Parents of Children with Developmental Disabilities and Their Experiences of Formal Support

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Doctoral Dissertation in Psychology
Department of Psychology
University of Gothenburg , 2017

Cover layout: Inge I. Kroon
Printed by Ineko AB, Gothenburg, Sweden, 2017

ISBN: 978-91-984178-5-2 (PDF)
ISBN: 978-91-984178-4-5 (Print)
ISSN: 1101-718X Avhandling/Göteborgs universitet, Psykologiska inst.
ISRN: GU/PSYK/AVH--365—SE

To my parents, Paul, Julian, and Connor

Thank you for being you

Abstract

The aim of this thesis was to investigate how UN conventions, national laws, regulations, and policies are manifested in everyday experiences of parents of children with disabilities. The specific aims of this thesis are to 1) investigate how parents of children with developmental disabilities experience their parenthood and received formal support, 2) investigate how parents and professionals experience the opportunity for children with disabilities to participate in decision-making process, 3) describe how individual factors (parental gender and country of origin as well as the child's diagnosis and age) contribute to parents' experience of their subjective need and experience of support during the course of childhood (age span in all the studies 1-20 years). **Study I** explored parents' experience of the received support through a semi-structured interview with six parents of children with intellectual disabilities in the Western region of Sweden. Parents reported difficulty in finding and obtaining information about and accessing available support. **In Study II** and **III**, parents of children with disabilities participated in a structured telephone interview. **Study II** aimed to compare parents' needs for formal parenting (e.g. information about diagnosis and services and meeting with other parents) and emotional support (e.g. couple counselling and crisis interventions) with their actual perceived availability thereof. Parents experienced that they had not received the support that they needed regarding information about their child's rights and available existing support. Parents also reported that their need for support for stress management and for individual counselling had not been fulfilled. Parents' needs for formal parenting and emotional support were related to the gender of the parent and their country of origin. **Study III** investigated professionals' and parents' ratings of the opportunities available to children with disabilities to participate in planning, decision-making, and evaluation of support, and parental satisfaction with current level of such child-participation. Most professionals indicated that they were able to meet with children directly, but relied more on parents' descriptions of the child's needs and opinions of support services than on direct communication with the child. Both parents and professionals rated children's opportunities to participate as limited, but the participation increased with age. **Study IV** investigated parents' who have young adult children with severe physical disabilities and attended a special upper secondary school program. The study specifically looked at their reflections of everyday life and their experience of parenthood during and after their young adult child attended the special upper secondary school program. Parents' experiences of parenthood were related to their youth’s capacities and environment. The environmental factors, however, played a significant role in the ways parents perceived their young adult children’s future.

Overall results from the studies show norms, rules, and regulations in regard to support services provide children with disabilities and their parents opportunities to apply for support services, giving them a chance to participate in the community, and to live as others in accordance with the UNCRC and UNCRPD. However, these support services are not equally accessible by all children with disabilities and their parents. Laws, regulations, and policies governing the right to support do not provide assurance that parents would be receiving the support that they need. The studies also show that plenty of work still needs to be done in implementing disability policy in Sweden.

Keywords: Children, disabilities, experience, parents, participation, policy, support.

Sammanfattning (Swedish summary)

Traditionellt har funktionsnedsättning uppfattat som ett individuellt problem vilket kan innebära att individen förväntas ta ansvar och anpassa sig till den miljö som hen befinner sig i. Begreppet funktionshinder är idag inte enbart relaterat individen, utan även till hur miljön bidrar till att skapa barriärer och hindra individen att vara delaktig i samhället på samma villkor som andra. Idag lever och växer barn med funktionsnedsättning oftast upp med sina familjer med samma rättigheter som andra barn. För att det ska fungera kan olika former av stöd och insatser behövas, beroende på individens och/eller familjens behov.

Det övergripande syftet med avhandlingen var 1) att undersöka hur lagar som reglerar stöd till föräldrar till barn med funktionsnedsättning samt FN konventionen (konventionen om barn rättigheter och konventionen om rättigheter för personer med funktionsnedsättningar) manifesterar sig i föräldrars dagliga upplevelser och 2) hur individuella faktorer som barnets diagnos och ålder samt föräldrarnas kön och ursprungsland bidrar till föräldrars behov av stöd. I avhandlingen presenteras tre olika modeller: den medicinska, sociala och relativa modellen. Dessa tre modeller används för att tydliggöra hur perspektiv på funktionsnedsättning kan påverka de strukturer och stödprocesser som finns i samhället. Därutöver används Bronfenbrenners Proces-Person-Context-Time (PPCT) modell för att ge en övergripande bild av hur relationen mellan barn med funktionsnedsättning, deras föräldrar samt yrkesverksamma påverkas av de lagar som styr stöd och insatser i Sverige.

Syftet med **Studie I** var att undersöka föräldrars upplevelser av det stöd som ges till dem och deras barn. Fem mammor och en pappa intervjuades om sina upplevelser av att ha barn med funktionsnedsättning och om stöd de får från samhället. Tematisk analys användes för att analysera intervjuerna. Tre teman identifierades i intervjuerna: 1) information om diagnos och insatser, 2) tillgänglighet av insatser och 3) kvalitet av insatser. Resultatet från Studie I visar att föräldrarna var osäkra på vad deras barns diagnos betydde för barnet och för familjens vardagsliv. Dessutom upplevde föräldrarna att de saknade information om insatser och de behövde kämpa för att barnet skulle få de insatser som det behövde.

Empirin från **Studie II** och **III** är hämtad från en undersökning som studerat befintligt föräldrastöd. Undersökningen baseras såväl på strukturerade telefonintervjuer med 142 föräldrar som hade barn med funktionsnedsättning som en webbenkät riktad till yrkesverksamma som arbetar med barn med funktionsnedsättning och deras familjer.

Syftet med **Studie II** var att undersöka föräldrarnas upplevelser av stöd samt deras behov av stöd i sitt föräldraskap och känslomässigt stöd. Resultatet från telefonintervjuer med 142 föräldrar visade att flertalet föräldrar inte uppfattade att de behövde något ytterligare stöd. Bland de föräldrar som angav att de hade behov av stöd upplevde att deras behov av stöd inte hade uppfyllt. Resultatet visade att mammor efterfrågade mer känslomässigt stöd än pappor, speciellt inom stress och krishantering samt par samtal. Mammor rapporterade dessutom att de hade behov av att träffa andra föräldrar i liknande situation.

Syften med **Studie III** var: 1) att undersöka föräldrars och yrkesverksammas uppfattning av barn med funktionsnedsättning och deras deltagande i planering, beslut, och utvärdering av insatser, och 2) hur nöjda föräldrarna och yrkesverksamma var med barnets deltagande. Resultatet visade att de flesta yrkesverksamma hade möjlighet att träffa barnen personligen. Dock skattade föräldrar till äldre barn (13-18 år) bättre möjligheter för deras barn att komma till tals i planeringen av insatser än föräldrar till yngre barn (0-6 år och 7-12 år). Både yrkesverksamma och föräldrar beskrev att yrkesverksamma hellre kommunicerar via föräldrarna än att fråga barnen.

Studie IV undersökte föräldrar till ungdomar som har gått på Riksgymnasiet och föräldrarnas erfarenheter av sitt föräldraskap under tiden då ungdomarna gick på gymnasiet samt efter att de hade tagit studenten. Resultatet visade att föräldrarollen förändrades påtagligt när ungdomarna flyttade hemifrån till skolans elevhem. Föräldrarna uppskattade stödet de fick från yrkesverksamma, speciellt från de som arbetade direkt med deras ungdomar på elevhemmet. Samtidigt visade resultatet att föräldrarna upplevde en stor oro när de unga flyttade hem igen efter studenten. Föräldrarna upplevde att stödet tog slut och de återupptog föräldraansvaret. De upplevde att deras ungdomar hamnade i en situation där sociala förutsättningar, meningsfull sysselsättning samt och andra möjligheter för unga personer med funktionsnedsättning var mycket begränsade.

Resultatet från avhandlingens studier visar att FN konventionen den internationella och svenska funktionshinderpolicyn påverkar föräldrarnas upplevelser av att ha ett barn med funktionsnedsättning. Studierna visar att makrosystemet i Sverige har ger stöd till föräldrar med barn med funktionsnedsättning.

Samtidigt visar resultatet att det finns brister, exempelviss, begränsad information om rättigheter och stöd som finns samt lång ansökningsprocesser att få stöd, som kan påverka föräldrarnas vardagsliv upplevelser samt interaktionen och relationen mellan föräldrar och yrkesverksamma. Resultatet visar också föräldrar till barn med funktionsnedsättning behöver mer känslomässigt stöd, exempelviss, med stresshantering. Föräldrarnas behov av stöd påverkas inte bara av de funktionsnedsättningar som barnen har utan också av föräldrarnas kön och födelseland. Dessutom spelar den sociala omgivningen stor roll i föräldrarnas upplevelser av stöd. Lagar och konventioner hjälper till så att föräldrarna och barn med funktionsnedsättningar kan få möjligheten att leva som andra, men det är viktigt att lagarna implementeras i verksamheter som ges stöd till barn med funktionsnedsättning och deras föräldrar och når ut till familjerna.

Acknowledgements

My sincere gratitude and deepest appreciation to my supervisors Professor *Malin Broberg* for whom I cannot thank enough for the privilege to learn from and work with. Your pedagogical skills are admirable. To Associate professor *Mikaela Starke*, who despite her busy schedules, managed to always willingly spare her time when I needed her guidance. For both of you, thank you for the ongoing support, guidance, and friendship throughout this journey. Thank you for widening my perspective academically, in research, and in life.

To my former colleagues and friends at FoU I Väst/GR and Vårdals institute, I will forever be grateful for your kindness and for sharing your experiences and knowledge with me. To my colleagues at the department of Psychology, thank you for the laughs, exchange of experiences, and words of encouragement. To all the members of PIP group, thank you for sharing your experience. David Norlin, Petra Boström, and Isac Sehlstedt, thank you for your friendship and wisdom! Last but certainly not least a very special thanks to Elaine Mc Hugh, for whom I cannot thank enough for her abundant words of encouragements, kindness, and all the happy teatime (and lunches).

To Dr. Ole Hultmann, Dr. Ulf Axberg, and Karin Thorslund, thank you for your comments on the earlier version of this thesis. I also deeply appreciate the feedback from my examiner Professor Erland Hjelmquist and Professor Anders Gustavsson.

Special gratitude to my parents and my siblings (Vera, Inge, Christine, & Deny) for their unconditional love, humor, and support. To my mother in law thank you for your help with the kids. To the Reimers, the Xaviers, the Ödmans, the Gunnarssons, Sundari Nilson, Gheraldine Larsson, and Maria Bohlin, I am also grateful for your presence in my life, for the exchange of stories of parenthood and parenting, and most of all for all the wonderful times together.

