did not participate themselves. The majority of the families had lived in Sweden for more than five years and three of the youths had been born in Sweden. Most of the youths lived with their caregivers but three had left home. Two lived by themselves and one lived in special service housing. According to medical documents that participants showed to the interviewer or information from those who had mediated the contact, all youths except one had an ID, but neither the youths nor caregivers used the term "intellectual disability". Descriptions mentioned were "thinks like a child", "slow to understand" or "learning difficulties". However, different types of disability were represented, including CP, autism, visual impairments and hearing impairments. More detailed characteristics of the youths in study B are described in Paper III, Table 1.

Table 1. Characteristics of participating caregivers (Study A and B)

	Study A (N=15)	Study B (N=16)
Gender		
Male	7	5
Female	8	11
Country of origin		
Sweden	14	0
Iraq	--	9
Unspecified country outside Europe	1	--
Other Middle Eastern country	--	7
Marital status		
Married/cohabiting	12	14
Single or divorced	3	2
Relation to the youth		
Biological parent	13	15
Adoptive parent	2	--
Sibling	--	1
Youth lives with		
Both parents	8	14
Mother	4	1
Father	0	0
Alternately with mother/father	3	0
Special service housing	--	1
Educational background		
Less than elementary school	0	2
Elementary school	0	7
Secondary School	8	6
College/University	7	1
Employment status		
Employed	15	7
Unemployed	--	2
Unpaid housework	--	3
Retired	--	2
Student	--	2
Employed as personal assistant to the youth		
Not	14	12
Partly	1	1
Main employment	0	3

Table 2. Caregivers' (Paper II) perceptions of their youths' intellectual disabilities and levels of GMFCS-E&R

Parental perception of their youths' intellectual disability	
None / mild / moderate or severe	4 / 7 / 4
Parental perception of the youths' GMFCS E&R[1] level	
I / II / III / IV / V	8 / 3 / 1 / 1 / 2

[1] Gross Motor Function Classification System - Expanded and Revised (Palisano et al., 2007)

Data Collection

In study A, the data was collected through focus group and individual interviews. The intention was that the data should primarily be collected through focus group interviews and that individual interviews were to be offered as an alternative for those who were not able, or did not want, to participate in group interviews. Eight youths and ten caregivers participated in focus group interviews one or more times. Seven youths participated in individual interviews and one of them participated twice. Altogether five focus group- and eight individual interviews were conducted with the youths. Three of them also participated in one or three focus group interviews, either before the individual interviews depending upon the youths' preferences. Nine caregivers participated in individual interviews and four of them also participated in a focus group interview, either before or after depending upon their preferences. Altogether four focus group- and nine individual interviews were conducted with the caregivers. Interviews with youths were carried out between December 2011 and June 2012 and with caregivers from February 2012 to May 2013. The amount and distribution of participation in focus group interviews and/or individual interviews are presented in Table 3.

Table 3. Participation in focus groups and/or individual interviews in Paper I and Paper II respectively.

Youths Paper I	1	2	3	4	5	6	7	8	9	10	11	12
Focus group interview	III	I		III	I			I	I		III	III
Individual interviews		I	II	I	I	I	I			I		

Caregivers Paper II	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Focus group interview	II	I	I	II	I	I		II	II	I	I	I			
Individual interviews		I			I		I			I	I	I	I	I	I

Most of the interviews in study A were performed in the Skåne region, except for individual interviews with caregivers living outside the region. Five focus group interviews with youths were performed in a separate room at a habilitation centre. Four focus group interviews with caregivers were performed in separate rooms at a habilitation centre or in a local hospital.

In study B, data was collected through individual structured and semi- structured interviews. Interviews with both youths and caregivers were carried out in parallel from September 2014 until January 2015. To enable participants with Arabic as their mother tongue, they were offered to participate in interviews in either Swedish or Arabic. Those in Arabic were conducted by the bilingual PA. However, as he was a man, all participants were able to choose to be interviewed by him even if they preferred to speak Swedish. The interviews were performed in the regions Skåne, Blekinge and the municipality in the VG region.

All individual interviews (Study A and B) were held in places chosen by the participants. The most common venues were their homes but interviews were also performed in other places such as, for example, in a separate room at the Health Science Centre, in a separate room at a habilitation centre, in schools or facilities for 'daily activities'. Interviews with caregivers were also performed in cafés or in the caregivers' working office.

Focus group interviews

All focus group interviews (study A) were moderated by the author of this thesis. At each interview, an assistant moderator was present whose task was to support the moderator in various ways, for example with ensuring that anyone who wanted to say something was seen, and with practical matters.

During the focus group interviews, snacks were served, as recommended by Krueger & Casey (2009). In the interviews with the youths, pizza slices and juice were served, and during the interviews with caregivers, coffee and sandwiches were served. All focus groups began with the moderators presenting themselves and the study. The moderator also informed about the freedom of participating as well as the freedom for the participants to refrain from speaking about anything they did not wish to speak about. Thereafter, the participants were asked to introduce themselves and the caregivers were also asked to tell something about their youth and to fill in a questionnaire with characteristics of themselves and their youth.

The interviews with the youths (Paper I) started with asking them to narrate how they experienced life just then when they were soon to become adults. The moderator continued asking them to narrate their experiences in relation to topics connected with the transition to adulthood, for example participating in leisure activities, managing daily living and socialising. Topics about health concerning sleep,

nutrition, smoking and alcohol habits were also in focus. In connection to each topic an image and a pictogram image was shown, as recommended by Cambridge & Forrester-Jones (2003) and Krueger & Casey (2009), and as exemplified in Figure 2. In connection to each topic, the youths were asked to narrate their experiences of actual needs and their thoughts of needs for the future. In one part of the interview, the moderator verbally used statements with which the youths could agree or disagree by showing a red or a green card (Kitzinger, 2013). Thereafter, a discussion started as to why they answered in the way that they did. An example of a statement concerning alcohol habits was: 'It is more difficult to dance when I have been drinking alcohol'. During the whole interview, the moderator encouraged the youths to develop what they meant by asking 'can you say anymore?' or 'what do you mean?' They were also encouraged to discuss with each other.

The interviews with caregivers (Paper II) started with asking them to narrate how they experienced life right then when their youth were soon to become an adult. The interviews contained three parts. During the first part the caregivers were asked to narrate their experiences of their own health. During this part of the interviews, as recommended by Krueger & Casey (2009), the caregivers could pick and choose among images associated to health that were scattered over the table. The purpose of these images was to stimulate the caregivers' reflections over their own health. In the next part, the moderator made statements with which the caregivers could agree or disagree by showing a green or a red card. The caregivers were then asked to explain, one-by-one, why they agreed or did not agree, and to discuss with each other. In the last part of the interview the caregivers were asked to think about and narrate their own needs during their youths' transition to adulthood. To stimulate this part of the interviews, as recommended by (Wibeck, Abrandt Dahlgren, & Öberg, 2007), the caregivers were divided in pairs and invited to choose and to take a small play figure, from among those that were scattered on a sideboard. They were asked to imagine the figure as 'a caregiver needing support', and thereafter to settle down in separate rooms without any of the moderators present and discuss with each other for ten minutes. After that, all the participants gathered again and each pair told the others about their discussion.

At the end of each focus group interview, the youths were orally asked, and the caregivers were asked to fill in a form, whether they wanted to participate in additional interviews, in a group or individually, and which times were the most suitable. The focus group interviews lasted approximately 90 to 120 minutes and were audio-tape recorded.

Individual interviews

In study A, the setup of the individual interviews was the same as in the focus group interviews and the same artefacts were used for both youths and caregivers. However,

the discussions in focus groups were replaced, if needed, with the possibility to have a dialogue with the interviewer.

Two youths (Paper I) had a proxy present during the interviews, who narrated the youth's experiences as she/he perceived and interpreted the youth's signs. One of the youths used pictogram images (National Agency for special needs Education and Schools 2010) and keyword signing (Cambridge & Forrester-Jones, 2003; Meuris, Maes, & Zink, 2014), in order to support own speech, and had a caregiver present. The individual interviews with youths lasted approximately 60 minutes and with caregivers between 50 and 90 minutes.

In study B, youths and caregivers were interviewed separately and mostly on different occasions. However, when interviews were conducted in the families' homes, other family members were sometimes around. Three of the youths used pictogram images and keyword signing and had a sibling present for support. One of the youths was interviewed through a professional sign language interpreter.

The interviews were performed in a structured or semi-structured manner, depending on questionnaire. The questionnaires for background characteristics and the questionnaires FNS, RTP were read in the same order to all participants but individually customised depending on e.g. the youth's intellectual level. The caregivers were instructed to have their 'youth' in mind when answering to the statements in FNS. Last in every interview, the COPM interviews were conducted following the major categories of COPM. Initially, the participants were asked to identify what they/their youth perceived important but problematic during transition, then to rate the importance of each problem they identified on a scale of 1 (not important at all) to 10 (extremely important). Secondly, the participants were instructed to select up to five major important problems. Finally, the participants were asked to rate each problem of performance and satisfaction on a scale of 1 to 10. The scoring cards were illustrated with smiley faces showing a sad, a neutral and a smiley face (scoring 1, 5 and 10 respectively). The scorings were made in dialogue between the participant and interviewer who also completed the COPM form.

In study B, fifteen interviews with youths, of whom one youth was interviewed through a professional sign language interpreter, and four with caregivers were conducted in Swedish. Two interviews with youths and twelve with caregivers were conducted in Arabic. The author of this thesis was present during all interviews with youths. The interviews lasted 60 to 90 minutes with no difference between youths and caregivers. Upon consent, all interviews except two with youths and five with caregivers were audio recorded. Notes were taken for those not audio recorded.

All recorded interviews in both studies (A and B) were transcribed verbatim and those in Arabic were translated into Swedish.

Data analysis

In study A, qualitative content analysis at both manifest and latent levels was used to analyse the text from the transcribed interviews (Graneheim & Lundman, 2004). The analysis process was first carried out with the transcribed interviews with youths, which resulted in Paper I, and then with the transcribed interviews with caregivers, which resulted in Paper II. The analysis processes were the same in both papers.

In study B, different treatments of the data were made depending on the questionnaires. Descriptive statistics (Björk, 2011) using SPSS for Windows, version 22.0 were used to present characteristics of the study population, the youths' current support and habilitation contacts, the participants' experiences of information about transition to adult support and habilitation and to present the distribution of the RTP and FNS. The open ended questions were analysed using qualitative content analysis at manifest level (Graneheim & Lundman, 2004). The data from COPM were analysed deductively using the categories in COPM first and then ICF as a theoretical framework (Law et al. 2005; Cieza et al. 2005). The Z-score test was used for testing differences in the proportion of most prioritized problems in COPM between youth and caregivers (Social Science Statistics, 16-02-12).

The processes of qualitative content analysis and the ICF coding are described under the following sub-headings.

The process of qualitative content analysis

In study A, the transcribed interviews were analysed following the steps described below.

1) All transcribed interviews were read independently several times to obtain a sense of the whole. Thereafter, the overall picture gained from the text material in relation to the aims and main questions of the studies were discussed among three researchers until an agreement regarding the overall picture was reached.

2) Meaning units (MU) were identified in the texts. MUs are defined as a part of a text or a sentence that relates to the central meaning of the whole (Downe-Wamboldt, 1992; Graneheim & Lundman, 2004). The MUs were then discussed repeatedly among three researchers until they agreed on them all.

3) All MUs (manifest level of analysis) were condensed, in the sense that sentences or parts of a text were minimized so that they retained the meaning of what had been said, as recommended by Graneheim & Lundman (2004). This means that parts of the text could expand, for example from interviews with the youths using pictogram-images.

4) All MUs were interpreted (latent level of analysis) in order to assure their underlying meaning, as recommended by Graneheim and Lundman (2004), and thereafter discussed among three researchers, resulting in an overall agreement.

5) All MUs were labelled with codes, according to the topic. A code is a kind of etiquette explaining the main meaning of the MU (Downe-Wamboldt, 1992; Graneheim & Lundman, 2004). Comparisons regarding similarities and differences were made of the codes and a discussion among three researchers resulted in agreement about them.

6) All codes were abstracted into sub-themes by three researchers critically discussing and reviewing the codes in relation to the MUs and the transcribed interviews. This ended up in five sub-themes for Paper I for and Paper II respectively.

During the entire analysis, an oscillation between the analysing and the text material was made. The interview texts were also read through again to identify that nothing of importance had been left out and, if anything had been left out it was then included in the analysis.

7) In the last step, one main theme was identified from the text material from interviews with the youths (Paper I) and another from the interviews with the caregivers (Paper II). Examples of the analysis process are shown in table 4.

In study B, the transcribed interviews/notes from the open-ended questions were analysed following the steps 1 to 3 and 5. Thereafter the MU´s were sorted into categories at a manifest level, based on their similarities and differences. This ended up in four categories for youths and three categories for caregivers (Paper III).

Table 4. Example of analysis process (Paper I)

MU	Condensed MU	Interpreted MU	Code	Sub-theme
(talking about the family) *Pointing at the image 'safe and secure' Do you mean you feel safe in your family?* ... Yes	I feel safe in my family	The family means security to me	Family means security	
You can always talk to them (parents and siblings) if you're bored…	I can talk to my parents and siblings if I'm bored.	Always someone to talk to in the family	Socializing in the family	
(*talking about activities by the computer and on Internet*) Parents usually, or can sometimes, spy on me...I don't think it's nice but they do it anyway	My parents usually spy on me when I'm on the Internet	Experience that parents are suspicious and control activities on Internet	Parents are experienced as controlling	Belonging to a family means security but may be "too much"
... .I may not always want to spend time with my mum. I usually lock the door to my room and listen to music or watch TV	I don't always want to be with my mother and then I stay in my room	Important to be alone in the room without parents being around	Doesn't always want to be with parents	
It's easy to imagine that the best thing a teenager knows when he starts to become like us is being at home alone … Then you're the king…	It feels good to be at home alone because I then experience power	Likes being at home alone and experiences power then	Nice being at home alone	

The process of ICF coding

Based on the completed COPM forms, the youths' top five self-identified prioritised problems were noted in a table and those identified by caregivers in another. All notes were then coded using the ICF-CY framework with focus on the component 'Activity and Participation' (WHO, 2007). The ICF general linking rules were followed (Cieza et al. 2005). All codes were discussed among three researchers until consensus was reached. The coding process is described step wise below.

1) Each annotation was linked with a specific ICF-CY code. During this process, imprecise notations were continuously checked with the completed COPM forms or the transcribed interviews.

2) In the cases where annotations were not sufficient for deciding the most precise code, a less detailed code was chosen. Additional codes were assigned for annotations that had more than one obvious component depending on its content. Annotations not identified in ICF-CY were marked as 'not definable ('nd') and noted verbatim.

3) All codes were compared in order to use same codes for similar content of the annotation. The fully ICF- CY coding of preferences is shown in Appendix 4 for youths and Appendix 5 for caregivers.

4) All main codes were organised on a group level by categorizing into the ICF-CY components and chapters (WHO 2007) using 'word findings' in Microsoft Word.

5) To test for differences in proportions between what the youth and caregivers deem as prioritized problems, an on-line Z-score test for proportions was used (Social Science Statistics, 16-02-12). P-values below the standard value of 0.05 were considered statistically significant (Björk, 2013).

Pre-understanding

The pre-understanding of the author of this thesis derives from experiences from several years of practice in social work, with both children and young people in general, and children and young people with disabilities in particular e.g. in 'daily activities' (LSS) and as an LSS administrator. This involved a useful pre-understanding which was an asset when interviewing both youths and caregivers. Further, the author is trained in keyword signing which was beneficial when conducting interviews with youth using this. To assure that the analysis process was not affected in a biased way, critical and reflecting discussions with two other researchers was done during the whole analysing process.

Ethical considerations

The World Medical Association (WMA, 2013) Declaration of Helsinki involves particular attention to participants' freedom to participate and to the declaration of confidentiality. In research involving children and youths, especially those with intellectual limitations, special considerations must be made both concerning informed consent and the guaranteed confidentiality and the researcher must ascertain whether each participant really understand what it means (Lewis & Porter, 2004; WMA, 2013). This also concerns immigrants (Study B) who might are used to different circumstances concerning research studies than those who had grown up in Sweden. During the period of data collection in study B several misunderstandings related to agreed dates and times for interviews occurred. In two cases caregivers thought that the invitation concerned a medical intervention for their youths. These types of misunderstandings were also experienced in a Norwegian study concerning needs in immigrant families with disabled children and were understood as different expectations due to cultural and language barriers (Berg 2015).

Youths and caregivers alike were carefully informed about the freedom to participate and were guaranteed confidentiality. Ethical approval and permission to undertake the study was given for study A by the Regional Ethical Board (Reg. no. 2011/350) and for study B (Reg. no. 2014/238) including an additional approval for continuing the recruitment with assistance from persons/professionals.