To my dearest husband, Paul, this journey would not be possible without you. Thank you for everything! To my children Julian Aiden and Connor Wilhelm, you are the joy of my life and my mindfulness. Thank you for giving me courage, life lessons, and a daily dose of laughter.

A thousand thanks to the parents, who shared their experiences and time, and to the professionals, who had contributed their time and energy with the data collection. This thesis would not exist without their contributions and participations. Finally, this research was not possible without the financial support from the Swedish Health Institute and Vårdals Institute.

Gothenburg, 2017

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Preface

This thesis consists of a summary and the following four papers:

I. Nowak H., Broberg, M., and Starke, M. (2013). Parents' experience of support in Sweden: Its availability, accessibility, and quality. Journal of Intellectual Disabilities, 17 (2), 134-144. DOI: 10.1177/1744629513486229

II. Nowak H, Starke, M., and Broberg, M. *The Availability of Formal Parenting and Emotional Support to Parents of Children with Disabilities in Sweden.* Manuscript submitted for publication.

III. Nowak H., Broberg, M., and Starke, M. *The opportunity for children with disabilities to participate in planning and evaluation of support: Parents' and professionals' perceptions.* Journal of Intellectual Disabilities.

IV. Nowak H., Broberg, M. and Starke, M. *Now what? Parents' experiences of parenthood and formal support during and after a special upper secondary school program for their young adult children with severe physical disabilities.* Manuscript submitted for publication.

CONTENTS

Introduction

Although institutions designed to care for children with disabilities, still exist around the world, many children with disabilities now have the possibility to grow up at home with their families since the start of the deinstitutionalization during the last part of the 20th century (Tideman & Tøssebro, 2002). In Sweden, it has been expected that parents care for their children at home even when the child has severe disabilities and medical needs since the beginning of the 1980s. By growing up at home, children have the opportunity to spend time and develop close relationships with their siblings, parents, and other family members, however it also poses challenges to parents and siblings. It is well known that parents of children with disabilities have to take on greater and more complex caring tasks than parents of children without disabilities. Studies have reported that raising a child with disabilities affects parents' experiences of parenthood (Murphy, Christian, Caplin, & Young, 2007) and parents' well-being (Olsson, Larsman, & Hwang, 2008). Many different factors have been studied in relation to the well-being of parents of children with developmental disabilities (DD). The factors can be related to (a) the child, (b) the parent and (C) and contextual factors such as the cultural norms, laws and formal support available to parents of children with disabilities (Families Special Interest Research Group of IASSIDD, 2013).

The parents who participated in the studies included in this thesis all have children with DD. According to the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-V), DD refers to a lifelong disability including physical and/or intellectual disabilities with onset occurring during the developmental period and affecting the individual's development, adaptive function and everyday life (American Psychological Association, 2013). Physical disabilities are characterized by limitation in the physical functioning/mobility, whereas, intellectual disabilities (ID) is characterized by limitations both in intellectual functioning and adaptive behavior affecting the individual's everyday social and practical capacity (DSM-5, APA 2013). DD includes, for example, individuals with specific diagnoses such as Down syndrome (DS), cerebral palsy (CP), autism spectrum disorders (ASD), and ID.

In Sweden, parents of children with DD are entitled to apply for various types of financial, social, practical, and medical support. Despite the support, parents of children with disabilities in Sweden experience higher levels of stress compared with parents of children without disabilities (Olsson, 2009). Despite this, parents do not tend to describe their child as the source of stress and reason for decreased wellbeing (Olsson & Hwang, 2008). Rather factors related to the interaction with the environment and support system seems to play an important part in the parents' everyday life experience.

The general aim of this thesis was to investigate how UN conventions, national laws, regulations, and policies are manifested in everyday experiences of parents of children with disabilities. The specific aims of this thesis are to 1) investigate how parents of children with developmental disabilities experience their parenthood and received formal support, 2) investigate how parents and professionals experience the opportunity for children with disabilities to participate in decision-making process, 3) describe how individual factors (parental gender and country of origin as well as the child's diagnosis and age) contribute to parents' experience of their subjective need and experience of support during the course of childhood (age span in all the studies 1-20 years).

This thesis is organized as follows; first, the concept of parenthood, different ways of understanding the concept of disabilities, and the prevalence of children with developmental disabilities will be discussed. Next, previous studies about parents of children with disabilities including research on the strategies related to parents' adaptation to the daily challenges of raising a child with disabilities will be provided. Then, studies on support for parents of children with disabilities including the support system in Sweden will be presented. Afterwards, a theoretical model in relation to the interaction between the individual and his/her environment will be provided. Lastly, a summary of the studies included in this thesis and discussion of the results will be provided.

Background

Parenthood

Becoming a parent is often viewed as a transition in one's life and a developmental stage involving growth and change (Berk, 2009; Demick, 2002). Being a parent also means that one is bound to certain responsibilities such as caring for the child and assuring that the child's needs are properly met. Becoming a parent comes with responsibilities such as the responsibility to make decisions necessary to assure that the well-being of the child is assured. In Sweden, the rights and responsibilities of parents are legally set forth in the Children and Parents Code (1949). According to this code, parents are obliged to 1) ensure that their child's needs are met 2) consider the best interests of their child in their decision relating to their child, and 3) take into account the wishes of the child according to his or her age and maturity (chapter 6§2a). Being a parent is related to individual experiences and to the environment he/she is currently in (Demick, 2002). This means that the experience of parenthood is dynamic and complex yet adaptable, and related to the social context parents are in.

Most parents are not aware that their child has a disability before the child is born. It has been reported that parents' experience is affected when they realize that their child has disabilities (Graungaard & Skov, 2007). Thus, a child's disabilities not only affect the child but also his/her parents. Despite the extraordinary situation, it is reported that most parents adapt well to the challenges of living with and raising a child with disabilities (Emerson, Hatton, Llewellyn, Blacker, & Graham, 2006; Hassal & Rose, 2005). It is reported, for instance, that most parents are able to cope and redirect their focus from their child's impairments into addressing their child's needs (Beresford, 1996; Poslawsky, Naber, Daalen, & Van Engeland, 2014; Rentnick, Gorter, Ketelaar, Lindeman, & Jongmans, 2009). They also develop and employ a variety of coping strategies to manage the demands that come with their child's disabilities (Glidden & Natcher, 2009; Lee, 2009).

Raising a child with disabilities involves, as all parenthoods, challenges as well as great love and joy (Bayat, 2007; Blacher & Baker, 2007; Blacher, Begum, Marcoulides, & Baker, 2013). Having a child with disabilities, for example, has been found to strengthen family relations and connectedness (Bayat, 2007). Parents also report that having a child with disabilities increases their tolerance, self-understanding, personal growth, and strength (Hasting & Taunt, 2002; Scorgie & Sobsey, 2000). Moreover, most mothers express their experience of caring for their child with disabilities as emotionally rewarding (Green, 2007).

The literatures mentioned above indicates that despite the special circumstances, the experiences of parenthood when your child has disabilities are similar to those related to raising a child without disabilities. While it is important to focus on the positive news, it is also important to address how everyday parenting differs when one has a child with disabilities and what kind of support parents might need for their child and directed towards them as parents. Before discussing parents' support needs further, it will be useful to look at how disability can be defined and the different discourses in relation to disability.

Different ways of understanding disabilities

Over the last 35 years research into different ways of describing and understanding disability has emerged. This research has identified different discourses that are nowadays often referred to as different models of disabilities. Our view of, or discourse about disability has an important impact on our view of individuals with disabilities, their support needs and the needs of the families, as well as implications for policy and laws within society. Three models have dominated the discussion (Grönvik, 2009). Traditionally, the term of disabilities has been used to describe impairments, limitations and restrictions of an individual. This approach of looking at disabilities as intrinsic to the individual has been described as the medical model (The British Council of Organisations, 1997). From this view point interventions should primarily focus on providing treatment and interventions in the purpose of limiting the child's impairments and normalizing child functioning.

Disabilities, however, can also be looked at from a socio-ecological perspective. The social model "distinguishes between the impairments that people have and the oppression which they experience" (Shakespeare & Watson, 2002). It recognizes that while people have physical, psychological, or intellectual variations, their disabilities are a result of the failure of society to account for and include people regardless of their individual differences (Adams, Dominelli, & Payne, 2009) and focuses on the barriers of society rather than on an individual's condition. From this standpoint, parents' need for support has been focused towards the availability and adequacy of support as well as the attitudes a society holds towards children with disabilities and their parents.

Lastly, disabilities can be looked at as a mismatch between an individual and his/her environment, and can be defined by looking at the environment and the current situation the individual (Tøssebro, 2004). The relationship and interaction between the individual impairment and an inaccessible environment is therefore emphasized (Gustavsson, 2004). The surrounding environment includes physical aspects, social relations, and the situation an individual is in (Tideman, 2000). Thus, from this perspective parents' need for support is related to the challenges due to the child's impairments and to the parents' own needs such as improving skills to manage daily stress and having the opportunity to socialize with other parents.

Although the three different ways of looking at and understanding disability were originally discussed in relation to individuals with disabilities, such as children with disabilities, it is also useful to understand the daily challenges faced by parents of children with disabilities as these challenges might be related to both the impairments that their child has and the existing support system. As the focus of this thesis is parents of children with developmental disabilities (DD), an estimate of the prevalence of parents of children with disabilities is warranted. This can be done by looking at the prevalence of children with disabilities.

Prevalence of children with disabilities in Sweden

It is reported that there are approximately 93 million children with disabilities around the world (UNICEF, 2017). The prevalence of children with disabilities, however, varies between one society and another. It is reported, for instance, that the prevalence is higher in poorer countries and in areas with lower socioeconomic status which can be explained by greater exposure to risks during pregnancy, childbirth, and childhood such as poor nutrition, infections, environmental hazards, drugs, and poorer access to healthcare (Families Special Interest Research Group of IASSIDD, 2014).

In Sweden, the prevalence of children with DD changes due to medical advancements such as prenatal diagnosis and the increased awareness and diagnosis of certain conditions such as neuropsychiatric difficulties (Reichow, Barton, Boyd, & Hume, 2012). It is worth highlighting that the prevalence number is affected by different factors, such as changes in diagnosis criteria in Diagnostic and Statistical Manual of Mental Disorders (DSM), which is a manual widely used in the Swedish health system, and when the support system requires diagnoses to support children (Fernell, Eriksson, & Gillberg, 2013).

The prevalence of children with disabilities, between the age of 3 and 18, is reported to be approximately 3-5 % in Sweden (Ryberg, 2011). This number includes children with vision and hearing impairments, physical disabilities, intellectual disabilities, and neuropsychiatric disorders. The focus in this thesis is parents of children with DD and their experience of support. Swedish studies show that 0.22% of children have severe cerebral palsy (Himmelmann, Hagberg, & Uvebrant, 2010), and the overall prevalence of Autism Spectrum Disorder (ASD) is estimated to be 1 in 68 children (Hedvall, Fernell, Åsberg, Gillberg, & Billstedt, 2013).

As stated earlier, the parents who participated in the four studies included in this thesis have children with DD, which are largely eligible to also seek support under the Act concerning Support and Service for Individuals with Certain Functional Impairments (known as LSS). Statistic Sweden (2015) showed that in 2011, there were approximately 20 000, Swedish children and young adults between the age of 0-22 who received some form of support according to the Act concerning Support and Service for Individuals with Certain Functional Impairments (1993). Of the 20 000, approximately 3700 (19%) reside within the Southwestern region. Of those that reside in the Southwestern region, approximately 60 % of the children and young adults came from the areas where Study II and III were conducted (approximately 1100 (29.5%) from the municipality of Gothenburg, 126 (3.3%) from Kungälv, and 27 (0.7%) from Tjörn). This means that the prevalence of parents of children with disabilities were approximately 2000-2500 in these three municipalities.

The (extra) ordinary parenthood

It is known that raising a child with disabilities affects the everyday parenting experience. Throughout the development of the child, many parents of children with disabilities have to manage disruptive behaviors (Plant & Sanders, 2007), difficult child temperament (Bailey, Hatton, Mesibov, Ament, & Skinner, 2000; Gartstein, Marmion, & Swanson, 2006), and heavy care-giving responsibilities (Gupta & Singhal, 2005) on a daily basis. Considerable evidence from different countries suggest that parents of children with disabilities experience higher levels of stress compared to parents of children without disabilities (Gerstein, Crinic, Blacher, & Baker, 2009; Hastings, 2002; Olsson, 2009; Singer, 2006; Veisson, 1999). Smith, Oliver, & Innocenti (2001) investigated the relation between the level of a child's impairment and parental stress and found that the level of the child's impairment had minimal impact on parental stress.

Substantial studies found that factors such as family functioning, family resources, and social support also play vital roles in predicting parenting stress. Families of children with disabilities, for instance, are more likely to be faced with social disadvantages and pervasive economics problems than families without children with disabilities (Cassidy, McConkey, Truesdale-Kennedy, & Eamonn, 2008; Emerson et al., 2006; Shearn & Todd, 2000). Additionally, being a parent of a child with disabilities often involves a longer time of practical everyday responsibility compared to parents of children without disabilities (Olsson & Hwang, 2001). Parents of children with disabilities are also at risk for being exposed to stigma and marginalization from society (Cassidy et al., 2008; Reed, 2000). The negative attitude towards disabilities in society (Green, 2003; Green, 2007), the difficulty of obtaining support (Gray, 2002), and negative interactions between parents and professionals can contribute to the parents' stress (Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009; Summers et al., 2007), and well-being in parents of children with disabilities (see Miodrag and Hodapp, 2010; Singer, 2006). Yet, it is worth repeating that most parents adapt well in spite of these challenges (Emerson et al., 2006; Hassal & Rose, 2005). The next section addresses the strategies and strengths related to parents' ability to adapt to these various challenges.

Strategies and strengths related to parents' ability to adapt

People interpret, respond, and deal with stressful situations actively (Lazarus & Folkman, 1984). Individuals thus differ in their interpretation and response to similar events, such as raising a child with disabilities. Wallander & Varni (1998) proposed that there are risk and resilience factors that influence parental adjustment in raising a child with disabilities. Risk factors include, factors related to child impairments (e.g. type of diagnosis and tensions related to caring for a child with disabilities) and stress factors directly and indirectly related to the child (e.g. financial strain). Resilience factors includes, factors related to parents' own abilities to process stress, parents own interpersonal factors, and socio-ecological factors (formal and informal support). In addition to the internal factors related to the individual parents, external factors such partner relationship and availability of support has been considered factors that influence parents' ability to adapt to raising a child with disabilities.

Substantial research has been conducted to investigate factors related to strategies and strengths in parents' ability to adapt. Positive attitudes about the situations (Hasting & Taunt, 2002) and parental self-efficacy (Hastings & Brown, 2002) have been found to contribute positively to adaptive coping skills of parents of children with disabilities. Parental adjustment also has been reported to be related to emotional coping strategies as well as higher levels of social support (Pakenham, Samios, & Sofronoff, 2005). Studies also found that most parents were able to cope better with the daily challenges of raising children with disabilities (Emerson et al., 2006; Gray, 2002; Hassal & Rose, 2005) by developing and employing various strategies to manage the demands and challenges of raising their child with disabilities (Lee, 2009). Some parents, for example, focus on seeking support and interventions for their child, to deal with the daily challenges and care giving demands (Dykens & Hodapp, 2001), while others use informal support to exchange information and to build social networks (Carlhed, Björk-Åkesson, & Granlund, 2003). It is reported also that informal support, such as support that parents receive from extended family members and friends enhance the adaptation of parents of children with disabilities (Bromley et al., 2004; White & Hastings, 2004). Beside informal support, formal support has been reported to positively impact families (Cowen & Reed, 2002; Ellis, Luiselli, & Amirault, 2002; Romer & Richardson, 2002).

Formal support has traditionally has been treatment oriented, that is directed towards the functioning of the child. However, different models of support focusing on the need of the parents have also emerged. An example of this is respite care, which aims to support families by providing care relief to parents, or support focusing on collaboration and partnership. Support focusing on the partnership between support provider and parents has been found to increase parents' confidence, improve quality of parent-child interaction (Brookman-Frazee & Koegel, 2004; Regan, Curtin, & Vorderer, 2006), communication between parents and professionals (MacKean, Thurston, & Scott, 2005), and satisfaction with service providers and programs (Dunst, Trivette, & Hamby, 2007). Another example is support aimed to reduce parental stress such as cognitive behavioral therapy or counseling programs for parents, which aims to support parents to identify issues and then set goals and plans accordingly. Emotional support for parents of children with disabilities has been found to positively affect parents' well-being (Broberg et al., 2010). Despite the increasing trend of adopting a family-centered principle many programs still focus on interventions directed towards the individual child or individuals with disabilities, instead of focusing on the whole family (Hiebert-Murphy, Trute, & Wright, 2011).

As shown above, the role of informal and formal support is vital in parents' ability to adapt. And as highlighted by Wallander & Varni (1998) the risk and resistance factors influencing parental adaptation that are related to the individual (child and parent) as well as the environment. This means that needs for support are subjective (Thompson et al., 2009). Thus, support is a relative concept in the sense that it should be identified from the perspective of the receiver of the support.

Supporting parents of children with disabilities

Child related factors. The parenting role for parents of children with disabilities extends long after childhood (Olsson & Hwang, 2001; Starke, 2003), thus, support for parents has to be seen in a life-long perspective. Studies exploring parents' health in relation to raising a child with disabilities report that having a child with disabilities influences parental physical health across the course of life (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). This might be because parents continuously have to adapt to the ongoing stress and crisis related to the child. A recent study by Hartley & Schultz (2015) investigating support needs of parents of children between 5 and 18 years with autism reported, that the number of support needs that parents deem as important were related to the child's biological age. It is worth highlighting, however, that even if parents rated the same number of needs, it did not necessarily mean that they need the same type of support. For example, Siklos & Kerns (2006) reported that parents of children with ASD and parents of children with DS report on the importance of the various support needs differently from each other. Their study found that parents of children with ASD rated education in autism for parents, being involved in the treatment and education for their child, and the continuation of services as very important needs. However, parents of children with DS rated information about their child's progress in education as very important. Parents of children with DS also rated highly that it is important for their child to have their own friends, and to have information about available special programs and services.

Additionally, parents might also need special support in different phases of their child's life such as during transition when their child enters adulthood. It is reported, for instance, that parents of adolescent children with disabilities frequently feel that they are unable to support their children effectively when they transition into adulthood (Hetherington et al., 2010). Parents often feel confused and overwhelmed in supporting their child's transition into adulthood as support from and collaboration between children and adult-oriented services are limited (Martinez, Conroy, & Cerreto, 2012). This indicates parents' needs could also be related to the different phases of their child's life.

Another type of support that parents might need is to increase their child's involvement and participation in society. For children to be able to be involved in decision-making processes, they need support from adults, such as parents and professionals. Giving children the opportunity to participate actively in decision-making processes in issues concerning them, can also advance children's development in recognizing their own strengths and limitations. Additionally, child participation can also be seen as a tool to develop and expand the children's capacity and skills needed to be active citizens. Studies report, however, that the concept of child participation is difficult to implement when children have disabilities (Cavet & Sloper, 2004; Franklin & Sloper, 2006, 2009). Professionals working with children with disabilities, report insufficient age and/or maturity as a main reason why direct child participation in the planning and evaluation of support that affects children's daily life is difficult to implement (Cavet & Sloper, 2004). Parents and professionals often fail to take the views and experiences of children with disabilities into account (Kelly, 2010; Mitchell, Franklin, Greco, & Bell, 2009) as they often question how such participation can be meaningfully implemented especially when children have complex needs and/or communication impairments.

Even if parents have a child with similar disabilities and age, parents' support needs might be different. Two of the variables that might affect parents' need for support in relation to raising a child with disabilities are parents' gender and country of origin.

Parent related factors. Mothers' and fathers' are impacted by their child's disability differently (Pelentsov, Fielder, & Esterman, 2016). Studies found that a parent's gender influences the type of support need that the parents perceived they needed (Pinquart & Teubert, 2010; Singer, 2006; Tamres, Janicki, & Helgeson, 2002). It is reported, for example, that mothers are more likely to use formal support (Lee, 2009). A recent study by Hartley & Schultz (2015) investigating support needs in fathers and mothers of children between 5 and 18 years old with ASD and found that mothers reported higher number of needs as well as a higher proportion of unmet support needs compared to fathers. Mothers and fathers were also found to rate unmet support needs differently, mothers tended to focus on child related support such as interventions for their child, whereas fathers tended to focus on support directed to parents such as the opportunity to have a family dinner (Hartley & Schultz, 2015).

Despite the increasing development in gender equality in Western countries, the child-care responsibilities are more often than not, still being held by mothers. Hedov, Anneren, & Wikblad (2002) reported that mothers of children with disabilities perceived that they are responsible for most of the daily care of their child, which makes them more open than the fathers to stress and demanding circumstances in everyday life. Mothers have also been reported to be more involved in direct care-giving activities than fathers (Hedov et al., 2002).