Informed consent

The invitation to participate in the studies contained information regarding the right to discontinue at any time, and assurance that refraining from, or terminating participation would not detrimentally affect the contacts with for example the Habilitation Services in any way. In order to enable the youths to fully understand this freedom, the invitations included a youth-friendly and easy to read versions and their caregivers received a copy of the information so that they could support their youths in their understanding. Furthermore, youths were given oral information before each interview, which entailed discussions and exemplifications as recommended by Lewis & Porter (2004). The youths were also offered an 'easy-to-read' brochure describing an interview. The caregivers were informed through the information letter and, later on, orally by telephone, as well as when finally participating in the interviews.

In focus group interviews, the moderator made sure that everyone understood the meaning of the freedom that allowed the participants to only tell what they really wanted to during an interview.

All participants gave their written informed consent. In the event they were younger than 18 years old, both the youth and their caregivers gave written informed consent. In the cases youth were unable to read and write, they were mutually informed and their caregivers gave written informed content. However, in study B, one of the youths with a mild ID was to be 18 years in a month wanted to participate in the study but refused to bring the papers home for written consents from a caregiver. This was accepted as children older than 15 years of age who realizes what participation in research involves are able to sign informed consent (*Riktlinjer för etisk värdering av medicinsk humanforskning : forskningsetisk policy och organisation i Sverige*, 2000).

Confidentiality

In accordance with the Declaration of Helsinki (WMA, 2013), all participants were guaranteed confidentiality; this meant that no names, only codes, were shown in completed questionnaires, the files, or in the transcribed interviews, and no connection to any individual could be made.

The participants in focus group interviews were informed regarding the fact that participating in group interviews means that confidentiality cannot be guaranteed within the group but that everyone should treat what they hear from each other with respect, as recommended by Krueger & Casey (2009). In the interviews with the youths (Paper I), this was carefully discussed within the group in a youth friendly manner by giving examples illustrating how youth can tell friends about what they have heard from others without realising the consequences. Computer files, transcribed interviews, completed questionnaires and analysis tables were stored in locked cabinets and/or encrypted computer systems. No citations can be traced to specific individuals. The citations may however be recognised by other participants from the same focus group interviews which all focus group participants was informed about.

Findings

The findings are presented under the headings; *Health and Wellbeing*, *Challenges* and *Preferences and Needs*. In this section, when presenting the finding from papers I and II, youths and caregivers will be referred to as from study A and findings from papers III and IV as from study B. The findings further reference papers and page numbers.

Health and Wellbeing

The youths' main experiences of health and wellbeing were related to participation, socializing and love. On one hand, caregivers' views of health and wellbeing were perceived as dependent on their youngsters' wellbeing. On the other, their own health and wellbeing was said to revolve around sorrow, stress and anxiety, but also a sense of coherence.

Family living

Family life was important for youths (Paper I) and caregivers in study A (Paper II) alike, and was described in both positive and negative terms. Families spent a lot of time together in everyday life and leisure activities, which were expressed as convenient, safe and pleasant but could also involve arguing and disagreements. Youths spoke of caregivers as supportive and being dependent on them to request and organize support and health care. They felt safe and secure and their caregivers felt needed. Youths (Paper I) experienced that caregivers, as a whole, assured healthy living by being good examples and by arranging for proper meals to be served and ensuring they went to bed in time. However, they also voiced the opinion that caregivers were sometimes overprotective and could be snoopy and suspicious. Youths said that it felt good to spend time away from their caregivers on occasion, and they intended to leave home in the future.

A majority of the youths in B were dependent on their caregivers for service and care demands (Paper III, Table 4). Receiving support from their caregivers was also seen as a job opportunity for the caregivers. However, they also expressed a desire to receive

support from persons who are not caregivers; the youth felt that caregivers had rules and expectations, which were not conducive to a normal life as a youth in Sweden.

Caregivers in study A (paper II) felt that family life was convenient and perceived a strong sense of community in the family and with other relatives. Co-operation between caregivers facilitated this sense of community and the family was run like a company. Most of the time, caregivers were pleased to have young people around and enjoyed their company. Being a caregiver of a youth with a disability and always feeling needed gave a sense of coherence. On the other hand, caregivers could appreciate when their youth was away, spending time with friends, another caregiver or some other reliable person.

Participating, socializing and love

Age-appropriate activities, friends and love were important issues for the youths in both studies (Papers I and III). They participated in leisure activities mostly organized for youths with disabilities, and they had friends in these activities and in school. Those who received the help of a companion service, contact person or personal assistant believed such a person could outwardly be presented as a friend. Half of the youth in study B (Paper III) were dependent on caregivers or personnel for organizing leisure activities.

Love was another important matter, and being able to experience love was something the youths in both studies longed for. For the youths in study A, the most important thing was just to 'have someone', but having sex was not yet experienced as central. When it comes to experiences of love as intimate and sexual relationships, the majority of youths in study B (Paper III) had no or few experiences of dating and kissing but were expected to get married in the future, a situation with which they were concerned and worried about.

The youths' participation in leisure activities and their friends were also important for their caregivers in both studies (Papers II and III). They were affected by their youths' lack of friends. On one hand, they wanted their youths to have leisure activities, but on the other hand, they became very anxious when their youth was away from home. They also hoped their youngsters would find someone to love; caregivers in study B (Paper III) hoped their youths would get married in the future. However, thinking about the challenges that this presented – for their youths to both find someone and then manage a marriage – caused them to worry.

Caregivers in study A (Paper II) experienced that their own social life outside work mostly took place at home with family and other relatives. Coordinating the jigsaw of family life with social life, keeping up with friends outside the family, was a challenging task. However, many had coping strategies such as using free time when their youths were at school or in organized activities. Some took turns looking after

children, whether they lived together or not, which enabled caregivers themselves to have time to engage in health-promoting activities. Furthermore, having a good love life was seen as important for their wellbeing, but concerns during the youths' transition could affect their marital, sexual and romantic relationships. Intimacy within relationships could be disturbed by the presence of young adults in the home for most of the time or by having assistants around.

Anxiety and stress

Anxiety and stress was mostly found among the caregivers (studies A and B). The anxiety related to the youths' actual life but also their future lives without the caregivers' support. Facing their youths' transition made caregivers more anxious about the future.

Caregivers in study A (Paper II) spontaneously recounted events that had occurred years ago and spoke of the sorrow and feelings of loss when thinking about what life might have been like for their youths, had they not had a disability. Stories concerned the first information of the child's condition and unsympathetic professionals they had met over the years. Fresh memories from their youths' early childhood and everything that had happened then were expressed. Being a caregiver to a youth with a disability also entailed the normal common types of conflicts between youths and caregivers. This was considered even more difficult, since their youngsters were more vulnerable and more dependent. Caregivers were also concerned for their other own children and experienced having less time to spend with them and they had guilty consciences since they felt that the other own children became side-lined.

Worries were expressed by caregivers in study B (Paper III) for the growing child and for the youths' physical development into adult men and women. They worried about their daughters' menstrual periods and how to handle these new situations. Their sons had grown up and become men, and mothers felt it was inappropriate to help their sons with their intimate hygiene, which made them worried. Caregivers also worried that they no longer would be able to take care of their youths in the future. Concerns over handing over the care to personnel were expressed. They were anxious as to whether these professionals really would have knowledge about proper food and medicines the youths might need.

Challenges

The transition was experienced as a demanding time, when youths and caregivers in both studies alike had to prepare for the youths' transition to adult living and for the transition from the support and health care for children and youth to adult services.

Both youths and caregivers lacked readiness when facing the transition, and found the service systems confusing. They lacked adequate information and had a feeling of being lost.

Challenges with participating, socializing and love

Problems managing spontaneous activities such as going to the pub or cinema were experience by the youths in study A (Paper I), because such activities had to be arranged a long time in advance. Participation in regular youth activities was experienced as challenging for the youths in both studies, since it was difficult to order a taxi or to travel by means of public transport, and to orientate oneself in the community without support (Papers I, III and IV). 'Hanging out' and keeping up with peers were perceived to be impossible, as friends were not always there and those who had friends found it problematic to meet them without having the family around. Youths in study B (Paper III) wanted to join sports activities aimed at people of both sexes, but they were not allowed. They found it challenging that their caregivers had different rules for them than what applied to their Swedish peers.

An important issue for the youths in study B (Papers III and IV) was planning for leaving school, getting a job, and earning their own money. They were aware they lacked opportunities to get a job for immigrants in general. To search for a job or to find any 'daily activity' was seen as a great challenge.

Caregivers in study A (Paper II) had difficulties finding time for their own leisure activities. Furthermore, they found it challenging to give due attention to their marriages, as partners mostly had individual recreational activities. They also expressed that having a child with disability made it more or less impossible to separate and break up a marriage. If divorced, finding a new partner was experienced as problematic and caregivers who remarried did not always find it easy to share emotions and experiences of being a parent of a disabled child with the new partner.

Challenges managing daily life

Performing simple tasks such as making a sandwich or buying inexpensive items was considered by the youths in study A (Paper I) to be manageable. By contrast, the youths in both studies (Papers I, III and IV) found it challenging to handle more advanced financial matters such as saving money or buying expensive items. Ordering fast-food or preparing simple food was also perceived as difficult (Studies I and IV). Youths (Papers I and IV) found it problematic to travel by themselves to unknown places by public transportation, because the bus numbers and time tables were considered difficult to understand.

Caregivers in study A (Paper II) experienced challenges with coordinating everything in daily life. They were always busy transporting and supporting their youths. They organized support, they had meetings with support and health-care professionals, and they had numerous phone calls to make. This in combination with their own work and family responsibilities made the everyday life challenging.

There were both similarities and differences between the problems identified by the youths in study B during their transition to adulthood and their problems as identified by their caregivers (Paper IV). The similarities related to problems in domestic life, such as simple cooking and preparing meals after school. However, a statistically significant difference was shown between the youths' prioritized problems and that of their caregivers in their problems identified in the ICF-CY chapters "Major life areas" (P-value=0.010) and "Self-care" (P-value=0.000). The youths' most commonly identified problems concern major life areas, searching for a job and handling pocket money. The caregivers believed their youths' prioritized problems related to issues such as showering, using the toilet, shaving and dressing/undressing (Paper IV, table 4).

Challenges with transition to adult support and health care

Youths in both studies (Papers I and III) had little or no experience of activities intended to prepare them for their transition to adulthood. The youths in study A knew that there were activities available at the child and youth habilitation unit. There were information meetings about the transition to adulthood and about the possibilities of moving on to adult support and health care, but youths felt that there was too much information and that most of it did not concern them. The youths in both studies only had vague ideas about what kind of support would be available in the future. A majority of the youths in study B (Paper III) attended special schools. Several of them had support in accordance with LSS (Paper III, table 1) but none of them had experiences of individual plans in accordance with LSS (Paper III, table 3).

Caregivers in study A (Paper II) felt a great deal of information was demanded, and that it was problematic to find out when different things should be done and applied for, and exactly what was required. They had been to information meetings about transition but felt they were given too much information and that it was difficult to sort out what really concerned them and their youths. Furthermore, they found that these meetings sometimes took place too early in the process, when the information did not yet feel relevant. However, issues of how to prepare for the situation when their youths turned 18 and would potentially be in need of a trustee, and future opportunities of activities and/or employment or higher education, were important.

Caregivers in study B (Paper III) expressed a need for information about their youth's condition. All married caregivers stated that their husband/ wife also needed the

information (Paper III, Table 5). Caregivers were unfamiliar with how youths were diagnosed according to their intellectual level in Sweden. They also thought that native-born Swedish youths received different treatment to their own youths at school. None of the caregivers had experiences of an individual plan for their youth, in accordance with LSS (Paper III, table 3).

Preferences and needs to manage the transition

The youths in both studies (Papers I and III) wished they had someone who could guide them through the transition. This guide could be any professional, but should be a person they know well and have confidence in. The physiotherapist or the teacher was in any case perceived as someone they knew well and whom they met with on a regular basis. Youths in study B (Paper III) wanted someone to talk to them about future marriage and parenthood, and they wanted help with seeking employment, special service housing or accommodation. In addition, youths in study A (Paper I) believed that leaving their parental home gradually might facilitate their transition to independent living. They expressed a desire to live on their own but near their caregivers for the first period after leaving home or to live in housing. They felt that this might reduce their feelings of loneliness and ensure that they could receive support if and when they needed.

The caregivers in both studies (Papers II and III) expressed a desire for professional and individualized information to help them increase their own awareness of how to support their youths in their transition to adulthood. The most desirable situation would be one in which they had a contact person who could support the whole family and act as a coordinator. According to the caregivers in study A, this contact could be anyone but needed to be someone who was able to find out appropriate information that both youths and caregivers actually needed. He or she should support them by sorting out information that was appropriate for the unique needs and wishes of the family at the time they needed it. A desire that this coordinator would provide hands-on support with for example making applications for them, was expressed by caregivers (Paper II).

A majority of the caregivers in study B (Paper III) needed information about services that their youths might receive in the future. Half of them also needed information about transition to adulthood, including information about trusteeship. Caregivers preferred individual support and information.

Discussion

Methodological considerations

A combination of methods was used according to a triangulation method (Kazdin, 2014). In study A, an inductive qualitative design was chosen to understand the experiences of the youths and caregivers, which is in line with recommendations by for example Kazdin (2014). Study B was designed to enable immigrant youths with disabilities and their caregivers from Arabic speaking countries residing in Sweden to describe their challenges, preferences and needs. A combination of quantitative and qualitative methods based on structured interviews with questionnaires for data collection was employed, in order to ensure that all participants were interviewed in a similar manner, regardless of language and interviewer (Kvale & Brinkmann, 2009).

Recruitment of participants

Youths aged around 17 (and their caregivers) were invited to participate in study A, as young people in Sweden become adults by law at age 18, which in general implies personal responsibility for decisions on matters relating to their own health and support. The decision to include youths with CP was based on the fact that this condition involves motor limitations often associated with other limitations such as ID, meaning a great variation of disabilities (Palisano et al. 2007). Youths with CP often need habilitation services during their lifespan, which is why planning for their transition to services for adults is important.

In study B, youths aged 13-25 years (and their caregivers) from specific Arabic speaking countries were invited as a linguistic group for two main reasons. Firstly, almost none of the participants in study A were born outside of Sweden, which made these results less transferrable to people living in a multicultural society. Secondly, people from Arabic speaking countries are an increasing linguistic group of immigrants residing in Sweden, which stress the importance of obtaining more knowledge about their specific preferences and needs (Nilgert, 2009). The rationale behind having a larger age group than in study A was that it is recommended that the preparations for transition to adulthood commence in early adolescence, when in reality, the present situation is that youths commonly live with their caregivers until

they are at least 25 years of age (Arnett, 2004; Gorter & Roebroeck, 2013). The reason for including youths with any disability was the challenges encountered when recruiting participants to study A.

In both studies, the recruiting process started with invitations sent from habilation units and schools. In study A, the habilation services and schools that were responsible for identifying participants decided to invite the youths who according to their register corresponded to the target group. Because confidentiality law protects youths and families, they may not be contacted directly for research purposes by personnel at habilation units, for example. The author of this thesis only contacted those who had returned the interest form for further details about the study (Sekretess inom hälso och sjukvård, 2013). The invitation letter was in Swedish, which may explain why there were so few participants with non-Swedish backgrounds that responded. This implies that youth and caregivers might have been interested in participating if they had been given verbal information about the research project, and in their language of preference. The low number of responses may also be understood in the light of the situation that families with youths with disabilities receive high volumes of information by mail. In fact, it became known during the interviews that youths did not always open all envelopes they received from the habilation services.

In study B, the invitations could not be sent from schools or habilation units in the same manner as in study A. Because the country of origin is not recorded in support and health care registers, this information is based only on professionals' knowledge. The recruiting process therefore began with asking responsible persons in habilation services and schools to assist with the recruiting by identifying whom to invite. The responsible persons in habilation services in the municipality and the schools granted permission for professionals to assist but permission was only granted in one of the two counties.

An additional ethical approval was necessary in order to request assistance directly from personnel, who had first-hand contact with the target group, and ask if they could mediate information and contact with the researcher. A large number of contacted personnel were willing to assist, and actually did. A remarkable number, directly or indirectly, refused. The reason they gave was that they did not want to 'disturb' families with respect to their 'vulnerable situation'; both having a disability and being an immigrant. On one side, the Medical Research Council defines people with disabilities as vulnerable (Riktlinjer för etisk värdering av medicinsk human-forskning: forskningsetisk policy och organisation i Sverige, 2000). On the other side, according to the Declaration of Helsinki (WMA, 2013 p 3) 'groups that are underrepresented in medical research should be provided appropriate access to participation in research'. Nind (2008) cites Lennox et al., (2005) and argues that personnel may be too suspicious of the research and therefore not want to assist and be involved. When professionals do not grant permission and personnel do not assist

in the process of recruiting, they are acting as gatekeepers. This might lead to those linguistic minorities not get the possibility to give their voice in research (Ingvarsdotter, 2014). Lack of knowledge about specific immigrants' self-identified needs consequently leads to their needs being neglected when planning transition information and designing transition programmes. It is also worth mentioning that when those interested in participating in this thesis (youths and caregivers alike) were finally interviewed, they expressed their gratitude when asked about their situation. They were very hospitable and helpful in arranging a time and place for interviews. This indicates that taking time to build trust is important and is consistent with the experiences in earlier studies involving linguistic minorities that found that trust-building was essential (Berg 2015; Lindsey et al. 2012). The assumed fear of disturbing 'vulnerable people' might not be well-founded. Another vulnerable group, siblings to children who have died of cancer, were found to be positively affected by being able to share their experiences in research (e.g. Eilegård, Steieck, Nyberg, & Kreicbergs, 2013).