Cultural context can also have an impact on parents' perceptions of raising a child with disabilities as well as their expectations of formal and informal support. Parent's decisions about treatment and support, for example, may rely on their beliefs about the nature and cause of their child's disabilities (Danseco, 1997). Pinquart & Teubert (2010) investigated ethnic differences in caregiver stress and social support in the United States (US) and found, for instance, that African-American parents reported lower caregiver burden and use of more cognitive coping than Caucasian-American parents, and Asian-American caregivers used less formal support and had lower psychological well-being than Caucasian-American caregivers. This indicates that parents' need for support could vary depending on parental ethnicity or country of origin. However, a recent US study (Long, Kao, Plante, Seifer, & Lobato, 2015) found that parents with immigrant backgrounds were not a predictor of maternal distress when other demographic variables such as household income, and number of children in the household were taken into account. Studies from the United Kingdom (UK) have reported that parents from ethnic groups other than Caucasian have a weaker understanding of the role of service agencies (Fazil, Bywaters, Ali, Wallace, & Singh, 2002) and are more likely to have limited access to and/or utilisation of formal support (Fazil et al., 2002; Hatton et al., 2010) in comparison to Caucasian parents. This indicates that parents with immigrant background might have a higher risk of not receiving the formal support that they are entitled to receive.

Besides all the numerous variables mentioned above, parents' support needs depend heavily on the structure of the support system in a specific country. As most societies, Swedish government has recognized that parents of children with disabilities need support. This has resulted in the development of different support systems to assist both children with disabilities and their parents.

Ensuring the right to support can be seen as an important element in the Swedish disability policy, as it is critical for parents' ability to adapt to the daily challenges of raising a child with disabilities.

Formal support for parents of children with disabilities in Sweden

Sweden can be considered a country that provides many benefits for parents. The responsibility to provide formal support for parents is shared by the state, the county council, and the municipality. For example, all parents in Sweden are entitled to financial support such as child allowance, housing allowance, and parental benefits from the Swedish Social Insurance Agency (The Social Insurance Act, 1999). Parents of children with disabilities, however, may apply for extra allowances for extra expenses due to the extra needs of the child and may receive a care allowance to help with the care for their child. Additionally, according to (The Health Service Act, 1982), all citizens including parents of children with disabilities have the right to receive medical support, which might include emotional support such as crisis and stress management as well as counseling.

Parents of children with (and without) disabilities can also apply for services in accordance with the Social Service Act (2001). According to this act, parents may apply for services such as home facilities modification, assistance in the home, and support and guidance in their role as parents. The Act expanded its regulations regarding support for caregivers in 2009. This broadening of the regulations aims to offer support and to reduce psychological and physical strain on caregivers such as parents of children with disabilities.

Furthermore, the Act concerning Support and Service for Individuals with Certain Functional Impairments (1993), also known as LSS, entitles parents of children with intellectual and/or physical disabilities and ASD to apply for support such as respite care, transportation, contact individuals, daily activities, and individual assistance. This Act applies, however, only to parents of children with intellectual disabilities, autism, and individuals with physical and intellectual impairments not due to normal aging.

While the laws and regulations provide opportunities for parents to apply for support, the rights of parents and their children with disabilities are also regulated in the United Nations Conventions on the Right of the child (CRC) and in the United Nations Conventions on the Right of the Individual with disabilities (CRPD).

The role of parents in promoting the rights of their child with disabilities. The substantive articles of the CRC set an international precedent by putting focus on the rights of the individual child as an active citizen who has the right to participate in society including participation in the decision-making process (article 12). The CRC, however, also recognizes the importance of the role of the parents in guaranteeing and promoting the rights of the child and the role of the state in assisting parents to fulfill their duty. The CRC preamble states, for instance,

> *"the family, as the fundamental group in society and the natural environment for the growth and well-being of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community"* (UN General Assembly, 1989).

In addition, article 18 highlighted the obligation of state to support parents,

> *"States Parties shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities and shall ensure the development of institutions, facilities and services for the care of children"* (UN General Assembly, 1989).

Similar to article 3 on the CRC, the responsibility of parents and guardians as well as the government to assure the right of children with disabilities to express their view is also mentioned in article 7 (3) of the CRPD. Article 7(3) emphasized:

> *"States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disabilities and age-appropriate assistance to realize that right"*(UN General Assembly, 2007).

This means that governments are obliged to provide resources and support for parents to enable them to fulfill their responsibility. In Sweden, the ratification of the Convention does not mean that all of the values within the convention are integrated automatically into Swedish law. Thus, the basic values of CRPD and CRC have been used only as a guide for the national laws, regulations and policy regarding support services for individuals with disabilities (The Swedish Agency for Participation, 2014). To monitor the implementation of the CRC and CRPD, the Swedish Agency for Participation was formed in 2014. The agency aims to ensure that the goals and strategies of Swedish disability policies are upheld by the state agencies.

In Sweden, the obligations and responsibility for the implementation rests on the municipalities and county councils. In practice, this could be interpreted as that professionals hold the responsibility to inform parents about their right to receive support and about different support available to enhance the development of children with disabilities.

In the latest concluding observation report from the general CRPD in 2014, Sweden was applauded for its work in advancing issues such as inclusive education (Office of the High Commissioner for Human Rights, 2014). The report, however, also highlighted issues such as the lack of knowledge about disabilities among professionals working with children with disabilities and their family, as well as the gap between policies and practical implementation.

Parents' perceptions about support

All the laws mentioned above provide the framework and objectives for different agencies to implement support for individuals with disabilities and parents of children with disabilities (The Ministry of Health and Social Affairs, 2000). It is reported that support affects families positively (Cowen & Reed, 2002) and as such a key to giving parents the ability to adapt to ever changing needs is for parents to be able to access the available support services (Floyd & Gallagher, 1997). In order to access available support, parents need information. Studies found, however, that parents of children with disabilities find it hard to obtain precise information about what the agencies can provide (Broberg, 2004; Lärka, Bernehäll, & Brodin, 2001). This might be due to a shortage of guidelines regarding how information about available support should be distributed by agencies (Lilja, Månsson, Jahlenius, & Sacco-Peterson, 2003). Additionally, parents also feel that they lack knowledge regarding the process of obtaining support-services (Samuel, Hobden, LeRoy, & Lacey, 2012) and perceived that they need to fight for their children's rights for support (Högberg, 1996; Gray, 2002; Olsson & Hwang, 2003).

To be able to provide adequate support for children with disabilities and their parents, it is critical that parents and their children are actively involved in the decision-making process of support. Parental involvement has been identified as a key for building strong and effective support for children with disabilities, since parents have a unique understanding of their child's condition (Stoner et al., 2005). Parents express that they need regular communication with the professionals who provide support services for their child (Rently & Roeyers, 2006; Stoner et al., 2005). Collaboration between support agencies, and between parents and professionals is therefore required to support the child with disabilities, and the parents themselves. Collaborative relationships and interaction based on respect and mutual understanding between parents and professionals are factors that parents regard as helpful (Prezant & Marshak, 2006). To develop trust and collaboration, parents and professionals are required to have frequent and open communication to increase understanding of their needs and the needs of children (Law et al., 2003). This understanding is critical in order to enable professionals to provide adequate and appropriate support (Harris, 2008). Support focusing on the partnership between support provider and parents has been found to increase parents' confidence, improve quality of parent-child interaction (Brookman-Frazee & Koegel, 2004; Regan, Curtin, & Vorderer, 2006), communication between parents and professionals (MacKean, Thurston, & Scott, 2005), and satisfaction with service providers and programs (Dunst, Trivette, & Hamby, 2007).

Shearn & Todd (2000) reported that parents feel that they cannot rely on the existing support and everyday interaction with service providers sometimes become an additional stress (Reed, 2000). Parents report, for instance, that maintaining contact with professionals is often time consuming and frustrating, adding to the daily stress (Dempsey et al., 2009; Summers et al., 2007). At the same time, parents also expressed that they need regular communication with the professionals who provide support services for their child (Rently & Roeyers, 2006; Stoner et al., 2005). However, a Swedish study by Olsson and Hwang (2003) found that overall parents were satisfied with the support that they have received and that parents' perception of support is highly dependent on their interaction with specific professionals/support workers.

As emphasized by the relative model of disability and as discussed above, an individual is part of his/her environment. He/she is embedded in a dynamic and complex multiple-layer ecological system. This means parents' experiences of raising a child with disabilities is related not only to their child but also to the contextual environment. This thesis will use the Process-Person-Context-

Time (PPCT) model by Bronfenbrenner (2005) to further highlight the interaction between the individual (e.g. parents of children with disabilities) and his/her environment (e.g. professionals working within the agencies providing support).

The Process-Person-Context-Time (PPCT) model

In 1979 (Bronfenbrenner, 1979) developed a theory known as the ecological system theory to describe the dynamic interrelations among various individuals and environmental factors. Since then Bronfenbrenner has further developed this theory into a model known as the PPCT model. Tudge et al. (2016) advocates the use of PPCT model when employing ecological theory. As the ecological theory, the PPCT model is bidirectional in nature and it recognizes that an individual's relation to his/her environment changes overtime. Originally, the ecological system theory aimed to be used to explain how environmental factors play a role in a child's development, however, the PPCT model has also been used to illustrate how it can be applied to parenting (see for example Bornstein, 2002). In all parents, for instance, the arrival of a child in the family would most likely create some kind of a ripple effect in the parents' life, forming their parenting and their experience of parenthood. The four components in the PPCT model is described further in more detail below.

Process. The interaction between an individual and his/her surrounding environment in which the individual's development occurs is referred to by Bronfenbrenner (2005) as proximal process. These processes are considered to be the main drivers of individual development. One critical feature of proximal process is that it is bi-directional and occurs in the interaction between one individual and another as well as with higher-level systems. Thus, process can refer to the dynamic interaction not limited to parent-child interaction but also interaction between professionals and parents of children with disabilities, between mothers and fathers, as well as between parents and support systems. For example, compared to raising a child without disabilities, raising a child with disabilities may make the experience of parenthood unique as it requires parents to learn things that they otherwise (and most probably) would not. This includes but is not limited to learning about the diagnosis of their child and how to raise a child with for example different communication abilities. Raising a child with disabilities also requires parents to learn about different interventions for their child and available support for their child and themselves as parents.

Person. From an ecological perspective, individual characteristics are likely to influence the capacity to interact in the proximal process. According to (Bronfenbrenner & Morris, 1998), there are three types of personal characteristics: *force, resources,* and *demand* characteristics. *Force* characteristics (e.g. motivation and persistence) were described as individual characteristics that can set in motion a process to advance the individual's development and capacities to interact with the environment. This interaction will then create a reciprocal relationship that affects one another. For instance, with strong motivation and persistence, some parents of children with disabilities, will actively apply for the support that they need and might be persistent in their approach in attaining those services. *Resource* characteristic involves a set of resources such as experiences, skills, and access to others. An example are parents who are able to express their needs, have experience about the process of applying for services, and have access to a support worker, they are as such more likely to receive support that they need than parents who lack these resources. *Demand* characteristics are characteristics that could discourage or attract reactions from the social environments (e.g. gender, age, and disabilities). One example is a mother of a child with disabilities might receive extra support from their informal and formal network. Another example is adults perceiving that the older the child gets, the more mature and able that child will be to participate in various activities such as making decisions in their everyday life.

Context. Integrated within the PPCT model is the theory developed by Bronfenbrenner (1979), known as the ecological system theory. The theory includes four layers/ systems that influence an individual's development. Each system interacts with and is dependent on the others. The systems are named the microsystem, mesosystem, exosystem, and macrosystem. The ecological systems theory has two main characteristics: 1) it is bidirectional in nature, 2) the interaction is two-fold: within and between the different layers of the structures. The socioecological systems theory also recognizes that an individual's relation to his/her environment changes overtime.

The innermost layer is the microsystem. This layer consists of multiple layers and it involves the individual's closest surrounding environments that affect and interact with each other. A couple of examples of this are the relationship between a child with disabilities and his/her parents, or the relationship between a parent of a child with disabilities and his/her teacher. The content and structure of the microsystem is critical since it directly affects the process of the development of the individual (Bronfenbrenner, 1994). The mesosystem refers to the relation and interaction between two or more members in the microsystem (from two different environments). For parents of children with disabilities the mesosystem can constitute interaction between the home and school. The second outermost layer, the exosystem, includes systems that can influence the individual through the mesosystem and the microsystem. Some examples of the exosystem are connections between the health care system and the school system. The macrosystem, is the outermost layer in an individual's environment and consist of factors such as cultural values, traditions, and laws. Although this is the outermost layer, it penetrates and has critical influences throughout the interactions of all other layers since it acts as guidelines and/or rules that regulate the other systems.

Time. In addition, the PPCT model also highlights that individuals go through transitions and shifts during their lifespan. The shift during their lifespan is known as the chronosystem. The component in the chronosystem encompasses aspects such as an individual chronological age, family's developmental stage, and the historical period within the society. One example is that a phase in one's life, such as transition into adulthood can impact on the young adults as well as their parents. This impact might relate to the youth turning into adults biologically and legally, which generate certain expectations on the young adults to reach a certain independence and on the parents to reduce their involvement in the young adults' life. Another example is related to the time aspect within the macrocystem. This refers to the creation and abolition of regulations overtime and how this affects the life of children with disabilities and their families.

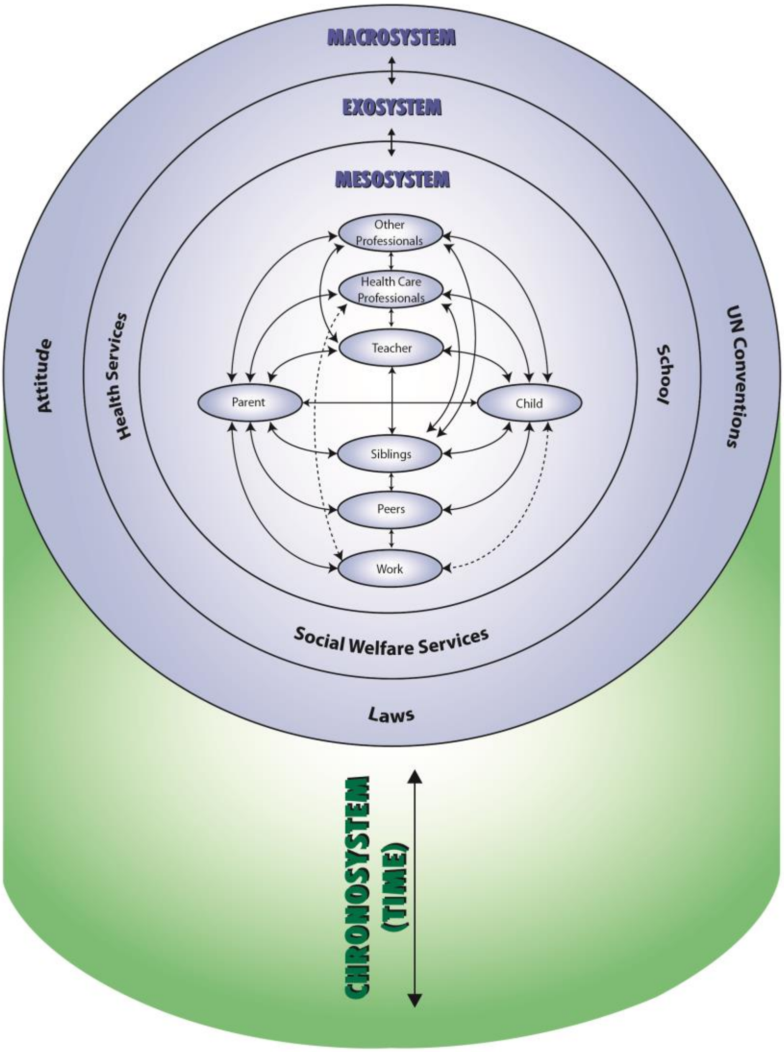

Figure 1. An example of the developmental contextual view of parents of children with disabilities within the PPCT model.

Summary of empirical studies

General aim

The overall aim of this thesis was to investigate how UN conventions, national laws, regulations, and policies are manifested in everyday experiences of parents of children with disabilities. The specific aim of this thesis is to 1) investigate how parents of children with developmental disabilities experience their parenthood and received formal support, 2) investigate how parents and professionals experience the opportunity for children with disabilities to participate in decision-making process, 3) describe how individual factors (parental gender and country of origin as well as child diagnosis and age) contribute to the need and experience of support during the course of childhood (in all the studies 1-20 years).

The specific aims of the studies included in this thesis are presented below:

Study I. The aim of this study was to explore parents' experience of the support they had received. The research question this study addressed was: How do parents of children with disabilities describe the availability, accessibility, and quality of support services in Sweden?

Study II. The aim of the present study was to compare parents' needs for formal parenting (e.g. information about diagnosis and services and meeting with other parents) and emotional support (e.g. couple counselling and crisis interventions) with their actual perceived availability thereof.

Study III. The aims of the study were to investigate professionals' and parents': 1) ratings of the opportunities available to children with disabilities to participate in planning, decision-making, and evaluation of support, and 2) satisfaction with current level of such participation.

Study IV. The aim was to explore parents' experiences of the formal support they received during and after their young adult children, who had a physical and other developmental disabilities, attended a special upper secondary school program.

Methods

Study I. This study was exploratory and based on six interviews with parents of children with intellectual disabilities. The interviews were conducted in the spring of 2010. Recruitment of the parents was done through sending brochures regarding the study to the different agencies in different communities and through acquaintances. Participants willing to participate made the initial contact. The main criterion for participation was to be a parent of a child with intellectual disabilities. The age of the child and the type and level of disabilities were not restricted. At the time of the interviews, all participants, but one, lived together with the child's other parent. Parents participated on a voluntary basis and no compensation was provided. The interviews lasted about 45 – 90 minutes and took place in the home of the families (n = 4) or at a place chosen by the parents (n = 2). The interview questions covered the background of the parent, the child, and family as well as parents' perspectives of received support.

The interview materials were analyzed using a thematic analysis. The analysis focused on the parents' experiences and perceptions of received support. First, parents' descriptions and statements regarding support were reviewed and statements relating to support from the respondent were assessed by the first author. Second, the data was reviewed to identify patterns and related concepts. Third, the materials were reviewed together in a search for similarities and differences. Finally, themes were identified to help answer the research question. Although the analysis was mainly done by the first author, the second and third authors in this study were constantly consulted at each step of the analysis, and any discrepancy in opinion was discussed. Three main themes were found in all interviews. From each theme, six subthemes were identified. The basic premises of symbolic interactionism by Blumer (1986) was then used to deepen understanding and the interpretation of the parents' experience of support. The premises of symbolic interactionism are based on: 1) how individuals assign meaning to things (i.e. object, other individuals), 2) how the meaning of things arises from the reciprocal social interactions, and 3) the meaning of things are the results of an interpretive process.

Study II and III. Study II and III were based on a project called Riktat Föräldrastöd (RiFS). The project aimed to investigate the general formal support available to parents of children with disabilities. The criteria to participate in the study for the parents were 1) a parent/primary caregiver of a child (0 and 18 years), 2) the child of the participants were entitled to seek support services according to Swedish Act Concerning Support and Service for Persons with Certain Functional Impairments (1993). 1004 children living in the municipalities of Gothenburg, Tjörn and Kungälv were eligible to seek support services according to this law in the autumn 2011. Fifteen percent of the total number of children from each municipality were randomly selected (n=151 families). We contacted both the mothers and fathers. From three hundred and two potential participants, 142 parents (95 mothers and 47 fathers) participated in the study representing 109 families. In 2011, approximately 21% of the population living in the municipalities of Gothenburg, Tjörn and Kungälv were foreign born men and women. In the present study, twenty percent of the participants were born in a country other than Sweden. Of these minority parents, 72 % came to Sweden as adults, 10 % came to Sweden as teenagers and 17 % came as pre-teenage children.

Through collaboration with the different agencies (from the municipalities, county councils, and the state) four hundred and forty-nine email addresses of were collected. The inclusion criteria for the professionals were; to hold a current position in the municipalities involving support to children with disabilities and their families. An email message describing the project was sent to these email addresses and one week later, a link to a web-based survey was sent. Reminders were sent after three and six weeks to those who had not yet completed the web-based survey. The response rate was 45% (*i.e.* 228 professionals completed the web-based questionnaire). Of the 228 professionals who participated, 156 professionals answered the questions about child participation. It is important to note that these professionals were not directly involved with the children of the parents interviewed in this study.

The structured telephone interviews with the parents consisted of 59 questions and lasted for 35-80 minutes (some interviews completed with the help of an interpreter lasted between one and a half to two hours) and the survey for the professionals consisted of 58 questions. The structured interview-guide was created based on earlier research and the research questions of the project. Both the interview and the survey consisted of four themes: background information, perceptions about needs and available support, parents' and children's participation, and collaboration between professionals. Parents were asked to share their experience of support of the last 12 months. The interviewers (n=20) were employed by the city of Gothenburg, the municipalities of Tjörn, and Kungälv, or were involved in the research project. All of the interviewers underwent a three-hour training program provided by the research group. All interviewers were provided with a standard script about the research project that they were obliged to read to the parents. Concerns about potential interview bias were addressed through consultation with parents involved in the project's reference group and parents involved in the pilot testing of the interview.