Data collection

This thesis included various methods of data collection involving methodological considerations when interviewing participants such as youths with ID and non-Swedish-speaking participants.

Individual interviews

Semi-structured interviews (Papers I and II) were found to be appropriate in order to gain a deeper knowledge of youths' and caregivers' experiences. Kvale & Brinkmann (2009) claim that using qualitative methods allows the researcher to stay close to the empirical world, and by listening to people tell their stories it is possible to obtain first-hand knowledge about their experiences. A topic guide was used to stimulate and encourage participants to speak freely whilst keeping to specific topics related to health, wellbeing and needs. Follow-up questions were asked for clarifications. This created a structure for the interviews and helped the participants to think of various topics relating to their experiences of health, wellbeing and needs. The youths may for example not have reflected on their alcohol or sleep habits without these specific topics in the interview guide. This is in line with the recommendations of Krueger & Casey (2009).

The COPM (Canadian Occupational Performance Measure) was used in semi-structured interviews with both youths and caregivers (Paper IV) as this is a well-known and accepted semi-structured instrument used world-wide in rehabilitation interventions to identify experienced problems/challenges with activities (Carswell et al. 2004; Chiarello et al., 2010; Law et al. 2015). COPM has also been used to set goals for youths with disabilities in transition planning, on the grounds that is

purportedly reliable and youth-friendly (Gorter et al. 2015). However, challenges were encountered in that the interviews took longer than expected and it was demanding for some of the youths to concentrate all the way to the end of the interviews. To facilitate the process for the youths, the COPM form was filled in together with the youth, sitting at his/her side, and short brakes were taken. For the caregivers, it was difficult to focus on their youth's problems and not their own problems. To counteract this, they were continuously reminded to think of how they believed which problems their youth prioritizes. Moreover, both youths and caregivers found it difficult to score on the VAS scale, scoring either 1 or 10 and nothing in between, hence support and dialogue with the interviewer. This was the reason for not summarizing the total scores for performance and satisfaction when analysing the COPM interviews in accordance to the instructions by Law et al. (2005). A seven-point Likert scale might have been easier, as Laerhoven (2004) discovered that children found numeric VAS in questionnaires to be difficult and that the Likert scale was preferred.

The tool RTP (Paper III) has been used in earlier research with youths with CP, mainly without ID (Donkervoort et al. 2009). However, the majority of the youths in study B had mild ID. Because the RTP interviews were individually customized, yet based on the structured arrangement, this functioned as a means of discussing where in the transition phase the youths believed they were. Some of the challenges encountered were that the some of the interviewed male youths found the part concerning household management to be irrelevant, arguing that men never have to cook or clean as this is a female activity in their culture. This was not the case for all boys participating, however, and RTP may function as a tool for assessing the readiness for transition of a youth with any disability, regardless of cultural differences, if it is customized.

FNS (Paper III) has been found to have good test-retest reliability as a structured questionnaire for use in interviews with caregivers to help them to identify their needs (Baily & Simeonsson, 1988). FNS has also been tested for utility and acceptability in research with caregivers, including immigrants in the United States (Baily & Blasco, 1990). Their results showed that although the majority of caregivers were satisfied with FNS as a standardized questionnaire to help them recognize their needs, nearly 60% of the mothers preferred sharing their needs through interpersonal discussions with professionals. This was the reason similar items were not added to FNS used for caregivers (Paper III) as adopted by Palisano et al. (2010) and instead use open-ended questions intended to cover caregivers' needs specifically in connection with their youths' transition to adulthood. The rationale behind using the original version (Bailey and Simeonsson 1988), despite FNS having previously been translated and adapted to Swedish (Granlund & Roll-Pettersson, 2001), was that the translation to Arabic had to be made from the original English version as the person providing the Arabic translation did not speak Swedish.

FNS contains a statement concerning needs of respite service for the child during services in the "church or synagogue". This statement was moderated in the Swedish version used in course material for family support tailored specifically to caregivers of children with mild ID. So as to fit in a Swedish context, the phrase 'church or synagogue' was changed to "spontaneous activities" (Public Health Agency of Sweden 16-02-25). However, because all caregivers (Paper III) talked about regularly visiting the Mosque – and thus none of the caregivers expressed a need for respite service for their youth during services in the Mosque – the term 'Mosque' should be added to the FNS with respect to diverse religious beliefs.

Combining focus groups and individual interviews for data collection

The purpose of conducting interviews in a focus group is to collect a range of opinions among people who have something in common which they are able to discuss, rather than having them answer questions (Kitzinger, 2013). Group members may vary in terms of age, gender, occupation or education but they still have something in common (Kitzinger, 2013; Krueger & Casey, 2009). Nind (2008) discusses in a methodological paper review that, in focus groups with people with ID, participants may experience difficulties discussing and interacting in a group due to communication problems and lower intellectual ability, for example. To enable interaction among the youths (Paper I), the groups were therefore organized so that the youths, as far as possible, were on the same intellectual level. The focus group including youths with mild ID met three times and none of them used Alternative and Augmentative Communication (AAC) to communicate. Youths using AAC or who were interviewed by proxy did not participate in focus groups based on their preferences.

Taking into account participants' wishes in terms of specific times was necessary. The interviews with caregivers (Paper II) were organized according to their requested time and place out of respect for their assumed fully-booked and stressful daily life (Broberg et al., 2014). This resulted in two married couples taking part in the same session. The moderator noted that two caregivers did not voice their experiences but let the wife/husband talk instead. Because all participants were asked about their interest in further interviews, these two caregivers participated in other occasions. One of them participated in a further focus group interview with other caregivers and the other caregiver was interviewed individually after one week, which enabled them to express their experiences.

Interviewing in focus group or individually are two different kinds of methods for data collection. Because interviews in focus groups are based on interactions between the participants, this might result in a variation of experiences, whereas individual interviews can lead to a greater depth in the answers (Kitzinger, 2013; Krueger & Casey, 2009). In Paper I and II, the combination of different interview techniques had practical and ethical considerations. By offering various opportunities with

respect to those who were unable or unwilling to attend a focus group, or unable to express their experiences in a group, all those who were interested were included. Lambert & Loiselle (2008) argue that although focus group interviews and individual interviews are independent methods for data collection, a combination of these methods enables the collection of a richer and deeper data material, which was the case in Papers I and II. The same layout was used in both focus group and individual interviews to underpin that the interviews as far as possible should result in equal depth in the participants expressed experiences. Furthermore, both youths and caregivers participated in both types of interviews (Table 3). However, structured interviews differ from open-ended questioning in a number of essential aspects, which is why the combination of semi-structured, open-ended questions and structured interviews was used in Papers III and IV. The combination of qualitative and quantitative approaches in this thesis, involving different strengths and limitations, may have been a complementary one, resulting in a variation of experiences among those who had the transition to adulthood in common (Kazdin, 2014).

Interviewing in two different languages

In study B, the rationale behind giving participants the opportunity to be interviewed in Arabic without the use of interpreters was that collaborating with interpreters is complex and may not always yield true and fair answers in interviews (Ingvarsdotter, Johnsdotter, and Ostman 2012). Participants do not always trust that their confidentiality is respected by interpreters and may be reluctant to speak freely (e.g. Berg 2015). It is also common that interpreters are known persons among linguistic minorities, which can lead participants to refrain from participating in an interview or feel too afraid to speak about their experiences. The challenges presented by conducting interviews with two different interviewers might mean that nuances in expression when discussing experiences may be missed. To avoid this, the interviewers discussed both sets of notes and transcribed interviews after each interview, during the process of transcription and analysis, in order to confirm what the participants expressed. To calibrate the interviews, both interviewers were trained in COPM interviews in one and the same session and both interviewers were present during the first interviews with both youths and caregivers.

Most of the youths in Study B spoke fluent Swedish and preferred to be interviewed in Swedish. This is partly due to the fact that the majority of the families had lived in Sweden for more than five years. In some cases, the youths were born in Sweden. Kuczynski and Knafo (2013), for example, argue that by participating in school, immigrant youths find it easier than their caregivers to adapt the language and culture of their host country.

Interviewing participants who needs special attention

Interviews with children and adolescent youths in research are based on the same method as interviews with adults, but the researcher should be aware of the

importance of the young people having the real possibility to express their experiences in their own way and ensure this condition is met (Gill, Stewart, Treasure, & Chadwick, 2008; Hansen Orwehag, 2013). When interviewing youths with disabilities, in particular those with ID, it is important to facilitate the communication in a way that suits the individual (Cambridge & Forrester-Jones, 2003; Kroll et al., 2007). This could for example mean including images and symbols, but may also involve providing physical support where necessary (Kroll et al., 2007; Lewis & Porter, 2004). In all of the interviews with youths, pictogram images and key word signing were offered in order to strengthen the youths' understanding and speech, but only four youths (Papers I, III and IV) used AAC to communicate. The author of this thesis is trained in key word signing, meaning that an interpreter was not required. Using predetermined images might however have affected the youths' own train of thought (Wibeck et al., 2007). The strength of using pictograms and interviewing by proxy was that youths with severe speech limitations, who most often are excluded in research, also had the possibility to 'have their voice heard' in this thesis (Bailey, Boddy, Briscoe, & Morris, 2015; Hart and Chesson 1998).

The interviews were emotional for the caregivers (Papers II, III and IV), and youths and caregivers raised questions concerning support during the interviews. At the beginning of each interview, the interviewees were informed about the possibility to ask questions after the interview. The interviewers took time to talk and answer general questions after each interview, to make sure that everyone felt comfortable before ending the meeting. Dahlberg, Dahlberg, and Nyström (2008) believe that a researcher must be aware of participants' emotional reactions during an interview, and that emotions which participants were unaware they were carrying can be brought to life, giving rise to tears, anger and even happiness during an interview. The participants were therefore informed about the opportunity to receive support from their local habitation services who offer counselling to families.

Analysis process

The qualitative analyses were made using content analysis at both manifest and latent levels (Papers I, and II) as it is suitable for analysing large amounts of text material, which was the case in these papers (Downe-Wambold, 1992). The steps in the process of analysis were followed as the studies had an inductive approach involving an open-ended process of analysing empirical data (Kazdin, 2014). The qualitative analyse aims to organize empirical data in a structured way so that the results elicit meaning from the research data. Analysing in several steps proved useful as the data collection in both studies involved large bodies of text which needed to be condensed and interpreted in order to be manageable and understandable (Kazdin, 2014). The interpretation was also useful when analysing interviews made with those who used

pictogram images to communicate or who were interviewed by proxy. Analysing texts from interviews made by proxy requires special considerations (Nind, 2009). In the texts from the two interviews made by proxy, large parts could not be analysed due to uncertainty whether the experiences were the youths' own or the proxy's depictions.

The results were mainly analysed descriptively. Due to the limited number of participants, it was impossible to analyse the data material from the questionnaires from FNS and RTP in the manner adopted in other studies. For example, it was not possible to examine the interaction between age, GMFCS level and type of family needs as Palisano and colleagues did in 2010. Furthermore, the intention was to examine differences in the need of mother and fathers and whether lengths of residence in Sweden had any impact on caregivers needs. Nor was it possible for the results to be analysed to examine youths' readiness for transition in relation to biological age and GMFCS levels (Donkervoort et al. 2009).

According to the COPM, the aim of summarizing total scores on a scale is to follow up changes over time. This was however not the aim in paper IV. As the notes from the participants' prioritised problems were not detailed enough and too few participants were included, they could not be analysed according to the categories and sub-categories in COPM, as suggested by Law et al. (2005). Therefore ICF-CY was used as a framework for a deductive analyse of the participants prioritized problems. ICF-CY represents a standardized language which enables a more detailed organization and comparison of problems identified by youths and caregivers respectively (WHO, 2007). In addition, the Swedish National Board of Health and Welfare (2011; 2015) recommend ICF/ ICF-CY be used for describing peoples' needs, using a collective language within services for people with disabilities. By using a standardized language, increased collaboration within and between systems of social service and health care might be facilitated. In habilitation services and in LSS assessments, the use of ICF in documentation is used (Föreningen Sveriges Habiliteringschefer, 2014; The National Board of Health and Welfare, 2015), but more knowledge of the usefulness of ICF-CY is needed, including its usefulness in transition planning.

Linking texts to the ICF-CY involves challenges in terms of e.g., interpretation, as several codes share common topics in the components which have been discussed by Klang Ibragimova and colleagues (2011). Discussions regarding code assignment therefore continued between three researchers throughout the analysis process. When interviewing using COPM (Paper IV), the interviewer made short notes based on the problems voiced by participants (Law et al. 2005). When the meaning of the notes was found to be unclear during the coding process, the completed forms and/or the transcribed interviews were checked for what and in which context the problems had been explained. Any statement not definable in ICF-CY, for example 'to get' a daily activity in accordance with LSS, was coded as not definable ('nd') according to the linking rules (Cieza et. 2005).

Quality considerations

This thesis comprises different, mainly qualitative but also more quantitative methods. Evaluating the quality of research with a qualitative approach calls for a dialogue on *trustworthiness* comprising the following concepts: c*redibility*, *dependability*, *confirmability* and *transferability* (Kazdin, 2014). To evaluate the quality in quantitative research, the corresponding terms are *validity* and *reliability* (Kazdin, 2014).

Trustworthiness

Credibility refers to confidence in the truthfulness of the data and deals with how data represents what it was meant to describe (Lincoln & Guba, 1985; Kazdin, 2014). This depends for example on the distribution of informants and whether or not there is sufficient representation by gender, age or degree of disability. To establish the credibility, a variation in this thesis was ensured by the representation of both male and female youths, representing both youths with PD and ID and that the caregivers represented both mothers and fathers. A limitation in study B was that, although the intention was to involve youth with a variation of disabilities, almost all youth attended special school and had ID.

The amount of data is also an important factor in ensuring credibility (Kazdin, 2014). In Papers I and II, several participants were interviewed on more than one occasion (Table 3). This enabled the participants to reflect and extend their reasoning which resulted in a large amount of material including deeper and more fully described experiences. The answers to the open-ended questions (Paper III) supplied an unequal amount of data as some of the participants told long stories whilst others were quite short in their answers. This was the reason for analysing at a manifest level; the issue of credibility also concerns how well categories and themes cover what the texts says, and ensures that no relevant data is excluded, which can lead to biased results (Kazdin, 2014). To further strengthen the credibility, quotations were presented in connection with themes and categories (Papers I, II and III).

Dependability concerns whether the interpretations are representative (Kazdin, 2014). To strengthen the dependability, the data was collected using semi-structured interviews involving the use of follow-up questions to ensure that every one of the participants was able to fully explain what they meant. To improve the dependability, careful verification of all statements should be made throughout the research process (Kazdin, 2014). Therefore, throughout the analysis process and the presentation of the results, the whole process, from invitation to participation, was carefully described. The process was also discussed and deliberated on with two co-authors of the papers.

Confirmability refers to the objectivity of the data (Lincoln & Guba, 1998; Kazdin, 2014). In qualitative studies, a researcher cannot be objective due to pre-

understanding. In order to reduce the risk for subjective analyses it was assessed by two co-authors with different experiences in the field of children and families. The analyses of the transcribed interviews (Papers I, II and III) were read independently by three of the authors in the papers and then discussed until consensus was reached. The coding using ICF-CY (Paper IV) was made with assistance from one of the co-authors and involved comprehensive discussions. Furthermore, preliminary results were discussed and critically reviewed in a multidisciplinary research group consisting of approximately 25 persons – among which doctoral students and senior researchers – as recommended by Lincoln & Guba (1998).

Transferability deals with how the results from a study can be transferred to other groups (Kazdin, 2014). Whilst the small sample size studies limit the possibility to transfer the results, some important issues deserve a mention. The participants represented a variation of age, gender and country of origin. The youths represented a heterogeneous group with a variation of disabilities and intellectual levels, including mostly youth with normal verbal ability but also those with speech limitations. Participants were living in different parts of Sweden and therefore had contact with different social and habilitation services. It is therefore reasonable to assume that the results can be used as a reference for understanding or conveying an understanding of other youths and caregivers' experiences in similar situations. There may however be cause to believe that those who participated had a special interest in the topic and were perhaps more engaged than most people are. This might make the results less transferable to youths and caregivers not as engaged as the participants in this thesis. The participants in study B only represented a small group of people with Middle Eastern origin, making the results less transferrable to Middle Eastern immigrants in general. To further strengthen the transferability, as recommended by Graneheim & Lundman (2004), each quotation (Papers I, II and III) was marked with for example age and whether the participant was male or female and whether the citation came from a focus group interview or from individual interviews (Papers I and II).