Study II was based on the data regarding parents' experience of support. The answer from the open-ended questions about how parents found information about available support was coded into two categories: 1) searching for information on their own, and 2) receiving information from professionals. Chi-square tests were used to compare parents' perception of support in relation to parent gender and country of origin. Due to the limited numbers of non-Swedish born fathers (n = 6), the study has only compared data from non-Swedish born mothers (n = 22) and Swedish born mothers (n = 73). Odds ratio was then used to measure the effect size of the analysis using Chi-square tests.

Study III was based on the data from the parents and professionals regarding the topic of child participation. One-way between-group analysis of variance (ANOVA) was used to compare results between child diagnosis and age groups. The responses to the parents' interview and the professionals' survey were divided into three groups: preschool children (ages 0 to 6 years), school age children (ages 7 to 12 years), and teenage children (ages 13 to 18 years). Paired *t*-test was used to compare the results between the child's gender as well as parents' reports on the current level of their child's participation and the parents' wishes.

Study IV. The participants in study IV were 22 parents (13 mothers and 9 fathers) of young adult children with disabilities (from 18 families). At the time of the interview, the children had already graduated from the specially directed high school and were between 20 and 21 years old. All of the young adults have various degrees of physical disabilities and cognitive disabilities, a need for rehabilitation, and in some cases, a need of residential accommodation or care in their homes. Most of the parents chose to be interviewed separately, except for five couples. The interview time and place was determined by the parents. Almost all of the participants chose to be interviewed in their home. The interviews lasted for 90-120 minutes. The interviews were recorded and then transcribed. Two interviews representing two families did not give consent for the interview to be recorded. The information from their interviews was used as reference after all other interview information was analyzed. In this study, the interviews were done by two social workers working for a non-profit organization. The two social workers also work as the leaders for the project. It is worth noting that these two social workers do not work and/or have any direct connection with the parents and/or their children. All names and information that could lead to the identification of the participants were excluded. The purpose of the interview was to capture the parents’ experience of the special high school program.

Thematic analysis and NVivo software was used to analyze the interview materials in Study IV. The process of analysis was done inductively by reading and rereading materials gathered in the interviews and then make some exploratory comments and initial noting of those words and/or sentences that are deemed as essential. From those notes, the emergent themes and the cluster of these initial themes were formed.

Results

Study I. The results are divided into three categories: 1) Information regarding diagnosis and services, 2) accessibility of support services, and 3) quality of support services. The presentation of the themes is available in Table 1.

Table 1. Categories and Themes

Categories	Themes
Information of diagnosis and services	Information on diagnosis: vague meaning Information on services: a sense of hopelessness
Accessibility of support	A battle Time consuming The repeated questions
Quality of support services	The unfulfilled expectation

Parents in this study described positively the vast and various support services that their child with disabilities can receive from society. In the first category, information of diagnosis and services, two themes were found: *vague meaning* and *a sense of hopelessness*. Parents described that they did receive and appreciate the information about their child's diagnosis, however, they experienced that the information did not provide information on the meaning of the diagnosis for their child, the family, and their everyday life. One of the mothers stated, for example,

> *"Yes, we got very good information (about the diagnosis) and then I looked and read as well on my own, because I actually did not get very good information about . . . what this really means for her".*

In contrast with information about diagnosis, parents described that they have to find information about the support available by themselves. As one of the mothers said,

> *"It is not easy to get to know information, for example, maybe it needs to be better also. [. . .] one has to have the energy to find out about things and know where one can get help, and it depended so much on oneself and it's not easy when one is in this situation. It is not easy to be awake and have the energy or take in such things".*

The obstacles to finding information about the support available may then create an additional workload to the already energy consuming circumstances and barriers to accessing the services.

Three themes were found in the second category: *a battle*, *time consuming and the repeated questions*. Similarly, to the information searching for available services, accessing available services was described as an energy-and time-consuming process. One of the mothers described her experience as,

> *"I think if we have not been so active and complained after this treatment, and followed up with it, we probably would not get anything".*

Parents described their experiences of accessing the support services as a time-consuming battle that involved repeated questions resulting in loss of valuable time (e.g. delay of their child possibility to obtain needed treatment) as well as physical, and emotional constraints.

The theme *the unfulfilled expectation* that was found in the third category showed a discrepancy between parents' and professionals' perspectives of support and needs. A father stated,

> *"All the assistants, they have not been educated. He has not learnt anything . . . you know! I had requested a few times that they need to teach him to read time, so that he knows what time it is, it was nothing, he never learned [to read time]. [. . .] It took me a month to teach him to read time. It was so easy. They could not teach him for 20 years. I thought the municipality did a bad job at hiring personal assistants"*

Parents in this study viewed people who work as assistants to their child, for example, as individuals that have the capability to teach, support, and help the child learn certain skills and not merely being a caregiver.

Study II. The results showed that of the 142 parents interviewed, approximately 70% of the parents perceived that they do not need support in relation to parent education, information about the child's diagnosis, meeting with other parents, and support for the siblings of the child with disabilities. However, of the 34 % of those parents who rated that they need parenting support, approximately 86% rated that their needs had not been fulfilled. The highest rating of needs (52%) and unfulfilled support (96%) within the parenting support category concerned information about rights and services. In an open-ended question, all of the parents were asked how they found information about available support. In an open-ended question, approximately 70% of the parents reported that they had to search for information about their rights and available support themselves, mostly by internet and from other parents who also have children with disabilities. The remaining 30 % percent of the parents stated that they have received knowledge from professionals.

Regarding emotional support, approximately 30% of the parents reported that they have not received the support that they need in crisis management and couple counseling. Approximately 41% of the parents also reported that their need for support in managing stress and in individual counseling has not been fulfilled. Of those parents who reported needs in emotional support, 93% have reported that their needs have not been fulfilled.

No significant association was found between gender and parents' rating of needs for parent education, information about diagnosis, rights and support, and support for parenting sibling(s). The results, however, indicated that mothers were 3.92 times more likely than fathers to rate that their need to meet other parents (X^2 (1) =8.66, p = .003) has not been fulfilled. The results also indicated that more mothers than fathers reported needs for emotional support. Mothers were 2.44 times more likely than fathers to report unfulfilled needs in crisis management (X^2 (1) =4.17, p = .04). Mothers were also 2.27 more likely to rate unfulfilled needs for support in stress management (X^2 (1) =4.46, p = .035). The results also showed that mothers were 2.86 times more likely than fathers to report that their need for couple-counseling has not been fulfilled (X^2 (1) =5.41, p = .02). In regard to parents' country of origin, the results indicated that the odds of non-Swedish born mothers to report that their need to meet with other parents has not been fulfilled were 4.42 higher than for mothers, who were born in Sweden (X^2 (1) = 9.10, p = 0.003).

Study III. No significant differences between the child gender or diagnosis and parents' report on the current opportunity for their child to participate in planning, decision-making, and evaluation of support were found. Parents experienced that their child's participation in planning of support (M= 2.37 on a scale of 1-5) and evaluation of support (M= 2.60 on a scale of 1-5) is limited. Parents of teenage children reported more child participation in planning of support compared to parents of school-aged and preschool-aged children, F (2,

138) = 6.23; p = 0.003, ω = .29. Parents also wished that professionals should ask their child with a disability more often about his/her opinion of support than what they currently did (t (140) = -11,55*; p = .00, d =* 1.11). Parents wished for more direct communication with their child compared with the current situation where professionals often relied on parents' report the child's needs and opinions instead of asking the child him/herself, t (140) = 4.88, *p* = .00, *d* = .42.

The result from the survey with professionals indicated that regardless of the child's age, professionals often have the opportunity to meet face to face with children with disabilities. Yet, professionals reported that children only sometimes participated in planning and evaluation of support services. Professionals also indicated that older children had more opportunities to participate both in planning and evaluation of support and in more direct ways than younger children. Professionals reported, for instance, that teenagers participated more in planning of support than preschool children and school-aged children, F (2, 331) = 31.89, *p* = .00, ω = .40. Professionals also reported that they used direct means of participation 1) more with teenagers than with school-aged children and 2) more with school-aged children than preschool children in planning of support, F (2, 283) = 74.47, *p* = .00, ω = .59. Professionals also reported that they used direct means of participation 1) more with teenagers than with school-aged children and 2) more with school-aged children than preschool children, F (2, 231) = 10.44; p ≤ 0.01, ω= .29.

Study IV. Parents' experience of their parenthood was related to their youth's capacity but also dependent on their environmental context (e.g. such as available formal support and opportunities). The results will be presented in relation to the distinct temporal phases described by parents: 1) during the program, 2) the time after graduation, and 3) thoughts and worries about the future.

Table 2. Phases, themes and sub-themes.

Phase	Themes	Sub-themes
1. During the program	1.1 Adjustment	1.1.1 moving to a boarding home 1.1.2 Sharing responsibili-

		ties with staff
	1.2 Increased capacities and independence	
2. The period after graduation	2.1 Support and activities	2.1.1 Mourning the loss of the program 2.1.2 An uncertain period
	2.2 Back to the early days of parenthood	
3. Thoughts and worries about the future.	3.1. Future prospects	3.1.1 Limited opportunities 3.1.2 Parents’ aging
	3.2 Guiding the young adults	

The experience of parenthood during the first phase consisted of parents’ reflections of their adaptation to the new situation when their young adult child lives in the boarding home and received support from the program. The parents’ experience of their young adult child living away from the parental home range from feeling enthusiasm to the changes, to worrying about the youth’s safety and well-being. Parents’ reflections of their adjustment to the program were related to their contact and communication with the support workers. Parents perceived the support worker as another person that they could trust while their child was living in the boarding home. Parents also reflected on their children developing into young adults. Parents reflected about new capacities of their young adult children, such as self-management and money management. At the same time, they described that despite the development, their young adult children have neither the opportunities nor the full capacities to enjoy the privileges or responsibilities of adulthood. They reflected that the normative expectations of the young adults being independent once they have reached the legal age may not be reasonable, especially when the young adults have disabilities. One parent stated,

> *"Our children are not as other children, that when they turn 18 they can do everything by themselves. I absolutely think that they have to take more responsibility but then one has to take into consideration the whole picture [the physical and cognitive impairments of the child and environmental aspects]."*

The second phase consisted of parents' descriptions of the time when the young adults returned to the family's home after they had graduated. This was described as a (re)adaptation period where the parents took back responsibilities and became more involved in their young adult child's life again. Many parents mourned the loss of the program as they experienced that support for young adults as lacking and perceived that this social barrier is interfering with their youth's opportunities to continue to develop their capacities. One of the parents described,

> *"When he graduated from school (the program), it is supposed to be the time when we should have a graduation party for my son, just like with other children of the same age. For other children, when they are older, this is when their journey began, for my son, it's the opposite. Now the support disappears. He had others to care for him but now it's all disappeared."*

This period is described as an uncertain period where opportunities for young adults with disabilities to join meaningful activities are limited. The combination of a lack of support, and limited opportunities resulted in parents terminating their employment to support their young adult children. Parents' reflections indicate that graduation from the program meant that their involvement in their young adults' life became similar to their involvement prior to when their child began the program. Most parents described the role of being the main source of support for their youth (e.g. being the contact person and having the task of having to advocate for support for the young adult) once again ended up in their lap.