Reliability and Validity

Reliability refers to the degree of consistency or accuracy with which a questionnaire measures what it is designed for (Kazdin, 2014). Validity refers to the degree of which a questionnaire measures what it is aimed for (Kazdin, 2014). To increase the reliability and validity of the questionnaires in this thesis, the questionnaire RTP has previously been tested for validity for use with youth with CP and mild or no ID (Donkervoort et al., 2009). The translated version used in this thesis was adapted to fit in a Swedish context and for use with youths with ID, including youths that receive support according to LSS. This version was tested for validity with five Swedish speaking youths with various physical and cognitive disabilities (CP, ID and autism) and was found valid (Paper III). FNS has also been tested for reliability and validity with caregivers of children and adolescents with disabilities and designed to support caregivers to share their needs with professionals. By using a structured

instrument, caregivers were able to recognize needs they had not considered previously (Baily et al. 1988; Baily & Blasco, 1990). FNS have been used in research to identify needs in caregivers of children and youths up to the age of 21 in the United States (Palisano et al., 2010). This means that the testing for reliability and validity of FNS has been made in contexts other than the Swedish. The statements in FNS used in this thesis include for example the term 'play', which in a Swedish context might not be appropriate in relation to caregivers of youth in the ages of transition to adulthood. *Internal validity* refers to the extent to which research can be considered to account for differences in results (Kazdin, 2014). Therefore, to increase internal validity, the caregivers were instructed to have their 'youth' in mind when listening to the statements. Further, tables comprising all questions and answers of FNS (Paper III, Table 5) and descriptions of the stages in RTP (Appendix 6) are included to make the entire process transparent and to demonstrate that the study questions were asked in the manner intended. Internal validity also refers to whether the study population is representative or not (Kazdin, 2014). To increase the internal validity in this thesis, the variation of participants is carefully described and the characteristics of caregivers in paper II and caregivers and youths in study B are shown in tables. *External validity* refers to how a result can be generalized (Kazdin, 2014). The results of this thesis cannot be generalized since the studies involved relatively few participants. The participants represented youth with great variation of disabilities including different levels of motor limitations and intellectual levels. Further, the sample although small, represented both male and female youths in the ages 13-24 years. The low number of participants however entailed that it was impossible to identify factors related to gender, cognitive age or levels of motor limitations and health and wellbeing, preferences, challenges and needs of the youths during the transition to adulthood. They may however provide a representative sample for further understanding of these groups of youths and their caregivers.

General discussion of the findings

Selected findings are discussed from a health and wellbeing perspective using the ICF-CY as a conceptual framework to illuminate the importance of interaction between the components to understand youths' and caregivers' challenges, preferences and needs. The findings are also discussed in relation to youths' biological age, disability and cultural awareness.

The family life was important for both youths and caregivers' health and wellbeing. Youths experienced challenges and anxiety linked to socializing with peers, dating and future marriage, participating in activities and access to post-school options. These challenges concerned their caregivers as well. The immigrant caregivers were unfamiliar with diagnosis terms used in Sweden. The findings showed that both

youths and caregivers lacked necessary information on the transition to adulthood. Understanding the problems experienced by young people and their preferences in terms of support can facilitate individual transition planning. It is important to understand how young people function by examining the interaction between the components (Kraus de Camargo, 2011). Youths and caregivers desired individual information and support to manage the transition from services with a family centred to a person-centred approach. Collaboration between the different services systems is discussed in relation to the standardized language in ICF-CY. Lastly, the youths' rights to be involved in their own transition planning are highlighted, and tools that can facilitate youths' involvement are suggested.

Body functions and structure

In ICF-CY, *body functions and structures* are people's physical and mental functions, and *impairment* is a problem or loss of these functions (WHO, 2007). The findings in Paper III, showed that the immigrant caregivers were unfamiliar with the term ID thus most of them had been living in Sweden for more than five years. This is of great interest because in Swedish support and health care services a person's diagnosed impairment is essential, for example being eligible for support according to LSS (Proposition 1992/93:159). Caregivers from Middle Eastern countries might not be comfortable requesting support when they have to first clarify their child's diagnosed impairment, if they not are familiar with using the term for the diagnosis term. Avoidance of applying for support due to unfamiliarity with terminology used in a western country has also been discussed by Berg (2015) who has experiences of research concerning needs of immigrant caregivers of disabled children residing in Norway. However, unfamiliarity with professionals' use of medical jargon has also been experienced by non- immigrant caregivers (Arcuri et al., 2016). Furthermore, uncertainty about what a diagnosis means and its consequences for the child were also found in Swedish caregivers of children with disabilities (Nowak, Broberg, & Starke, 2013). According to Olsson & Hwang (2003) caregivers felt that they had to focus on their child's limitations to receive support, which was experienced as uncomfortable. This was also highlighted in the report by Broberg and colleagues (2014) who also found that half of those who had applied for support in accordance with LSS for their child had appealed against an unfavourable decision, of which 40 % later received a more positive result.

Attitudes concerning disability are therefore also related to environmental factors involving the attitudinal environment in which people have lived, live and conduct their lives (WHO, 2001; 2007). This might in particular concern ID associated with stigma which has been discussed in research from the United Kingdom. The researchers found that the stigma of having ID was more common among ethnic minorities than among those born in the country (Scior et al., 2013). In particular,

this concerns people from the Middle East where ID is stigmatized in many countries (Crabtree, 2007; Hasnain, Rooshey et al., 2008). Neither the term 'ID' nor the term 'disability' is universal and people from different linguistic cultures may are more comfortable using own descriptions (Raman et al. 2010; Leavitt, 2002; 2003). Therefore, in service delivery to caregivers not speaking the language in their host country, culturally sensitive service is important. According to Campinha-Bacote (2002) and Nochajski and colleagues (2008), this involves knowledge about the client's worldview and disability practices. To listen to each youth's/caregiver's description might give an understanding of their individual comprehension. Thereafter it is of importance to deliver adequate information about terminology and legislation in their host country. In line with culturally sensitive service, to assess the youth/-caregivers' linguistic needs, it is important to provide information and explanations of the individual youth's' condition in a language of preference (Broberg et al. 2014; Campinha-Bacote, 2002).

Environmental factors

In ICF-CY, *environmental factors* involve, besides environmental attitudes, the physical and social environment in which people live (WHO, 2007). The findings showed that the family played a central role for both youths and caregivers as an important *environmental factor* during transition. The importance of family life in leisure time for youths and of the sense of coherence for the whole family is consistent with earlier research showing that youths with disabilities commonly spend leisure time together within the family network (Anaby et al., 2013; Foley et al., 2012). Family life has also been found to be important for improved health in youths without disabilities (*Fokus 13: unga och jämställdhet,* 2013). For immigrant youths and caregivers, the family might be particularly important due to limited social network in a new country of resistance (al-Baldawi, 2014; Berg 2015). Furthermore, caring for family members is common among people with traditions of collectivistic living (Hasnain, Rooshey et al., 2008), which may involve strong family ties for immigrants with a Middle Eastern background.

Youths (Papers I and III) found it difficult to handle the matter of love, for example, meeting someone and knowing how to manage situations such as dating. The results from Donkervoort and colleagues (2009), based on the use of RTP in research involving youths with CP 18-22 years but without ID, showed delayed development in intimate relationships in comparison to youths without any disabilities. Lövgren-Mårtensson (2004) argue that youths with ID found it problematic to develop sexual relationships and love experiences due to being protected by caregivers and having personnel around in situations where they might have an opportunity to meet a love partner and experience intimacy. Wiegerink et al. (2010) argues for the importance of

self-confidence in the development of intimate relationships which in turn depends on possibilities to socialise with friends.

The results in Paper III showed however that immigrant youths were expected to get married in due time, which evoked anxiety and concerns in both youths and caregivers. On one hand this might be understood as involving the same concerns of challenges for youths in study A (Paper I) to experience love and intimate relationships. Youths who grow up in families where a young person should be married before having intimate relationships might simply use the term 'to marry' instead of 'having a girl-/boyfriend'. On the other hand, immigrant youths were worried about how to handle a marriage and future parenthood. This is consistent with the findings of Kosidou and colleagues (2012), which revealed that distress in young immigrant women without disabilities was associated with parenthood, or not being a parent.

The possibility of self-determination concerning intimate relationships may differ in cultures. The attitude towards intimate and sexual activity is generally permissive in the Swedish society and the 'free will' and also the right to marry might be obvious for many youths in Sweden (Hwang & Nilsson, 2011). However, it is of importance that immigrant youths who are expected to get married receive information about what marriage and parenthood involves and their human rights to make own choices. Any expectations concerning future marriage might therefore receive the attention of professionals in their encounters with immigrant youths, especially girls, who might need special information on these issues. Murphy and colleagues (2015) point out that sexuality might be a sensitive topic for many youths with ID and their caregivers and argues for the importance to discuss these issues 'in the moment'. This implies that it is important that any professionals are prepared to discuss sexuality and intimate relationships with the youths anytime when a question is raised. With a culturally sensitive approach, this should involve their caregivers (Lindsey et al 2012).

Supporting the youths' development of autonomy is important and in order to prepare the youths for sexuality, intimate relationships and prevention of undesirable pregnancy, it is of importance that all youths have the right to discuss such issues without having caregivers present (Wiegerink & Roebroeck, 2013). In delivery of consultation concerning intimate relationships, it is however important to consider the individual youth´s maturity, biological age and intellectual level. Young adults with for example CP but no intellectual disability have been found to have similar sexual interests as their non-disabled peers despite fewer sexual encounters than their able-bodied peers (Wiegerink & Roebroeck, 2013). Depending on intellectual levels, youths with ID may, by contrast, have delayed interest in intimate relationships depending on ability to interact with other youths (AAIDD, 2015; WHO, 2016). Because self-confidence is of great importance when interacting with peers and love partners, it is essential to support youths to *participate* in *activities* where they are able to meet and interact with peers and dating partners (Wiegerink et al. 2010).

Activities and participation

In ICF-CY, *Activity* is an individuals' execution of action meaning activity limitations are difficulties an individual has performing an activity. *Participation* is involvement in life situation, meaning restrictions of participation are the problems an individual may experience in these situations (WHO, 2007). Therefore, this component is of special interest in youths with disabilities and has been paid great attention in the literature.

The findings in Papers I, III and IV showed that youths felt they had few friends and experienced problems with finding new ones. Immigrant youths (Papers III and IV) perceived problems meeting friends without having their caregivers or siblings around. A literature review concerning youths with ID in transition revealed that these youths had greater difficulties forming friendships and engaging in activities in their community than those without ID (Foley et al. 2012). This is consistent with a Swedish report showing youths with moderate or severe disabilities were found to spend less time with friends compared to those without disabilities (Statens folkhälsoinstitut, 2012). Furthermore, it is almost three times as common that young people with disabilities in Sweden are dissatisfied with relationships with friends compared to young people without disabilities (Ungdomsstyrelsen, 2012). Kang et al. (2012) showed that the way in which a young person perceives him or herself as being a friend was of importance for participating with others, and that those who perceived themselves as having good social competence spent more time with friends. This might be understood in relation to for example age, gender and cultural background but also personal characteristics and preferences.

Some of the youths (Paper I and III) said that they had company services, contact persons or assistants (LSS) functioning as friends. Perceiving personnel – a contact person, for example – as a significant friend has been discussed by Mallander (2011), who argues that this is an important measure – according to LSS – as an organized way to construct friendship for people with disabilities. To have a contact person might however hamper possibilities to develop ordinary friendships with peers. Therefore, any personnel might also support the youths' socializing with ordinary peers.

Youths (Paper I) perceived participation in leisure activities as problematic, which is consistent with earlier research (Gorter and Roebroeck, 2013). The youths experienced problems with spontaneous activities due to their support having to be planned far in advance. This might be a consequence of the fact that a motor disorder can result in a lower degree of participation in activities outside the home due to environmental factors such as a lack of functional transportation (Palisano et al., 2009; Palisano et al., 2011). As the youths are on the threshold to adulthood, there is a risk that these problems may continue. In addition, researchers found that youths in transitioning age with lower levels of motor functions experienced several problems

such as a lack of mobility and participation in leisure activities due to lack of physical assistance or organized leisure activities (Orlin et al., 2010; Palisano et al., 2011). This was however reported by using ICF's components of body function and structures in relation to the components of activity and participation (Donkervoort et al., 2009; Nieuwenhuijsen, Donkervoort, Nieuwstraten, Stam, & Roebroeck, 2009).

Within the *activity and participation* component, the chapter "major life areas" (WHO, 2007) is of particular interest concerning transition to adulthood involving post-school options. For youths with disabilities, this is a matter of job options, supported employment or vocational training. They latter may involve e.g., participating in daily activities (LSS), depending on level of disability but also *environmental factors*.

Most of the youths in this thesis were still in educational programmes. However, the youths in study B (Paper III and IV), who a majority were older than the youths in Paper I and the majority of them had mild ID, were concerned about their possibilities of getting a job after school. They and their caregivers experienced problems obtaining information about and finding suitable employment or 'daily activities' (LSS). Work options for youths with ID have been considered poorer than for youths without any disability; thus young adults with mild ID are often able to work (May, 2001; WHO, 2015). Youth with moderate ID may however need varying degrees of support in work, and in Sweden, those who not are able to fulfil the demands of an ordinary employment have the rights to 'daily activities' in accordance with LSS (Proposition1993:387). However, the right to 'daily activities' does not cover youths without ID. This concerns youths with PD in particular, because if they do not gain access to the labour market they will have no 'daily activities' as adults. Donkervort (2009) found that only a quarter of youths with CP without ID had a job after education. To reduce worries about post-school options, both youths and their caregivers need adequate information about different options as well as the youths' legal rights to the LSS-measure 'daily activities'.

Personal Factors

The legitimacy of using the component of personal factors in rehabilitation has been disputed by Simeonsson and colleagues (2014) and by the Functioning and Disability Reference Group of the WHO-FIC (Leonardi et al., 2015). In the ICF/ICF-CY personal factors include for example age, gender, cultural background (country of origin), and social status (e.g. education and employment) although having no taxonomy of codes (WHO, 2001; 2007). Despite the controversy around personal factors as a construct in the ICF, certain elements in personal factors are considered important background variables in relation to the transition to adulthood for youths with disabilities and their caregivers in the discussion of findings. These are characteristics such as age, gender and country of origin. Thus, due to the lack of

taxonomy and the ongoing international debate these characteristics are not discussed as part of the personal factors component in this thesis.

Needs and preferences of information and support

The overall findings in this thesis showed that the support and health care systems were perceived as confusing for both youths and caregivers (Papers I, II and III), resulting in a limited readiness to handle their/their youths' transition to adulthood. Thus various experiences of information families lacked adequate information, some concerning current service and most concerning support and habilation available in the future. This might be understood in the light of the fact that the contact with services often is sparser when children are getting older (Broberg 2014). Neither youths nor caregivers in study B (Paper III) had received information about individual plans, which is noteworthy as it is a legal obligation to provide such information to anyone receiving measures in accordance with LSS (The National Board of Health and Welfare, 2014; Proposition 1992/93:159). Individual planning in accordance with LSS or other legislation such as SoL is useful in order to coordinate support for the youths and also to relieve their caregivers and should be a useful tool in transition planning (Broberg et al. 2014).

The findings from Papers I, II and III showed that youths and caregivers alike preferred and needed individualized support and information. A desire clearly expressed among youths and caregivers was that the information would target individual preferences and needs and would be timely. Individual support is considered to be an important predictor for a successful transition and also in line with FCS and PCS (Kingsnorth et al, 2011; Kraus de Camargo, 2011; Stewart et al. 2009). Furthermore, to meet the needs of immigrant caregivers, individual support given in the language of preference is in line with culturally sensitive service (Campina-Bacote, 2002). Within, for example, habilation services for children and youth, FCS is used as an approach for service delivery (Broberg et al., 2010). When it comes to caregivers, they have a vital role in guiding their youths in their transition as well as advocating their interests (Leiter & Waugh, 2009). In accordance with previous research, FCS is desirable by caregivers, represents best practice and improves wellbeing in caregivers irrespectively immigrant or not, which in turn benefits their youths (e.g. Arcuri et al., 2016; Dunst et al., 2002; Rosenbaum et a., 1998; Strock-Lynskey & Keller, 2007). FCS service actually involves responsiveness to individual current circumstances involving cultural traditions, which is why FCS should be cultural sensitive (Rosenbaum et al. 1998).

The findings (Paper II) showed that caregivers sometimes wished for hands-on support, which can be seen to mean that they actually experienced it as stressful to have full responsibility facing their youths' transition. Using FCS involves considerations for the individual caregiver's ability and current circumstances. There is cause to believe that they sometimes need some tangible form of release, even if they have a good capacity and have embraced the ideas of FCS. This may be assumed to mean that although the participants in this thesis seemed to be engaged and committed caregivers, they are in a period of their lives when they are active in their careers and have familial and social responsibilities. Raina et al. (2005) discuss that caregivers of youths are at an age when their physical capacity is often lower than in younger caregivers. In addition, during this period, caregivers are supposed to engage in their youth's transition from child to adult-oriented support and health care, which entails the need to acquire a certain amount of new information. Working in an FCS manner should involve awareness of the importance of offering hands-on support not only to those with clear limitations in matters such as organising support, transportations and appointments with professionals, but also to caregivers with limited Swedish language skills, for example, meaning such support may be desirable to any caregiver. It has also been discussed by others that increased demands imposed on caregivers by children with long-term functional limitations, which can be a consequence of FCS, may have a negative impact on their health (Byrne et al., 2010; Raina et al., 2005).

Caregivers (Paper II) experienced sorrow and anxiety over the youths' future life, which may be explained by the emergence of such emotions as a classic reaction to the child's transition to adulthood. This has been discussed by Whittingham and colleagues (2013), who argue that caregivers of children with disability often carry a life-long sorrow which can become more evident and emerge when facing changes in life at the time of their youth's transition to adulthood (Hamilton et al. 2014). Therefore, it is essential that professionals supporting caregivers of transitioning youths are aware of that these old feelings of grief might arise facing their youths transition to adulthood. The family – and in particular caregivers – are, as previously stated, considered to be essential to a successful transition (Foley et al. 2012) and an FCS involving a culturally sensitive approach is useful when helping caregivers to improve their health and to better support their youths in the transition to adult life.

The gap between the service systems

The findings in this thesis include a number of gaps, highlighted by youth and their caregivers, between the systems of support and habilitation for children and youths and for adults, which are down to environmental factors. Therefore, collaboration between the systems is necessary in order to facilitate the youths' transition between the child and adult services (Gorter et al. 2015; Stewart et al. 2014). Using ICF/ICF-

CY as a framework might lead to a holistic understanding and a language that can be similar across support and service systems (Vargus-Adams & Majnemer, 2014). The use of ICF's standardized language is suggested to be used in all documentation in services aimed for people with disabilities in Sweden to facilitate the collaboration between the systems of care (The National Board of Health and Welfare, 2015). Documentation made in collaboration with the youth, and his/her caregivers if needed may also facilitate the youth's transition between systems of care.

Transition from FCS to PCS

Trying to bridge the gaps by collaborating between services for children/youths and for adults is not enough. Because the Swedish social- and health care system is based on autonomy, youths with disabilities gradually need to be prepared to self-manage issues in adult living to be as independent of support from caregivers as possible. Transition to adult support and habilitation involves a transition from family to person-centred service, meaning youths gradually need to prepare for self-monitoring their own interests depending on intellectual levels and maturity, but also preferences. To strengthen the youths' autonomy, it has been found important to involve youths themselves in the transition process (Gorter et al. 2011; Gorter and Roebroeck, 2013).

The majority of the youths were dependent on their caregivers for health care demands according to the findings in Paper III, irrespective of age. This might be due to the age of individual youths, level of physical disability and intellectual level implying needs for support from caregivers. However, some dependency might relate to traditions of caretaking within the family. According to Campina-Bacote (2002) professions delivering culturally sensitive services need to master knowledge about various worldviews and traditions. Respect and awareness of those families with Middle Eastern origin, having a worldview and tradition of collectivistic caretaking in the family, is thus concluded to be important towards these finding. Development of independence in transition to adulthood in youths might not be supported by his/her caregivers who have a collectivistic worldview as has been identified in a review of transition program reports (Leake, Black, & Roberts, 2004). Therefore, evidenced based person centred service in transition planning would favour a focus on the youths' possibilities to develop independence by involving them in their own transition planning.

To strengthen youths' development of autonomy might prepare their readiness to demand for support, habilitation and other health care, with or without support from significant others. Today, it is highlighted in disability services (The National Board of Health and Welfare, 2014), and in line with the Convention on the Rights of the Child Article 12 (United Nations Human Rights, 1990), that children and youths should be involved in decision-making appropriate to their individual level of

maturity. This means allowing youths in their late adolescence to have more of a say in matters than younger adolescents. Depending on maturity and intellectual levels, all youths should in one way or another have opportunities for involvement. Furthermore, when youths with disabilities become legal adults, these rights should be provided in accordance with the principle in Convention on the Rights of Persons with Disabilities, Article 3, concerning the freedom to make one's own choices (United Nations Human Rights, 2006). For caregivers, this involves a transition from being a carer to more of an advisor to their youngsters by supporting them in the youths' own decisions about support and health care as well as in their planning for adult living. This includes issues connected to adult life for example living arrangements, love partners/marriages, higher studies and employment or 'daily activities'.

How to support youths to be more involved in transition planning

The findings and the discussion show that peer-related activities, to experience love and making friends were important but challenging for the youth during transition. Being a friend and socializing with friends is important for the development of self-confidence and has been shown as an important factor for well-being in youths with disabilities (Gerhardt, McCallum, McDougall, Keenan, & Rigby, 2015; Hwang & Nilsson, 2011; Kang et al., 2012). Goal setting is today recognized as an effective method to involve children and youth in habilitation planning involving enabling youths to both identify goals but also plans on how to reach them (Föreningen Sveriges Habiliteringschefer, 2007; 2014). Making friends has been identified as a common goal for youths in goal setting interventions (Gerhardt et al., 2015). Therefore, friend-making needs to be made a priority for professionals supporting youths with disabilities during transition to adulthood.

The two tools used for data collection, COPM and RTP, can be useful in the transition planning and in individual planning in accordance to LSS. COPM can be a useful tool for goal setting during person-centred transition planning including step-wise follows up how these goals have been reached. Because Association of Swedish Habilitation Managers (2007; 2015) suggested the transition phases; *getting started*, *on the move* and *almost complete,* RTP can be useful to support the youth to get insight to their individual transition process. In individual planning in accordance with LSS, all planning should be tailored according to individual preferences (Proposition1992/93:159). Both COPM and RTP can be offered for use as tools based on the individual youth's preferences.

However, the use of any tools needs to be customized to the youths' individual developmental and intellectual levels as well as ability to communicate. AAC- tools are suggested to be offered for youths with communication difficulties to facilitate to enable them to also give their independent voice. The use of AAC might also be

useful for youths not fully familiar with the language in their host country. 'Talking Mats' has been found effective as a communication resource for young persons with ID in person-centred transition planning (Cameron and Murphey, 2002). 'Talking Mats' as a pictorial system consists of images showing symbols for topics as well as symbols for options and emotions useful in individual planning. In addition, Cameron and Murphey (2002) suggest that, in transition planning and for example goal setting, professionals can offer the use of images that are relevant during transition to adulthood.

Conclusions and implications for practice

In this thesis, experiences of health and wellbeing, challenges, preferences and needs during transition to adulthood in youths with disabilities are illuminated from two perspectives; those of the youths and those of their caregivers. In addition, the study involved youths and caregivers with a Middle Eastern background residing in Sweden. Valuable knowledge that emerged when listening to those involved in the transition process may be used to develop and improve best practice guidelines for transition support within support and habilitation services in Sweden. Therefore, this thesis shows that so-called vulnerable people such as youths with disabilities and their caregivers - irrespective of their country of origin - who are in need of communication tools, proxy or interpreter, are willing and able to voice their opinions.

The main finding concerning health and wellbeing involves youths' and caregivers' positive and negative experiences, where family life was found to be important during transition. Socializing and participating is important for youths, but can be challenging. Problems with friends and with participation in activities were expressed as challenges with which the youths need support. Youths worry about how to manage the first period of adult life, how to find a job or 'daily activity' and how to manage love and marriage. Therefore, youths - and especially girls in families with cultural traditions different to those common to Sweden - need information about what marriage and parenthood involves. This includes information concerning free will when it comes to matters such as marriage, in accordance with human rights.

Caregivers may experience old sorrows from the past re-emerging during their youths' transition and stress caused by the demanding logistics in their everyday lives. The support and health-care system are considered confusing for youths and caregivers alike and the planning for transition and the youths' future is demanding for them. The results indicate that the transition might be challenging for any youths and demanding for any caregiver, regardless of level and type of disability, and irrespective of immigrant status, and that there is a need for support for the whole family. Individualized support and information given by one person was desired by both youths and caregivers and may correspond to individual needs. Immigrant caregivers were unfamiliar with the term intellectual disability and need more information about their youth's conditions as well as support in their host country.

In a multicultural society, there are great variations concerning youths' own desires and possibilities to live as independent adults. However, youths with disabilities living in Sweden, where autonomy is the cornerstone within adult support and health care, need to be prepared to voice their own preferences and needs and apply for services themselves. This preparation needs to start early by involving youths in their own transition planning. Two tools used in this thesis, COPM and RTP, can be useful in person-centred transition planning, if customized and applied with cultural sensibility. Because youths with intellectual disabilities, for example, might be in need of communications tools, this must be used for those in needs. By empowering the youths, irrespective of cultural background, they might be more prepared to enter the adult world with possibilities to fully participate in their society of resistance. As Sweden today is a multicultural society, cultural awareness is useful as an approach in all service delivery, which is why following the key components in culturally sensitive service are suggested for use in transition planning with youths with disabilities residing in Sweden. Irrespective of whether a client is a native or non-native, cultural competence in the delivery of social- and habilitation service involves empathizing and caring for people with respect, while putting into consideration their individual preferences and needs.

Even if youths and their caregivers no longer have to feel as though they are 'falling off a cliff', there is still a gap for them to pass over to make a successful transition between the systems of care. The gaps between different systems of service for support and health care, as well as between services for children and youths and for adults, might be closed with stronger cooperation between the systems. The use of the terminology in ICF-CY (ICF) in documentation could be an excellent means of facilitating this.

Future research

In all research involving people, participation is voluntary. In this thesis, which deals with youths and caregivers, it can be assumed that those interested in participating in interviews and interacting with people from academia actually took their time to have their voices heard. These people may already have an established contact with professionals within social services and habilitation for youths with disabilities. It would therefore have been both important and interesting to reach those 'outside the system' for further research concerning preferences and needs during youths' transition to adulthood. Since a great number of people have migrated to Sweden in recent years, it would have been interesting to reach youths with disabilities among them.

One of the lessons learned during the recruiting process during Study B was that the participants had many questions concerning support and service in Sweden. Professionals in services for migrants also noted that providing information about disability services to newly arrived migrants is a requirement, and such information meetings may present an opportunity to recruit participants for research. A more qualitative approach including open-ended questions might capture other experiences of importance for immigrant youths and caregivers that might have an impact on their situation during youths' transition. Therefore, it would have been of interest to conduct a qualitative study involving the latter group.

Populärvetenskaplig sammanfattning på svenska

Att växa upp och flytta fokus från barn- till vuxenvärlden kan vara en utmanande tid för ungdomar i allmänhet och för ungdomar med funktionsnedsättningar i synnerhet. Fokus i avhandlingen är övergången till vuxenliv, vilket för ungdomar med funktionsnedsättning även innefattar övergången mellan barn- och vuxenorienterat stöd och habilitering. Denna process benämns "transition". Ungdomar med fysiska och/eller intellektuella funktionsnedsättningar har, i olika grad, behov av stöd, sjukvård och habiliterande insatser under hela livspannet. Cerebral pares (CP) är en vanlig orsak till rörelsehinder hos barn och kan medföra associerande funktionsnedsättningar som exempelvis intellektuell funktionsnedsättning, syn- och hörsel nedsättning. Det ser olika ut i Sverige men vid cirka 18 års ålder lämnar ungdomar sina kontakter på barn- och ungdomshabiliteringen och flyttar de över till vuxeninriktad service. Service för vuxna bygger i grunden på egna beslut och val av insatser, varför ungdomar kan komma att behöva fortsatt stöd och vägledning av sina föräldrar. Att vara förälder till barn med komplexa funktionsnedsättningar innebär därför ett livslångt engagemang och föräldrar kan vara såväl fysiskt som psykiskt påverkade av många års omsorg. Eftersom föräldrar är de som i första hand stöttar sina barn under transitionen kan såväl deras hälsa och välbefinnande som deras syn på ungdomarnas behov påverka hur ungdomarna klarar transitionsprocessen. Ytterligare en utmaning för stöd- och habiliteringsverksamheter är att Sverige blivit mångkulturellt, och många människor har sitt ursprung i andra länder och kulturer vilket innebär nya utmaningar för stöd och habiliteringsverksamheter.

Det övergripande syftet med avhandlingsarbetet var därför att få en fördjupad förståelse av upplevelse av hälsa och välbefinnande samt önskemål och behov av stöd under ungdomarnas övergång till vuxenlivet för ungdomar och deras föräldrar boende i ett multikulturellt Sverige. Två studier bestående av fyra artiklar ingår i avhandlingsarbetet.

En kvalitativ design valdes för den första delstudien (A) (artikel I och II). Tolv pojkar och flickor i åldern 17-18 år med CP och varierande grad av motoriska och/eller intellektuella funktionsnedsättningar samt 15 mödrar och fäder deltog i kvalitativa intervjuer i fokusgrupp och/eller enskilt. Intervjuerna analyserades med hjälp av kvalitativ innehållsanalys. Resultatet visade att både ungdomarnas och föräldrarnas upplevelse under transitionen berörde främst psykisk hälsa och välbefinnande. För både ungdomarna och

föräldrarna hade samvaro och stöd inom familjen stor betydelse men kunde ibland upplevas som lite för snävt. Kamrater, åldersadekvata fritidsaktiviterer och kärlek var viktigt för ungdomarna, men tillgängligheten och förmågan till självständighet upplevdes som utmanande. Föräldrarna upplevde sina barns transition som en omvälvande tid då gamla känslor av sorg väcktes till liv. De upplevde också en stress över att koordinera allt i det dagliga livet och en oro för sina barns framtid vilket påverkade deras egen hälsa och välbefinnande.

I delstudie B (artikel III och IV) inbjöds ungdomar med funktionsnedsättning med arabiska som modersmål och deras föräldrar/vårdnadshavare att delta. Semistrukturerade intervjuer baserade frågeformulären Family Need Survey (FNS), Rotterdam Transition Profile (RTP) och Canadian Occupational Performance Measure (COPM) samt tilläggsfrågor frågor översatta till både svenska och arabiska genomfördes på det av språken deltagarna föredrog. Sjutton pojkar och flickor i åldern 13-24 år med huvudsakligen intellektuella funktionsnedsättningar och 10 mödrar, fem fäder och ett äldre syskon ursprungligen från länder i Mellanöstern deltog. Att rekrytera deltagare till studien innebar stora utmaningar. Såväl ansvariga för organisationer som enskilda professionella underlät att förmedla kontakt till presumtiva deltagare under förevändning att de ansåg invandrarfamiljer vara utsatta genom att vara både invandrare och med funktions-nedsättning eller förälder till barn med funktionsnedsättning. Det mest verkningsfulla sättet att nå deltagare var med hjälp av personer som har kontakt med dem i särskola eller fritidsaktiviteter.

Resultatet från intervjuerna med FNS, RTP och tilläggsfrågor frågor (artikel III) visade att föräldrarna behövde stöd och information för att förstå sina ungdomars begränsningar och behov. Ungdomarna ville vara delaktiga i det svenska samhällslivet men var beroende av sina föräldrar. Både ungdomarna och föräldrarna var bekymrade över att ungdomarna förväntades gifta sig och få barn i framtiden. I artikel IV redovisades resultatet från COPM intervjuerna där ungdomar och föräldrar fick identifiera sina egna/sina ungdomars problem under transitionen, vilket analyserades utifrån Internationell klassi-fikation av funktionstillstånd, funktionshinder och hälsa, - barn och ungdomsversionen (ICF-CY). Resultatet visade en signifikant skillnad i vad ungdomarna själva identifierade som problem och vad deras föräldrar identifierade som sina ungdomars problem. Detta belyser vikten av att ungdomar ges möjlighet att få framföra sina egna synpunkter och önskemål för att vara delaktiga i planerandet inför vuxenlivet.