The third phase captured the parents' reflections about the future for their young adult children. Parents were unsure and worried about the future of their children and had a hard time visualizing and describing what lies ahead of them, especially in the long term. Parents described the lack of support and opportunities for their young adults to continue their education, to find residency, and to gain paid employment. Some parents also reflected on their possibilities to guide and support their young adult over time as being more limited. Parents' worried about the time when they can no longer provide the support that their child needs:

> *"They [the young adult children] have to learn to take responsibility, because one day we are not going to be here anymore."*

Parents reflected about finding a good balance between being supportive of their young adult children exploring their dreams and protecting their them from potential disappointments. The parents expressed that guiding their children to make reasonable plans for the future has not been an easy task.

> *"You do not want to take away her dreams, but at the same time it is hard, when is the time to do it? I do not want to deceive her. (I) have told her that (if you want to do that) then you need this and this education and other requirements (to achieve her dreams, and to find a realistic alternative."*

General discussion

The overall aim of this thesis was to investigate how UN conventions, national laws, regulations, and policies are manifested in everyday experiences of parents of children with disabilities. The specific aims of this thesis were to 1) investigate how parents of children with developmental disabilities experience their parenthood and received formal support, 2) investigate how parents and professionals experience the opportunity for children with disabilities to participate in the decision-making process, 3) describe how individual factors (parental gender and country of origin as well as child's gender, diagnosis, and age) contribute to parents' experience of their subjective need and experience of support during the course of childhood (age for all the studies 1-21 years). The general discussion of parents' perception of parenthood is divided into two sections: parents' experience of support and their experience of parenting.

The PPCT model is useful in further understanding the complexity of the interaction between individuals such as parents and their environment in a specific context such as having a child with disabilities. The four components within the PPCT model will be integrated in the two discussion sections. As the studies included in this thesis were cross-sectional in nature, it resulted in an inability to assess the process of development (*process* component) in the way Bronfenbrenner conceptualized in the PPCT model. However, the studies included in this thesis investigated different types of process that were related to parenting such as parents' experience of the process of finding and accessing available support (e.g. study I and II) or the process of receiving adequate support from a certain program then losing support again after the child is no longer in the program (e.g. Study IV). The *person* component in the PPCT model in this thesis was assessed by looking at the personal characteristics (referred to as *demand* characteristic) through demographic variables such as the parent's gender, parent's country of origin, child's age and the child's diagnosis/impairments (e.g. study II and III). The concept of *context* within the PPCT model was studied by looking at existing laws and regulations (within the macrosystem), and the parents' experiences of their interaction with the agencies and professionals providing support for them and their children as well as how their children were given the opportunity to participate in the decision-making process (within the mesosystem and exosystem). The *time* component in the PPCT model was captured by looking at the parents' reflection of the process of accessing support (Study I) and the time when their child of youth age with disabilities transitioned into adulthood (study IV).

Parents experience of support

Support affects families positively (Cowen & Reed, 2002) and is considered to be a key in helping parents to adapt to the daily challenges and the ever changing needs of their child and themselves (Floyd & Gallagher, 1997). In Sweden, parents and the Swedish government share responsibilities to care and support all children. As mentioned earlier, there is generous support directed towards children with disabilities and their parents in Sweden. To access this support parents need information, such as information about their child's diagnosis and information about available support.

Information about diagnosis. Highly related to the medical model, information about a diagnosis is critical as it can be used as a base for parents of children with disabilities to make decisions about treatment and services appropriate for their child. Information about diagnosis can also be used to influence parents' expectations of the child and describe consequences the diagnosis may have for the family. Most parents in Study I and II experienced that their need for information about their child's diagnosis had been fulfilled. Parents expressed that they have received good information about their child's diagnosis from the professionals. One explanation for this result is that professionals have been diligent in providing information about diagnosis to parents, which can be seen as an interaction between parents and professionals. This can also reflect the impact of the medical model of disability in our society. Another explanation is related to the social context and time aspect, the availability of internet, a result of technological development in the last few decades. The cornucopia of information about diagnosis is widely available on the internet making it easier for parents to find this information. The combination of information gathered from professionals and the internet can, therefore, influence a parents' need to expand their knowledge. According to the PPCT model, these proximal processes are the engines of an individual's development. Via the information received from the professionals, parents in this study gained knowledge about their child's diagnosis, what the impairments mean for their child, what having a child with a particular diagnosis means for them as parents and how it will affect their family. Parents in Study I, for example, expressed that they sought more information because they wanted to know what the diagnosis meant for their child, themselves, and their family. Searching for further information may be a reflection of a parent's urge to understand their child's possibilities in life (Graungaard & Skov, 2007). It can also reflect a parent's concern regarding challenges in their everyday life in relation to the child's impairments. Both can be seen as indications of parenting development, an adaptation process in raising a child with disabilities. This internal motivation could set in motion a process to advance their child's development and capacities, for instance, by searching for information about the support available for their child and themselves.

Information about support. As information regarding diagnosis, information about support is also vital. Information about support provides parents with the knowledge about the type of support offered and which agencies that are responsible for what support. In line with the study by Samuel, Hobden, LeRoy, & Lacey (2012), the results from study I and II show that parents experience that information about support available for their child and themselves is inadequate. Parents in Study II, for instance, described that they often have to search for information about available support through the internet. The abundance of information regarding available support on the internet could be overwhelming for parents, especially if parents do not know what to look for. Additionally, parents may be interested only in information on support services that are specific for their child and their own needs. Previous studies also found that parents may not use the information from the internet due to a mismatch between the information provided and the actual support needed (Nieber, Cramm, Van Der Meil, B, & Huijsman, 2011). Parents are found to prefer personal information guidance in combination with good quality information (Mitchell & Sloper, 2002). Through the social model perspective, the lack of information about support can be interpreted as an obstacle that might hinder parents in supporting their child with disabilities. Lack of information about support may result, for instance, in parents with children with disabilities not being able to make decisions in the best interest of their child in accordance with the CRC (article 3) and CRPD (article[i] 7) as well as the Children and Parents Code (1949).

Information about diagnosis and the available support can be seen as one of the first steps of the *process* component in the PPCT model between parents of children with DD and his/her environment in which parents develop their knowledge about their child's impairments and what support they and their child need from different agencies. This process also related to the social interaction noted by Blummer (1986). Parents' perception that information regarding support is inadequate might also result in parents perceiving that support is not available as found in Study IV. The perception that information about support is lacking might then delay further interaction with other professionals (e.g. personal assistance for the child) and in accessing available support.

It is important to emphasize that the studies included in this thesis, investigated parents' perception about support. This means the focus lies on parents' subjective experience. As noted by (Blumer, 1986), it is important to keep in mind that the meaning and value of availability and accessibility may differ from one person to another and from the perspectives of the parents and the perspective of the agencies.

As noted in the *time* component in the PPCT model, it is worth highlighting that parents' experiences are susceptible to changes in the environment, such as changes in the mesosystem, exosystem, and macrosystem. Since the start of the studies included in this thesis, development of support for parents of children with disabilities have emerged in the municipalities. One of them is a support known as "Pilots" (Lots). Through the Pilots, parents are able to receive information and guidance about available support from different agencies. One of the important aspects of the service is the knowledge and competence of the support worker to find and access information from various agencies providing support for parents of children with disabilities in the city of Gothenburg (Göteborgs Stad, 2013). This might influence the parents' experience and thus alter some of the research findings related to parents' perception of the lack of information, especially in Study I and II.

Access to support. Bronfenbrenner (1998) highlighted that disadvantaged and unstable environments can influence the proximal process that can be vital to human development. In this thesis, the advantages and disadvantages influenced by the contextual environment can be traced through parents' experience about accessibility of support. In line with a recent study by (Leonard et al., 2016) that reported that parents often struggle to find meaningful activities and experienced that support for their young adults was limited, parents in study IV also described that they were worried about their son/daughter's possibility to find meaningful activities, social belongingness, education, work and independent living. One possible explanation of why parents struggle to find activities and/or support might be related to the social barriers highlighted in the social model, such as the limited alternatives offered by society for young adults with disabilities or by the inadequate information mentioned earlier. In addition to the limited support, the process to access services was reported to be time-consuming. Consistent with other studies (Dowling & Dolan, 2001; Olsson & Hwang, 2003), for instance, parents in Study I expressed the process of accessing the services as a battle. The experience of 'fighting for services' can result in a process reducing parental trust for the support system and agencies providing support services (Stoner et al., 2005). This might be because certain support requires parents to claim their right to receive support by applying for the support that they need. Parents' experiences of accessing support might also relate to the mismatch between parents' needs and the length of process in accessing support, emphasized in the relative model, parents might need access to specific support services during a specific time in their child's life. However, the process of applying and accessing the support that parents perceive they need, takes time.

Additionally, the requirements to receive support services at specific times also excludes some children with disabilities. LSS, for example, provides children with specific diagnoses and their parents the access to support services. Under this Act, however, support services can be provided only to those with certain diagnosis and specific impairments, to those who claim this right (Lewin & Westin, 2005), and to those who meet the requirements deemed by professionals. This means that only certain groups of parents might be able to access the available support, such as those who are able to find the right information, can navigate the system, those whose child's impairment falls under certain criteria and those who have the resources (e.g. energy, motivation) to apply for support. In addition, because the application of support is decided by the individual professionals working in each of the municipalities, the result of who obtains and does not obtain support differs in each municipality. This creates an ambiguity regarding who is entitled for support in practice.