Det fanns både likheter och skillnader mellan familjerna i de båda studierna. De ungdomar och föräldrar som deltog i båda studierna visade att de uppskattade att bli tillfrågade om sina önskamål och behov. Familjen var central för såväl ungdomar som föräldrar. Ungdomarna i båda studierna såg kamrater, delaktighet i fritidsaktiviterer och kärlek som viktigt men utmanande. Både ungdomarna och vårdnadshavarna i båda studierna hade dålig kännedom om hur stöd och habilitering fungerar för vuxna och kände sig inte förberedda inför ungdomarnas kommande vuxenliv. En skillnad var att

föräldrarna från Mellanöstern utryckte att de var skeptiska till hur ungdomar delas upp efter grad av funktionsnedsättning. De var inte heller bekväma med att använda veder-tagna begrepp för diagnosen intellektuell funktionedsättning. Att ungdomarna ska ges möjlighet att vara delaktiga i sin individuella planering för övergången till vuxenliv är centralt. Att få möjlighet att delta i ålderadekvata aktiviter, samvaro med jämngamla och få uppleva kärlek är viktigt. Att ungdomarna med annan kulturell bakgrund upplever oro för kommande äktenskap är något som bör uppmärksammas inom stödverksamheter. Vidare är lyhördhet för varje individuell familjs kulturella traditioner och erfarenheter viktigt att beakta med utgångspunkt att alla familjer oavsett härkomst kan ha olika förförståelse, förväntning, önskemål och behov.

Resultatet i avhandlingen har diskuterats utifrån ICF-CY och familjecentrerad kontra personcentrerad service. Genom att använda ICF-CY's tankemodell visar det att den är användbar vid stöd och planering vid övergång till vuxenlivet för att underlätta samverkan mellan barn- och vuxenorienterat stöd och habilitering. Familjecentrerad service är sedan många år är en filosofi och anses vare en evidensbaserad metod som används inom Barn-och ungdomshabiliteringens verksamheter i Sverige och andra länder. Familjecentrerat stöd anses användbar även i kulturellt anpassat stöd. Inför övergången till vuxenliv är det dock viktigt att ungdomarna förbereds på ett mer personcentrerat stöd varför deras självständighet och rätt att själva bestämma över sitt stöd bör underbyggas och upp-muntras genom att i ett tidigt stadium involvera den unge själv i övergångsprocessen. Vidare bör tiden för övergång mellan barn- och ungdomsorienterat- till vuxenorienterat stöd vara flexibel och inte knuten till biologisk ålder.

Resultatet från studien kan användas för att utveckla och förbättra såväl rutiner som transitionsprogram inom stöd- och habiliteringsverksamheter. En personlig guide eller en navigator som lär känna familjen och dess specifika behov kan hjälpa till att lotsa genom systemen. En sådan person kan också handgripligen avlasta med informationssökning och ansökningar när det tidsmässigt är lämpligt. COPM och RTP föreslås som användbara redskap vid person-centrerad transitionsplanering under förutsättning att de används utefter individuella behov och förutsättningar. Alternativ och Kompletterande Kommu-nikation (AKK) är nödvändigt att erbjuda för ungdomar med kommunikativa svårigheter så att de också får möjlighet att göra sina röster hörda. Slutligen påtalas vikten av samverkan mellan social service och den service som tillhandahålls av Habiliteringen samt service och habilitering för barn och unga och för vuxna. Detta med syfte att underlätta för såväl ungdomar som deras föräldrar med målet att det inte ska bli något glapp mellan de olika stödsystemen. Genom att använda ICF/ICF-CY i alla verksamheter för personer med funktionsnedsättningar och dess terminologi i dokumentation kan samverkan underlättas.

Acknowledgement

Kate Himmelmann, Associate Professor Clinical Sciences, Department of Pediatrics, Sahlgrenska Academy, University of Gothenburg, Sweden for cooperation with the translation and adaption process of the Rotterdam Transition Profile.

Anna Blomgren for support and hands-on help with the layout of this thesis.

My mentors, PhD Kajsa Landgren "just for being there for me" and associate Professor Emma Sorbring for all great support and advice, always when I needed it the most.

The Child, Family & Reproductive Health research group, for increasingly significant seminars with interesting discussions. I am really impressed by everyone's engagement in each other's text material. Special thanks to Professor Guðrún Kristjánsdóttir, for your useful supervision and to my colleagues Associate Professors Elizabeth Crang Svalenius and Linda Kvist for occasional language support.

My former room-mate and dear friend PhD Katarina Lauruschkus, for participating in several of the focus group interviews and for all great times together with debriefings, discussions and laughs during both master and doctoral studies. Had it not been for you, I would not be where I am today.

All my wonderful PhD student friends at Lund University and at University West, thank you all for your friendship and discussions during coffee breaks. Special thanks to Charlotte Castor, my room-mate during the last exciting year. You have really taken care of me and kept an eye on me. Special thanks to Åsa Lefèvre for pep talks and text messages late in the evenings.

Hans Mattsson, special needs teacher with long experience of communication tools, for supporting me with the pictogram images.

My beloved family for showing interest in my journey to my doctoral degree and for patience when sometimes I have not been available to participate in activities. Special thanks to my dearest mother Karin who, over all these years, has shown great interest in my studies.

Ann-Kristin Lilja, my landlady in Lund and now dearest friend, for your great hospitality during the years as a PhD student. You are the one who, most of all, showed interest in my process.

Bengt, my much-loved spouse, for your patience when not only my mind been somewhere else, but also when I myself have been away from home for days, and sometimes weeks. "Forgive me pretty baby but I always take the long way home". Thank you for still being there!

References

AAIDD, American Association on Intellectual and Developmental Disabilities. (2015). Definition of intellectual disability. Retrieved from: http://aaidd.org/intellectual-disability/definition#.VRuijaNvnrc (last assessed February 29, 2016)

al-Baldawi, R. (2014). *Migration och anpassning: den okända resan.* Lund: Studentlitteratur.

Al-Eithan, M., Al Juban, H., & Robert, A. A. (2013). Dissociative experiences and their relationship to mood problems among Arab mothers of disabled children. *Pan Afr Med J, 15,* 21. doi:10.11604/pamj.2013.15.21.2229

Al-Krenawi, A., Graham, J. R., & Al Gharaibeh, F. (2011). The impact of intellectual disability, caregiver burden, family functioning, marital quality, and sense of coherence. *Disability & Society, 26*(2), 139-150. doi:10.1080/09687599.2011.543861

Antle, B. J., Mills, W., Steele, C., Kalnins, I., & Rossen, B. (2008). An exploratory study of parents' approaches to health promotion in families of adolescents with physical disabilities. *Child Care Health Dev, 34*(2), 185-193. doi:10.1111/j.1365-2214.2007.00782.x

Arcuri, G. G., McMullan, A. E., Murray, A. E., Silver, L. K., Bergthorson, M., Dahan-Oliel, N., & Coutinho, F. (2016). Perceptions of family-centred services in a paediatric rehabilitation programme: strengths and complexities from multiple stakeholders. *Child Care Health Dev, 42*(2), 195-202. doi:10.1111/cch.12308

Armstrong, J., & Ager, A. (2005). Perspectives on disability in Afghanistan and their implications for rehabilitation services. *International Journal of Rehabilitation Research, 28*(1), 87-92.

Arnett, J. J. (2000). Emerging adulthood. A theory of development from the late teens through the twenties. *Am Psychol, 55*(5), 469-480.

Arnett, J. J. (2004). *Emerging adulthood: the winding road from the late teens through the twenties*. Oxford; New York: Oxford University Press.

Arvidsson, J., Widén, S., & Tideman, M. (2015). Post-school options for young adults with intellectual disabilities in Sweden. *Research and Practice in Intellectual and Developmental Disabilities, 2*(2), 180-193. doi:10.1080/23297018.2015.1028090

Azar, M., & Kurdahi Badr, L. (2006). The Adaption of Mothers of Children With Intellectual Disability in Lebanon. *Journal of Transcultural Nursing, 17*(4), 375-380. doi:10.1177/1043659606291550

Bailey, D. B., & Simeonsson, R. J. (1988). Assessing Needs of Families with Handicapped Infants. *The Journal of Special Education, 22*(1), 117-127. doi:10.1177/002246698802200113

Bailey, D.B., & Blasco, P.M. (1990). Parents' Perspectives on a Written Survey of Family Needs. *Journal of Early Interventions*,14(3), 196-2003.

Bailey, S., Boddy, K., Briscoe, S., & Morris, C. (2015). Involving disabled children and young people as partners in research: a systematic review. Child Care Health Dev, 41(4), 505-514.

Bee, H. L., & Boyd, D. R. (2007). *The developing child.* Boston: Pearson / Allyn & Bacon.

Beresford, B. (2004). On the road to nowhere? Young disabled people and transition. *Child Care Health Dev, 30*(6), 581-587. doi:10.1111/j.1365-2214.2004.00469.x

Berg, B. (2015). Immigrant Families With Disabled Children in Norway. In R. Traustadóttir, B. Ytterhus, T. E. Snæfríður, & B. Berg (Eds.), *Childhood and Disability in the Nordic Countries. Being, Becoming, Belonging* (pp. 215-230). Hampshire, England: Palgrave, MacMillan.

Berry, J. W., Phinney, J. S., Sam, D. L., & Vedder, P. (2006). Immigrant Youth: Acculturation, Identity, and Adaptation. *Applied Psychology, 55*(3), 303-332. doi:10.1111/j.1464-0597.2006.00256.x

Biggs, E., & Carter, E. (2016). Quality of Life for Transition-Age Youth with Autism or Intellectual Disability. *Journal of Autism and Developmental Disorders, 46*(1), 190-204. doi:10.1007/s10803-015-2563-x

Björk, J. (2011). *Praktisk statistik för medicin och hälsa.* Stockholm: Liber.

Björngren Cuadra, C. (2012). A study of approaches within research on problems of access to services for children and adolescents with functional, cognitive and developmental disabilities from a multicultural perspective. *Diversity & Equality in Health & Care, 9*(2), 125-140.

Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adolesc Health, 14*(7), 570-576.

Bostrom, P. K., Broberg, M., & Hwang, P. (2010). Parents' descriptions and experiences of young children recently diagnosed with intellectual disability. *Child Care Health Dev, 36*(1), 93-100. doi:10.1111/j.1365-2214.2009.01036.x

Brehaut, J. C., Kohen, D. E., Raina, P., Walter, S. D., Russell, D. J., Swinton, M., . . . Rosenbaum, P. (2004). The health of primary caregivers of children with cerebral palsy: how does it compare with that of other Canadian caregivers? *Pediatrics, 114*(2), e182-191.

Brehaut, J. C., Kohen, D. E., Garner, R. E., Miller, A. R., Lach, L. M., Klassen, A. F., & Rosenbaum, P. L. (2009). Health among caregivers of children with health problems:

findings from a Canadian population-based study. *Am J Public Health, 99*(7), 1254-1262. doi:10.2105/ajph.2007.129817

Broberg, M., Hedberg, E., Keit-Bodros, G., Lindquist, B., Rosenkvist, L., & Spjut Janson, B. (2010). Föräldrastöd inom barn och ungdomshabiliteringen. Retrieved from: http://www.habiliteringschefer.se/ebh/foraldrastod/dokument/Foraldrastod.pdf

Broberg, M. (2011). Expectations of and reactions to disability and normality experienced by parents of children with intellectual disability in Sweden. *Child Care Health Dev, 37*(3), 410-417.

Broberg, M., H. Nowak, D. Norlin, and M. Starke. 2014. Riktat föräldrastöd [Directed family support]. RiFS-projektets slutrapport: En aktionsforskningsansats för att kartlägga behov och förbättra stödet till föräldrar som har barn med funktionsnedsättning. Göteborg: Sandstens.

Brunnberg, E., Boström, M. L., & Berglund, M. (2009). Sexuality of 15/16-Year-Old Girls and Boys With and Without Modest Disabilities. *Sexuality & Disability, 27*(3), 139.

Byrne, M. B., Hurley, D. A., Daly, L., & Cunningham, C. G. (2010). Health status of caregivers of children with cerebral palsy. *Child Care Health Dev, 36*(5), 696-702. doi:10.1111/j.1365-2214.2009.01047.x

Cambridge, P., & Forrester-Jones, R. (2003) Using individualised communication for interviewing people with intellectual disability: a case study of user-centred research. *Journal of Intellectual & Developmental Disability*, 28(1), 2-23.

Campinha-Bacote, J. (2002). The Process of Cultural Competence in the Delivery of Healthcare Services: a model of care. *J Transcult Nurs, 13*(3), 181-184; discussion 200-181.

Carswell, A., McColl, M. A., Baptiste, S., Law, M., Polatajko, H., & Pollock, N. (2004). The Canadian Occupational Performance Measure: a research and clinical literature review. *Can J Occup Ther, 71*(4), 210-222.

Castle, K., Imms, C., & Howie, L. (2007). Being in pain: a phenomenological study of young people with cerebral palsy. *Dev Med Child Neurol, 49*(6), 445-449.

Chiarello, L. A., Palisano, R. J., Maggs, J. M., Orlin, M. N., Almasri, N., Kang, L. J., & Chang, H. J. (2010). Family priorities for activity and participation of children and youth with cerebral palsy. *Phys Ther, 90*(9), 1254-1264. doi:10.2522/ptj.20090388

Cieza, A., Geyh, S., Chatterji, S., Kostanjsek, N., Ustun, B., & Stucki, G. (2005). ICF linking rules: an update based on lessons learned. *J Rehabil Med, 37*(4), 212-218. doi:10.1080/16501970510040263

Coppus, A. M. W. (2013). People with intellectual disability: What do we know about adulthood and life expectancy? *Developmental Disabilities Research Reviews, 18*(1), 6-16. doi:10.1002/ddrr.1123

Crabtree, S. A. (2006). Family responses to the social inclusion of children with developmental disabilities in the United Arab Emirates. *Disability & Society, 22*(1), 49-62. doi:10.1080/09687590601056618

Cusick, A., Lannin, N. A., & Lowe, K. (2007). Adapting the Canadian Occupational Performance Measure for use in a paediatric clinical trial. *Disabil Rehabil, 29*(10), 761-766. doi:10.1080/09638280600929201

Dahlberg, K., Dahlberg, H., & Nyström, M. (2008). *Reflective lifeworld research* (2. ed.). Lund: Studentlitteratur.

Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., Davern, M., & Reddihough, D. (2010). The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. *Child Care Health Dev, 36*(1), 63-73. doi:10.1111/j.1365-2214.2009.00989.x

Diken, I. (2006). Review of Research: An Overview of Parental Perceptions in Cross-Cultural Groups on Disability. *Childhood Education, 82*(4), 236.

Dodge, R., Daly, A., Huyton, J., & Sanders, L. (2012). The challange of defining wellbeing. *International Journal of Wellbeing, 2*(3), 222-235.

Donkervoort, M., Wiegerink, D. J., van Meeteren, J., Stam, H. J., Roebroeck, M. E., & Transition Research Group South West, N. (2009). Transition to adulthood: validation of the Rotterdam Transition Profile for young adults with cerebral palsy and normal intelligence. *Dev Med Child Neurol, 51*(1), 53-62. doi:10.1111/j.1469-8749.2008.03115.x

Downe-Wamboldt, B. (1992). Content analysis: method, applications, and issues. *Health Care Women Int, 13*(3), 313-321. doi:10.1080/07399339209516006

Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2007). Meta-analysis of family-centered helpgiving practices research. *Ment Retard Dev Disabil Res Rev, 13*(4), 370-378. doi:10.1002/mrdd.20176

Eilegard, A., Steineck, G., Nyberg, T., & Kreicbergs, U. (2013). Bereaved siblings' perception of participating in research--a nationwide study. *Psychooncology, 22*(2), 411-416. doi:10.1002/pon.2105

Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Brink, E., . . . Sunnerhagen, K. S. (2011). Person-centered care--ready for prime time. *Eur J Cardiovasc Nurs, 10*(4), 248-251. doi:10.1016/j.ejcnurse.2011.06.008

Ekman, I., Hedman, H., Swedberg, K., & Wallengren, C. (2015). Commentary: Swedish initiative on person centred care. *Bmj, 350*, h160. doi:10.1136/bmj.h160

Erikson, E. H. (1968). *Identity, youth and crisis / Erik H. Erikson*: New York: W. W. Norton, cop. 1968 1. ed.

Fokus 13: unga och jämställdhet. (2013). Stockholm: Ungdomsstyrelsen.

Foley, K. R., Dyke, P., Girdler, S., Bourke, J., & Leonard, H. (2012). Young adults with intellectual disability transitioning from school to post-school: A literature review framed within the ICF. *Disabil Rehabil, 34*(20), 1747-1764. doi:10.3109/09638288.2012.660603

Frech, A. (2012). Healthy Behavior Trajectories between Adolescence and Young Adulthood. *Adv Life Course Res, 17*(2), 59-68. doi:10.1016/j.alcr.2012.01.003

Freeman, M., Stewart, D., Shimmell, L., Missiuna, C., Burke-Gaffney, J., Jaffer, S., & Law, M. (2015). Development and evaluation of The KIT: Keeping It Together™ for Youth (the 'Youth KIT') to assist youth with disabilities in managing information. *Child Care Health Dev, 41*(2), 222-229. doi:10.1111/cch.12199

Friberg, P., Hagquist, C., & Osika, W. (2012). Self-perceived psychosomatic health in Swedish children, adolescents and young adults: an internet-based survey over time. *BMJ Open, 2*(4). doi:10.1136/bmjopen-2011-000681

Föreningen Sveriges Habiliteringschefer. (2007, 2015). *Nationellt habiliteringsprogram för att understödja övergång från barn till* vuxen. Retrieved from: http://www.habiliteringschefer.se/dokument/kvalitet/2015-Nationellt_habiliteringsprogram_overgang_fran_barn_till_vuxen.pdf (last assessed February 29, 2016)

Föreningen Sveriges Habiliteringschefer. (2014). *Policy för habilitering i Sverige [Policy for habilitation in Sweden]* (Vol. 2009): Föreningen Sveriges Habiliteringschefer.

Gerhardt, S., McCallum, A., McDougall, C., Keenan, S., & Rigby, P. (2015). The goal of making friends for youth with disabilities: creating a goal menu. *Child Care Health Dev, 41*(6), 1018-1029. doi:10.1111/cch.12251

Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Conducting qualitative interviews with school children in dental research. *Br Dent J, 204*(7), 371-374. doi:10.1038/sj.bdj.2008.245

Gillberg, C., & Soderstrom, H. (2003). Learning disability. *Lancet, 362*(9386), 811-821. doi:10.1016/s0140-6736(03)14275-4

Gorter, J., & Roebroeck, M. (2013). Transition to adulthood: Enhancing health and quality of life for emerging adults with neurological and developmental conditions. In G. Ronen & P. Rosenbaum (Eds.), *Life Quality Outcomes in Children and Young People with Neurological and Developmental Conditions* (Hilary M. Hart ed., pp. 306-317). London: MacKeith.

Gorter, J. W., Stewart, D., Cohen, E., Hlyva, O., Morrison, A., Galuppi, B., . . . Punthakee, Z. (2015). Are two youth-focused interventions sufficient to empower youth with chronic health conditions in their transition to adult healthcare: a mixed-methods longitudinal prospective cohort study. *BMJ Open, 5*(5), e007553. doi:10.1136/bmjopen-2014-007553

Gorter, J. W., Stewart, D., & Woodbury-Smith, M. (2011). Youth in transition: care, health and development. *Child Care Health Dev, 37*(6), 757-763. doi:10.1111/j.1365-2214.2011.01336.x

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today, 24*(2), 105-112. doi:10.1016/j.nedt.2003.10.001

Granlund, M., & Roll-Pettersson, L. (2001). The perceived needs of support of parents and classroom teachers – a comparison of needs in two microsystems. *European Journal of Special Needs Education, 16*(3), 225-244. doi:10.1080/08856250110074382

Habilitation and Assistive Technology Services - a brief presentation (2011). Retrieved from: https://www.skane.se/Public/HAB/International/100-artnr-08-12-engelska.pdf (last assessed February 29, 2016)

Hamilton, A., Mazzucchelli, T. G., & Sanders, M. R. (2015). Parental and practitioner perspectives on raising an adolescent with a disability: a focus group study. *Disabil Rehabil, 37*(18), 1664-1673. doi:10.3109/09638288.2014.973969

Hansen Orwehag, M. (2013). Barnintervju- ur barnperspektiv och barns perspektiv. In S. Erlandsson & L. Sjöberg (Eds.), *Barn och ungdomsforskning. Metoder och arbetssätt.* Lund: Studentlitteratur.

Hart, C., & Chesson, R. (1998). Children as consumers. *Bmj, 316*(7144), 1600-1603.

Hasnain, Rooshey, Cohon Shaikh, L., & Shanawani, H. (2008). Disability and the Muslim perspective: An Introduction for Rehabilitation and Health Care Providers. 1-79. Retrieved from: http:/cirrie.buffalo.edu/monographs/ (last assessed February 29, 2016)

Hasnain, R., & Sotnik, P. (2003). Person-Centered Planning: A Gateway to Improving Vocational Rehabilitation Services for Culturally Diverse Individuals with Disabilities. *Journal of Rehabilitation, 69*(3), 10.

Hinckson, E. A., & Curtis, A. (2013). Measuring physical activity in children and youth living with intellectual disabilities: a systematic review. *Res Dev Disabil, 34*(1), 72-86. doi:10.1016/j.ridd.2012.07.022

Huber, M., Knottnerus, J. A., Green, L., van der Horst, H., Jadad, A. R., Kromhout, D., …, Smid, H. (2011). How should we define health? *Bmj, 343*, d4163. doi:10.1136/bmj.d4163

Hwang, P., & Nilsson, B. (2011). *Utvecklingspsykologi*. Stockholm: Natur och kultur.

Ibragimova, N., Granlund, M., & Bjorck-Akesson, E. (2009). Field trial of ICF version for children and youth (ICF-CY) in Sweden: logical coherence, developmental issues and clinical use. *Dev Neurorehabil, 12*(1), 3-11. doi:10.1080/17518420902777001

Ingvarsdotter, K., Johnsdotter, S., & Ostman, M. (2012). Lost in interpretation: the use of interpreters in research on mental ill health. *Int J Soc Psychiatry, 58*(1), 34-40. doi:10.1177/0020764010382693

Ingvarsdotter, K., 2014. "Kritiskt förhållningssätt och öppet sinne [Critical approach and open mind]." In *Tvärkulturella studier [cross-cultural studies]*, edited by Pernilla Ny. Malmö: Glerups

Kang, L. J., Palisano, R. J., King, G. A., Chiarello, L. A., Orlin, M. N., & Polansky, M. (2012). Social participation of youths with cerebral palsy differed based on their self-perceived competence as a friend. *Child Care Health Dev, 38*(1), 117-127. doi:10.1111/j.1365-2214.2011.01222.x

Karlsson, I., von Schantz, I., Ingbrant, K., & Rudervall, U. (2011). Nationellt Habiliteringsprogram för att understödja unga vuxna i processen till ett eget liv och till delaktighet i samhället Retrieved from:

http://www.habiliteringschefer.se/dokument/kvalitet/Nationellt_habiliteringsprogram_d
elaktighet.pdf. (last assessed February 29, 2016)

Kazdin, A. E. (2014). *Research design in clinical psychology*. Harlow, Essex: Pearson.

Khamis, V. (2007). Psychological distress among parents of children with mental retardation
in the United Arab Emirates. *Soc Sci Med, 64*(4), 850-857.
doi:10.1016/j.socscimed.2006.10.022

Kieling, C., Baker-Henningham, H., Belfer, M., Conti, G., Ertem, I., Omigbodun, O., . . .
Rahman, A. Child and adolescent mental health worldwide: evidence for action. *The
Lancet, 378*(9801), 1515-1525. doi:http://dx.doi.org/10.1016/S0140-6736(11)60827-1

Kitzinger, J. (2013). Using Focus groups to understand experiences of health and illness. In:
S. Zieblad, A. Coulter, J.D. Calabrese & L. Locock (red). Understanding and using
health experiences. Improving patient care (ebook). Oxford: Oxford University Press.

Kim, K.-H., & Morningstar, M. E. (2005). Transition Planning Involving Culturally and
Linguistically Diverse Families. *Career Development for Exceptional Individuals, 28*(2),
92-103. doi:10.1177/08857288050280020601

King, G., Desmarais, C., Lindsay, S., Piérart, G., & Tétreault, S. (2014). The roles of effective
communication and client engagement in delivering culturally sensitive care to
immigrant parents of children with disabilities. *Disabil Rehabil, 37*(15), 1372-1381.
doi:10.3109/09638288.2014.972580

King, G. A., Baldwin, P. J., Currie, M., & Evans, J. (2005). Planning successful transitions
from school to adult roles for youth with disabilities. *Children's Health Care, 34*(3), 193-
216.

King, S., Teplicky, R., King, G., & Rosenbaum, P. (2004). Family-centered service for
children with cerebral palsy and their families: a review of the literature. *Semin Pediatr
Neurol, 11*(1), 78-86.

Kingsnorth, S., Gall, C., Beayni, S., & Rigby, P. (2011). Parents as transition experts?
Qualitative findings from a pilot parent-led peer support group. *Child Care Health Dev,
37*(6), 833-840. doi:10.1111/j.1365-2214.2011.01294.x

Klang Ibragimova, N., Pless, M., Adolfsson, M., Granlund, M., & Bjorck-Akesson, E. (2011).
Using content analysis to link texts on assessment and intervention to the International
Classification of Functioning, Disability and Health - version for Children and Youth
(ICF-CY). *J Rehabil Med, 43*(8), 728-733. doi:10.2340/16501977-0831

Kosidou, K., Hellner-Gumpert, C., Fredlund, P., Dalman, C., Hallqvist, J., Isacsson, G., &
Magnusson, C. (2012). Immigration, transition into adult life and social adversity in
relation to psychological distress and suicide attempts among young adults. *PLoS One,
7*(10), e46284. doi:10.1371/journal.pone.0046284

Kraus de Camargo, O. (2011). Systems of care: transition from the bio-psycho-social
perspective of the International Classification of Functioning, Disability and Health.
Child Care Health Dev, 37(6), 792-799. doi:10.1111/j.1365-2214.2011.01323.x

Krause, S., Ware, R., McPherson, L., Lennox, N., & O'Callaghan, M. Obesity in adolescents with intellectual disability: Prevalence and associated characteristics. *Obesity Research & Clinical Practice*. doi:http://dx.doi.org/10.1016/j.orcp.2015.10.006

Kroll, T., Barbour, R., & Harris, J. (2007). Using Focus Groups in Disability Research. *Qualitative Health Research, 17*(5), 690-698. doi:10.1177/1049732307301488

Krueger, R. A., & Casey, M. A. (2009). *Focus groups: a practical guide for applied research* (4. [updated] ed.). Thousand Oaks, Calif.: Sage Publications.

Kuczynski, L., & Knafo, A. (2013). Innovation and Continity in Socialization, Internalization, and Acculturation. In M. Killen & J. G. Smetana (Eds.), *Handbook of Moral Development* (Vol. 2, pp. 93-112). New York: Psychology Press.

Kvale, S., & Brinkmann, S. (2009). *InterViews : learning the craft of qualitative research interviewing* (2. ed.). Los Angeles: Sage Publications.

Lambert, S. D., & Loiselle, C. G. (2008). Combining individual interviews and focus groups to enhance data richness. *J Adv Nurs, 62*(2), 228-237. doi:10.1111/j.1365-2648.2007.04559.x

Lauruschkus, K. (2015). *Participation in physical activities and sedentary behaviour among children with physical disabilities*. Lund: Lund University.

Law, M. (2006). *Canadian occupational performance measure: svensk version*. Stockholm: Förbundet Sveriges arbetsterapeuter.

Law M., S., Babtiste, A., McColl M,Carswell, H., Polatajko H, N., Pollock. (2005). The Canadian Occupational Performance Measure. 4th ed. Ottawa Canada: *Canadian Association of Occupational Therapists Publication*.

Law, M., Anaby, D., Imms, C., Teplicky, R., & Turner, L. (2015). Improving the participation of youth with physical disabilities in community activities: An interrupted time series design. *Aust Occup Ther J, 62*(2), 105-115. doi:10.1111/1440-1630.12177

Leake, D. W., Black, R. S., & Roberts, K. (2004). Assumptions in transition planning: Are they culturally sensitive. *Impact: Feature Issue on Achieving Secondary Education and Transition Results for Students with Disabilities, 16*(3), 1.

Leavitt, R. L. 2002. "Developing cultural competence in a multicultural world, part I." *PT: Magazine of Physical Therapy* 10 (12):36-48.

Leavitt, R. L. (2003). Developing cultural competence in a multicultural world part II. *PT: Magazine of Physical Therapy, 11*(1), 56-70.

Leiter, V., & Waugh, A. (2009). Moving out: Residential independence among young adults with disabilities and the role of families. *Marriage and Family Review, 45*(5), 519-537. doi:10.1080/01494920903050847

Lennox, N., Taylor, M., Rey-Conde, T., Bain, C., Purdie, D. M., & Boyle, F. (2005). Beating the barriers: recruitment of people with intellectual disability to participate in research. *J Intellect Disabil Res, 49*(Pt 4), 296-305. doi:10.1111/j.1365-2788.2005.00618.x

Leonardi, M., Sykes, C. R., Madden, R. C., Ten Napel, H., Hollenweger, J., Snyman, S., . . . Martinuzzi, A. (2015). Do we really need to open a classification box on personal factors in ICF? *Disabil Rehabil*, 1-2. doi:10.3109/09638288.2015.1089604

Lewis, A., & Porter, J. (2004). Interviewing children and young people with learning disabilities*: Guidelines for researchers and multi-professional practice. *British Journal of Learning Disabilities, 32*(4), 191-197. doi:10.1111/j.1468-3156.2004.00313.x

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry / Yvonna S. Lincoln, Egon G. Guba*: Beverly Hills, Calif.: Sage, cop. 1985.

Lindsay, S., King, G., Klassen, A. F., Esses, V., & Stachel, M. (2012). Working with immigrant families raising a child with a disability: challenges and recommendations for healthcare and community service providers. *Disabil Rehabil, 34*(23), 2007-2017. doi:10.3109/09638288.2012.667192

Livingston, M. H., Rosenbaum, P. L., Russell, D. J., & Palisano, R. J. (2007). Quality of life among adolescents with cerebral palsy: what does the literature tell us? *Dev Med Child Neurol, 49*(3), 225-231. doi:10.1111/j.1469-8749.2007.00225.x

Löfgren-Mårtenson, L. (2004). "May I?" About Sexuality and Love in the New Generation with Intellectual Disabilities. *Sexuality & Disability, 22*(3), 197-207.

Maher, C. A., Williams, M. T., Olds, T., & Lane, A. E. (2007). Physical and sedentary activity in adolescents with cerebral palsy. *Dev Med Child Neurol, 49*(6), 450-457. doi:10.1111/j.1469-8749.2007.00450.x

Mallander, O. (2011). *Nära vänskap?: en analys av kontaktperson enligt LSS*. Malmö: Égalité.

Mannberg, L., Gustafsson, A., Gustafsson, S. & Wetterholm, S. (2013). MIMI – Modell för Informationsutbyte Mellan vårdgivare I Sörmland. Slutrapport. Retrieved from: https://www.socialstyrelsen.se/SiteCollectionDocuments/Sormland-Modell-for-informationsutbyte-slutrapport.pdf

Marcia, J. E. (1966). Development and validation of ego-identity status. *J Pers Soc Psychol, 3*(5), 551-558.

May, D. (2000). *Transition and change in the lives of people with intellectual disabilities*. Philadelphia, Pa.: Jessica Kingsley.

Meuris, K., Maes, B., & Zink, I. *Key Word Signing Usage in Residential and Day Care Programs for Adults With Intellectual Disability*.

Molin, M., Sorbring, E., & Lofgren-Martenson, L. (2015). Teachers' and parents' views on the Internet and social media usage by pupils with intellectual disabilities. *J Intellect Disabil, 19*(1), 22-33. doi:10.1177/1744629514563558

Moore, D. (1987). Parent–adolescent separation: The construction of adulthood by late adolescents. *Developmental Psychology, 23*(2), 298-307. doi:10.1037/0012-1649.23.2.298

Municipal Special Schools: an increase in pupil variation and numbers admitted to the special school (2006) [*Kommunernas särskola : elevökning och variation i andel elever mottagna i särskolan*.]. Stockholm: Skolverket.

Murphey J. and L. Cameron. (2008). "The effectiveness of Talking Mats with people with intellectual disabilities". *British Journal of Learning Disabilities*, 36 (232-241).

Murphy, C., Lincoln, S., Meredith, S., Cross, E., & Rintell, D. (2015). Sex Education and Intellectual Disability: Practices and Insight from Pediatric Genetic Counselors. *Journal of Genetic Counseling*, 1-9. doi:10.1007/s10897-015-9909-6

National Agency for special needs Education and Schools (2010) [Specialpedagogiska skolmyndigheten]. 'This is not an umbrella'. Retrieved from: http://static.pictosys.se/pictogram/PictogramEng.pdf (last assessed February 29, 2016)

Nieuwenhuijsen, C., Donkervoort, M., Nieuwstraten, W., Stam, H. J., & Roebroeck, M. E. (2009). Experienced problems of young adults with cerebral palsy: targets for rehabilitation care. *Arch Phys Med Rehabil, 90*(11), 1891-1897. doi:10.1016/j.apmr.2009.06.014

Nilgert, E., 2009. Föräldrautbildning riktad till föräldrar med barn med funktionshinder och annan kulturell bakgrund. [Parent education targeted to parents of children with disabilities and different cultural background]. Habilitering & Hjälpmedel, Region Skåne.

Nind, M. (2009). Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges. National Centre for research Methods.

Nochajski, S. M., Matteliano, M. A., & Stone, J. (2008). A guide to cultural competence in the curriculum: Occupational therapy. *Center for International Rehabilitation Research and International Exchange.* Retrieved from: *http://cirrie. buffalo. edu/culture/curriculum/guides/ot. php# about.*

Novak, I., Hines, M., Goldsmith, S., & Barclay, R. (2012). Clinical prognostic messages from a systematic review on cerebral palsy. *Pediatrics, 130*(5), e1285-1312. doi:10.1542/peds.2012-0924

Nowak, H. I., Broberg, M., & Starke, M. (2013). Parents' experience of support in Sweden: its availability, accessibility, and quality. *J Intellect Disabil, 17*(2), 134-144. doi:10.1177/1744629513486229

Olsson, M.B. & Hwang, C.P. (2003). The influence of macro structure of society on the life situation of families with a child with intellectual disability – Sweden as an example. *Journal of Intellectual Disability Research*, 47, 328-341.

Orlin, M. N., Palisano, R. J., Chiarello, L. A., Kang, L. J., Polansky, M., Almasri, N., & Maggs, J. (2010). Participation in home, extracurricular, and community activities among children and young people with cerebral palsy. *Dev Med Child Neurol, 52*(2), 160-166. doi:10.1111/j.1469-8749.2009.03363.x

Palisano, R., Rosenbaum, P., Bartlett, D., & Livingston, M. (2007). GMFCS-E & R Gross Motor Function Classification System Expanded and Revised Retrieved from: http://www.canchild.ca/en/measures/gmfcs_expanded_revised.asp. (last assessed February 29, 2016)

Palisano, R. J., Kang, L. J., Chiarello, L. A., Orlin, M., Oeffinger, D., & Maggs, J. (2009). Social and community participation of children and youth with cerebral palsy is

associated with age and gross motor function classification. *Phys Ther, 89*(12), 1304-1314. doi:10.2522/ptj.20090162

Palisano, R. J., Almarsi, N., Chiarello, L. A., Orlin, M. N., Bagley, A., & Maggs, J. (2010). Family needs of parents of children and youth with cerebral palsy. *Child Care Health Dev, 36*(1), 85-92. doi:10.1111/j.1365-2214.2009.01030.x

Palisano, R. J., Orlin, M., Chiarello, L. A., Oeffinger, D., Polansky, M., Maggs, J., . . . Stevenson, R. (2011). Determinants of intensity of participation in leisure and recreational activities by youth with cerebral palsy. *Arch Phys Med Rehabil, 92*(9), 1468-1476. doi:10.1016/j.apmr.2011.04.007

Parkinson, K. N., Dickinson, H. O., Arnaud, C., Lyons, A., & Colver, A. (2013). Pain in young people aged 13 to 17 years with cerebral palsy: cross-sectional, multicentre European study. *Arch Dis Child, 98*(6), 434-440. doi:10.1136/archdischild-2012-303482

Priestley, M. (2003). *Disability: a life course approach*. Cambridge, UK; Polity Press.

Proposition (1992/93:159) [Government bill] Lag om stöd och service till visa funktions-hindrade [The Swedish Act Concerning Support and Service for Persons with Certain Functional Impairments]. Stockholm: Sveriges Riksdag.

Public Health Agency of Sweden 16-02-25. Kursmaterial- Riktat familjestöd. Cours material. [Directed family support]. Authors: Granlund & Olsson. Retrieved at: https://www.folkhalsomyndigheten.se/documents/livsvillkor-levnadsvanor/barn-unga/foraldrastod/Kursmaterial-Hogskolan-Jonkoping.pdf (last assessed February 25, 2016)

Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., …,Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics, 115*(6), e626-636. doi:10.1542/peds.2004-1689

Raman, S. R., Mandoda, S., Hussain, L. K., Foley, N., Hamdan, E., & Landry, M. (2010). Exploring the meaning of childhood disability: perceptions of disability among mothers of children with disabilities (CWD) in Kuwait. *World Health Popul, 11*(4), 49-60.

Riktlinjer för etisk värdering av medicinsk humanforskning: forskningsetisk policy och organisation i Sverige. (2000). Stockholm: Medicinska forskningsrådet (MFR).

Ronen, G. M., & Rosenbaum, P. L. (2013). *Life quality outcomes in children and young people with neurological and developmental conditions: concepts, evidence and practice*. London: Mac Keith.

Rosenbaum, P., & Gorter, J. W. (2012). The 'F-words' in childhood disability: I swear this is how we should think! *Child Care Health Dev, 38*(4), 457-463. doi:10.1111/j.1365-2214.2011.01338.x

Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-Centred Service: A Conceptual Framework and Research Review. *Phys Occup Ther Pediatr, 18* (1), 1-20.

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., . . . Jacobsson, B. (2007). A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl, 109*, 8-14.

Rosenbaum, P., & Rosenbloom, L. (2012). *Cerebral palsy : from diagnosis to adult life*. London: Mac Keith Press.

Rosenbaum, P., & Stewart, D. (2004). The World Health Organization International Classification of Functioning, Disability, and Health: a model to guide clinical thinking, practice and research in the field of cerebral palsy. *Semin Pediatr Neurol, 11*(1), 5-10.

Sam, D. L., & Berry, J. W. (2010). Acculturation: When Individuals and Groups of Different Cultural Backgrounds Meet. *Perspect Psychol Sci, 5*(4), 472-481. doi:10.1177/1745691610373075

Sandström, K. (2009). *Adults with cerebral palsy: living with a lifelong disability / Karin Sandström*: Linköping : Department of Medical and Health Sciences, Linköping University, 2009.

Sawyer, M. G., Bittman, M., AM, L. A. G., Crettenden, A. D., Borojevic, N., Raghavendra, P., & Russo, R. (2011). Time demands of caring for children with cerebral palsy: what are the implications for maternal mental health? *Dev Med Child Neurol, 53*(4), 338-343. doi:10.1111/j.1469-8749.2010.03848.x

Schuengel, C., Rentinck, I. C., Stolk, J., Voorman, J. M., Loots, G. M., Ketelaar, M., ..., Becher, J. G. (2009). Parents' reactions to the diagnosis of cerebral palsy: associations between resolution, age and severity of disability. *Child Care Health Dev, 35*(5), 673-680. doi:10.1111/j.1365-2214.2009.00951.x

Scior, K., Addai-Davis, J., Kenyon, M., & Sheridan, J. C. (2013). Stigma, public awareness about intellectual disability and attitudes to inclusion among different ethnic groups. *J Intellect Disabil Res, 57*(11), 1014-1026. doi:10.1111/j.1365-2788.2012.01597.x

Sekretess inom hälso och sjukvård (2013). Retrieved from: http://www.skane.se/upload/Webbplatser/vardwebb/Dokument/riktlinjer/sekretesshs.pdf (last assessed February 29, 2016)

Simeonsson, R. J., Lollar, D., Bjorck-Akesson, E., Granlund, M., Brown, S. C., Zhuoying, Q., . . . Pan, Y. (2014). ICF and ICF-CY lessons learned: Pandora's box of personal factors. *Disabil Rehabil, 36*(25), 2187-2194. doi:10.3109/09638288.2014.892638

Social Science Statistics. Availible on: http://www.socscistatistics.com/tests/ztest/Default.aspx (Last assessed February 12, 2016)

Socialförsäkringsbalk (2010:110). Availible at: https://lagen.nu/2010:110. (Last assessed February 13, 2016)

Statens folkhälsoinstitut [Public Health Agency of Sweden]. (2012). *Hälsa och välfärd hos barn och unga med funktionsnedsättning*. [The health and wellbeing of children and youth with disabilities] Östersund: Statens folkhälsoinstitut.

Stevenson, A. (2010). *Oxford dictionary of English [Elektronisk resurs]*. New York, NY: Oxford University Press.

Stewart, D., Freeman, M., Healy, H., Burke-Gaffney, J., Forhan, M., Young, N. L., & Guenter, S. (2010). The transition to adulthood for youth with disabilities: Evidence

from the literature. Retrieved from: http://cirrie.buffalo.edu/encyclopedia. (last assessed February 29, 2016)

Stewart, D., Freeman, M., Law, M., Healy, H., Burke- Gaffney, J., Forhan, M., … , Guenter, S. (2009). "The Best Journey to Adult Life" For Youth with Disabilities. An Evidence-based Model and Best Practice Guidelines For The Transition To Adulthood For Youth With Disabilities Retrieved from: http://cirrie.buffalo.edu/encyclopedia (last assessed February 29, 2016)

Stewart, D., Law, M., Burke-Gaffney, J., Missiuna, C., Rosenbaum, P., King, G., …, King, S. (2006). Keeping It Together: an information KIT for parents of children and youth with special needs. *Child Care Health Dev, 32*(4), 493-500. doi:10.1111/j.1365-2214.2006.00619.x

Stewart, D. A., Law, M. C., Rosenbaum, P., & Willms, D. G. (2001). A qualitative study of the transition to adulthood for youth with physical disabilities. *Phys Occup Ther Pediatr, 21*(4), 3-21.

Stewart, D. A., Lawless, J. J., Shimmell, L. J., Palisano, R. J., Freeman, M., Rosenbaum, P. L., & Russell, D. J. (2012). Social participation of adolescents with cerebral palsy: trade-offs and choices. *Phys Occup Ther Pediatr, 32*(2), 167-179. doi:10.3109/01942638.2011.631100

Stewart, D., Law, M., Young, N. L., Forhan, M., Healy, H., Burke-Gaffney, J., & Freeman, M. (2014). Complexities during transitions to adulthood for youth with disabilities: person–environment interactions. *Disabil Rehabil, 36*(23), 1998-2004. doi:10.3109/09638288.2014.885994

Statistics Sweden (SCB). (2012). Annual statistics 2012 *Statistisk årsbok 2012: Statistical yearbook of Sweden 2012*. Stockholm: Statistiska centralbyrån.

Strock-Lynskey, D., & Keller, D. W. (2007). Integrating a family-centered approach into social work practice with families of children and adolescents with disabilities. *Journal of Social Work in Disability & Rehabilitation, 6*(1-2), 111-134.

Stromme, P., & Valvatne, K. (1998). Mental retardation in Norway: prevalence and sub-classification in a cohort of 30037 children born between 1980 and 1985. *Acta Paediatr, 87*(3), 291-296.

Svedberg, L. E., Englund, E., Malker, H., & Stener-Victorin, E. (2010). Comparison of impact on mood, health, and daily living experiences of primary caregivers of walking and non-walking children with cerebral palsy and provided community services support. *Eur J Paediatr Neurol, 14*(3), 239-246. doi:10.1016/j.ejpn.2009.07.001

Swedish Social Insurance Agency. (2013). Parental benefit [Föräldrapenning] Retrieved from: http://www.forsakringskassan.se/sprak/eng (Last assessed February 15, 2016)

Taylor, S. J., & Bogdan, R. (1998). *Introduction to qualitative research methods: a guidebook and resource / Steven J. Taylor, Robert Bogdan*: New York, N.Y.; Chichester: Wiley, 1998 3. ed.

The National Board of Health and Welfare. (2009). *Swedish disability policy - service and care for people with functional impairments* (The National Board of Health and Welfare ed Vol. 2013): The National Board of Health and Welfare.

The National Board of Health and Welfare. (2010). *Habilitering och rehabilitering. Förutsättningar för uppföljning*. Retrieved from: http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/18207/2010-12-20.pdf (last assessed February 29, 2016)

The National Board of Health and Welfare [Socialstyrelsen] (2011). ICF/ICF-CY utbildningsmaterial. Del 1- Introduktion av modell, struktur och innehåll. Retrieved from: http://www.socialstyrelsen.se/publikationer2011/utbildningsmaterial-om-icf-icf-cy (last assessed February 29, 2016)

The National Board of Health and Welfare. (2014). *Stöd till barn och unga med funktions-nedsättning: handbok för rättstillämpning vid handläggning och utförande av LSS-insatser[Support for children and young people with disabilities. Manual for assessing and implementing measures according to LSS]*. (2014). Stockholm: The National Board of Health and Welfare.

The National Board of Health and Welfare. (2015). Utveckling av Klassifikation av socialtjänstens insatser och aktiviteter (KSI). Retrieved from: http://www.socialstyrelsen.se/klassificeringochkoder/ksi (last assessed February 29, 2016)

The Swedish Migration Agency (2016). S*tatistics asylum applications 2014*. Retrieved from:: http://www.migrationsverket.se/English/About-the-Migration-Agency/Facts-and-statistics-/Statistics.html (Last assessed February 15, 2016)

Todd, S., & Jones, S. (2005). Looking at the future and seeing the past: the challenge of the middle years of parenting a child with intellectual disabilities. *J Intellect Disabil Res, 49*(Pt 6), 389-404. doi:10.1111/j.1365-2788.2005.00675.x

Ungdomsstyrelsen. (2012). Fokus 12. Levnadsvillkor för unga med funktionsnedsättning [The Youth board-Living conditions for youth with disabilities]. Retrieved from: www.ungdomsstyrelsen.se (last assessed February 29, 2016)

United Nations (2016) *The definition of youth*. Retrieved from: http://www.un.org/esa/socdev/documents/youth/fact-sheets/youth-definition.pdf (last assessed February 29, 2016)

United Nations Human Rights (1990). Convention on the Rights of the Child. Retrieved from: http://www.ohchr.org/en/professionalinterest/pages/crc.aspx

United Nations Human Rights (2006). Convention on the rights of persons with disabilities. Retrieved from: http://www.un.org/disabilities/convention/conventionfull.shtml

van Laerhoven, H., van der Zaag-Loonen, H. J., & Derkx, B. H. (2004). A comparison of Likert scale and visual analogue scales as response options in children's questionnaires. Acta Paediatr, 93(6), 830-835.

Vargus-Adams, J. N., & Majnemer, A. (2014). International Classification of Functioning, Disability and Health (ICF) as a framework for change: revolutionizing rehabilitation. J Child Neurol, 29(8), 1030-1035. doi:10.1177/0883073814533595

Westbom, L., Bergstrand, L., Wagner, P., & Nordmark, E. (2011). Survival at 19 years of age in a total population of children and young people with cerebral palsy. Dev Med Child Neurol, 53(9), 808-814. doi:10.1111/j.1469-8749.2011.04027.x

Whittingham, K., Wee, D., Sanders, M. R., & Boyd, R. (2013). Sorrow, coping and resiliency: parents of children with cerebral palsy share their experiences. Disabil Rehabil, 35(17), 1447-1452. doi:10.3109/09638288.2012.737081

WHO, World Health Organization. (2013). Process of Translation and Adaption of Instruments. Retrieved from: http://www.who.int/substance_abuse/research_tools/translation/en/ (last assessed February 29, 2016)

Wibeck, V., Abrandt Dahlgren, M., & Öberg, G. (2007). Learning in focus groups: an anlalytical dimention for enhancing focus group research. doi:10.1177/14687941107076023

Wiegerink, D., Donkervoort, M. & Roebroeck, M. (2007). The Rotterdam Transition Profile. Concept 0.2. Retrieved from: http://www.erasmusmc.nl/Reva/Research/transition/RotterdamTransitionProfilev0.2 (Last assessed February 29, 2016)

Wiegerink, D., & Roebroeck, M. (2013). Romantic relationships and sexual experiences in young people with neuromental conditions. In G. Ronen & P. Rosenbaum (Eds.), Life Quality Outcomes in Children and Young People with Neurogical (Hilary M. Hart ed., pp. 107-119). London: Mac Keith.

Wiegerink, D., Roebroeck, M., Bender, J., Stam, H., & Cohen-Kettenis, P. (2011). Sexuality of Young Adults with Cerebral Palsy: Experienced Limitations and Needs. Sex Disabil, 29(2), 119-128. doi:10.1007/s11195-010-9180-6

Wiegerink, D. J., Roebroeck, M. E., van der Slot, W. M., Stam, H. J., & Cohen-Kettenis, P. T. (2010). Importance of peers and dating in the development of romantic relationships and sexual activity of young adults with cerebral palsy. Dev Med Child Neurol, 52(6), 576-582. doi:10.1111/j.1469-8749.2010.03620.x

World Health Organization. (2003). WHO definition of Health. Retrieved from: http://www.who.int/about/definition/en/print.html (last assessed February 29, 2016)

WMA. (2013). Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects (Article) Retrieved from: http://www.wma.net/en/30publications/10policies/b3/

World health Organization (WHO) (1980). International classification of impairments, disabilities, and handicaps : a manual of classification relating to the consequences of disease : published in accordance with resolution WHA29.35 of the Twenty-ninth World Health Assembly, May 1976. (1980). Geneva: WHO.

World Health Organization. (2001). International classification of functioning, disability, and health: ICF short version. Geneva: World Health Organization.

World Health Organization. (2007). International classification of functioning, disability and health: children and youth version: ICF-CY. Geneva: World Health Organization.

World Health Organization. (2015). Disability and Health. Fact sheet N˚352. Retrieved from: http://www.who.int/mediacentre/factsheets/fs352/en/ (last assessed February 13, 2016)

World Health Organization. (2016). ICD-10, version 2016. Retrieved from: http://apps.who.int/classifications/icd10/browse/2016/en#/F70 (last assessed February 12, 2016)

Young, N. L. (2007). The transition to adulthood for children with cerebral palsy - What do we know about their health care needs? Journal of Pediatric Orthopaedics, 27(4), 476-479.