Quality of support. Beside access to support, quality of support is also considered a strong predictor of personal well-being (Haber, Cohen, Lucas, and Baltes, 2007). Similar to other previous studies (e.g. Green, 2007; Olsson & Hwang, 2003) parents in study I described that after the long process of applying to receive support services, the support they finally receive at times does not meet their expectations. Ideas about quality of services, acquired by parents, are based on their own past experiences and influence their future service expectations (Mitchell & Sloper, 2002). These unfulfilled expectations appear to relate to the qualification and frequent change of, for example, student assistance, and personal assistance that their child received. This indicates that quality of support services can influence parents' trust in the agencies providing support services. Parents may be less likely to use the available support, despite it probably benefiting their child and their own social capital, because they think that the "battle" of applying for support outweighs the benefits they and their child with a disability will receive.

Quality of support can also be seen from the interaction that parents have with professionals. The results from study IV indicate that parents longed for adequate support such as good collaboration with and between agencies (e.g school, habilitering, and boarding home). Collaboration has been reported to be a critical factor in certain periods, such as transition into adulthood (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004) and parent-teacher contact has also been seen as valuable (Tucker & Schwartz, 2013). It has been reported (Reed, 2000), however, that everyday interaction with service providers could become an additional stress for parents of children with disabilities. Parents also reported that maintaining contact with professionals is often time consuming and frustrating (Dempsey et al., 2009; Summers et al., 2007) and collaboration with professionals is often very problematic (Tucker & Schwartz, 2013). The results from study IV, however, indicate that a problematic interaction might be the result of a lack of communication and contact as found in previous studies (Rently & Roeyers, 2006; Stoner et al., 2005). Parents in Study IV, for instance, experienced that they have to adjust to sharing responsibilities with professionals working in the project, especially those responsible for their son/daughter in the boarding home. Thus, trust given to professionals is a process that builds on the parent-professional relationship over a period of time. Contact and communication with support workers might give parents assurance that their concerns about the different areas of importance were addressed by the professionals (Rehm, Fuentes-Afflick, Fisher, & Chesia, 2012).

Norms, rules, and regulations in regard to support services provide children with disabilities and their parents a broad possibility and opportunity to develop relationships with different professionals. These resources, however, are not in practical terms equally accessible by all children with disabilities and their parents. Due to the process needed to access support services, for example, parents of children with disabilities need to actively advocate and participate so that they can help their child with a disability to receive the service they need. This means, parents who do not have the strength and time to apply and/or reapply for the different services that their child needs may not be able to develop or sustain the necessary support that they need. It is worthwhile to highlight, however, that even if all children with disabilities and their parents had equal access to the support available according to the existing laws, regulations, and policies, it would not guarantee that they would have the same outcomes in life (Bronfenbrenner, 1992). This may be due to many factors, such as how parents make use of the support available, a constructive and positive relationship between children and professionals and collaboration between professionals in different support systems. Parents' perception of support is highly dependent on their interaction with specific professional/support worker.

Experiences related to parenting

The overall results show that the parents' experience of raising a child with disabilities is related to numerous factors. These factors can relate to parents' experience of received support (Study I, II and IV) as has been discussed above but also to other factors related to their parenting, such as their support needs (Study I, II, and IV), parents experience of their child's participation (study II), and their perception of the future for their child (study IV).

The experience of parenthood can be seen from factors related to the parents' support needs. These support needs can be related to their parenting as well as factors related to the parents themselves, such as their need for emotional support. Most parents in Study II, for instance, reported that they do not need emotional support. This can be seen as a positive result, indicating that most parents adapted relatively well to the daily challenges of raising a child with disabilities as reported by many other previous studies (e.g. Emerson, Hatton, Llewellyn, Blacker, & Graham, 2006; Hassal & Rose, 2005). However, this result also indicates that some parents need support. The results from study II show that approximately 93% of those parents who rated that they need support, reported that they had not received the emotional support that they need (e.g. crisis intervention, stress management, and counseling). This result is rather worrying, as this indicates that those parents who need support to cope with the daily challenges of raising a child with disabilities and/or those who no longer have the resources to cope with the challenges, are not getting the support that they need. At the same time, emotional support has been found to positively affect the well-being of parents of children with disabilities (Broberg et al., 2010) which is important in fulfilling their parenting responsibilities. Through the disability models mentioned in the beginning of this thesis, this can be considered as one of the social barriers, which may affect parents' ability to attend to their child and to fulfill their parenting duty. This result can also be interpreted as a gap between the regulations such as the CRC preamble that emphasized that parents should be provided with the support that they need so they are able to fulfill their responsibilities in caring for their children (UN General Assembly, 1989).

In supporting parents throughout their parenthood, it is critical to consider the individual needs of the parents. From the PPCT model, *person* characteristic such as a parent's gender, country of origin, child's age and child's diagnosis are considered to be factors that could affect parents' experience related to parenting. The results of study II, for example, show that mothers were more likely than fathers to report that their need to meet other parents for crisis intervention and counseling were unfulfilled. This could reflect the gender role pattern where mothers are still more involved than fathers in childcare related activities. Despite the efforts from the Swedish government to increase gender equality, traditional gender roles still exist. A report from (Statistics Sweden, 2012) for instance, found that Swedish women in general still dominate activities associated with childcare and many do not work full time. Swedish studies (Hedov et al., 2002; Olsson & Hwang, 2003) investigating gender impact of raising a child with disabilities found similar results, where mothers of children with disabilities are less likely than fathers of children with disabilities to have fulltime employment. A parent's gender, however, is not the only factor influencing the parents' support. In study II non-Swedish-born mothers were more likely to report that their need to meet other parents had not been fulfilled compared to Swedish-born mothers. This result, however, is not unique to non-Swedish parents in Sweden. Other international studies have also found that immigrant parents often have limited social networks, limited knowledge about the role of the different agencies and are less familiar with how the support system works (see Begeer, El Bouk, Boussaid, Terwogt, & Koot, 2009; Zaroff & Uhm, 2012). Meeting other parents might be a tool for non-Swedish mothers not only to broaden their informal social network but also to gain information (informally) about the available formal support.

Aside from those factors related to the parents as individuals, experience of parenthood can also relate to how parents perceive that their child's rights are being upheld. From the ecological perspective, opportunity for children to participate in the decision-making process is related to the *process* component in the PPCT model, which is the interaction between the child and professional reported by parents and professionals. Parents in study III experience that their child's right to have their voices heard in decision-making processes have not been fulfilled. Parents in this study wish that their child could participate more in the decision-making process than they currently do. in line with other studies (Cavet & Sloper, 2004; Sinclair, 2004; Tates, Meeuwesen, Elbers, & Bensing, 2001; Wagner, Newman, Cameto, Javitz, & Valdes, 2012), the results from Study III found that *person* characteristics and *time* component such as the child's age, to some extent guides professional views of the child's ability to participate directly in planning and evaluation of support services. This is, however, not unique to children with disabilities. Professionals are more inclined to give opportunity to children to participate in decision-making process when children are older (Tates & Meeuwesen, 2000) by arguing that children need to be sufficiently mature to be able to be held responsible for important aspects of their lives (Coyne, 2008; James & James, 2012). As a result, the responsibility of fulfilling children’s needs relies mostly on the adults, mainly the parents. This can be seen as a contradiction to the principle highlighted by the CRC and the CRPD, which emphasizes the importance of recognizing children as active citizens. One theoretical reflection that needs to be considered that is not quite addressed by the PPCT model but that might be of importance is the resource characteristics of the person (e.g professionals) and agencies providing support. Thus, another possible reason for the limited opportunity could also be that professionals lack the resources that they need to move the issue forward. Another reason could be that agencies lack resources and knowledge about alternative communication. As Study III focused on opportunity for children to participate, the issue of availability of resources for professionals was not captured. This warrants further future study.

The last component of the PPCT model is *time*. In this thesis, the *time* component and the intertwining of all the components in the PPCT model are most apparent in Study IV. Although Study IV is a cross sectional study, parents reflected on their experience of support when their youth aged children were enrolled in a special program, their experience of their children returning to the parental home, and their perception about the future of their young adults with disabilities. The results of study IV indicate that as most parents of young adults, parents of young adults with disabilities continue to support their young adults with severe developmental disabilities even after they reach the age of maturity (18 years in Sweden). However, Study IV also showed that without adequate support and opportunities the journey into adulthood for the young adults with developmental disabilities is very difficult. Additionally, the lack of support also influences the experience of parenthood, as parents have to provide the same or higher level of practical support for their young adults.

The parents’ narrative (study IV) indicates that parents were concerned about their son/daughter’s future after high school. Rehm, Fuentes-Afflick, Fisher, & Chesia (2012) investigated the meaning of adulthood for youth with disabilities and their parents. Their study found that parents of youth aged children with disabilities rated safeguarding of their children's health as their priority followed by other factors such as being in a safe and supportive environment and for their son/daughter to have the ability to meet with other young adult children. It is noted in the *time* component in the PPCT model and in the earlier version of the ecological theory (Bronfenbrenner, 1979), that a person's earlier experience could affect the situation a person is currently in due to a particular event. In Study IV, parents reflected that their parenting role when their young adult children graduated from the special program and moved back to the family home was similar to their parenting role when their young adults were younger. Yet, the proximal processes occurring in the different stages of the child's life would be dissimilar. Before the child reached the age of maturity, parents had the full mandate on deciding the type of support that their child with disabilities would need. However, after their child transitioned into adulthood and reached the age of maturity, parents no longer have the legal mandate and obligation to decide about the support for their children, yet they are most likely will have to provide the same or higher amount of support to them.

In addition, as reported by other studies, parents in Study IV experienced that their son/daughter's opportunities in finding paid employment, (Leonard et al., 2016; Steward, Law, Rosenbaum, & Willms, 2002)further their education and finding their own residency are limited (Jobe & Glidden, 2008; Macgill-Evans, Wiart, & Darrah, 2005). This suggests that environmental factors such as limited opportunities might create barriers for young adults with disabilities (Steward et al., 2002) as well as for their parents in supporting their children in their transition into adulthood. In 2017, the Swedish government created new goals that will guide disability policy further. One of the goals is to improve the areas of education and employment for individuals with disabilities. These changes, which related to the *time* component within the macro-system could improve the situation in young adults with disabilities and therefore the experience of parents. At the same time, these changes will only matter if implemented adequately.

Conclusion

As children without disabilities, children with disabilities are closely connected to their parents. However, children with disabilities are heavily dependent on their parents especially in accessing available support so that they can have the opportunity to live as other children. Positive aspects and challenges experienced by parents of children with disabilities in their everyday life are therefore related to the impairments of their child as well as the existing social context. This suggests that the well-being of children with disabilities and their parents is connected to the professionals working within the existing support system, guided by laws, regulations, and policies, and influenced by the cultural values in their environment.

One way to trace the concrete manifestation of the macrosystem is by investigating the process of applying for services. The results of the studies showed that the structural processes of applying for support can directly influence parents' perceptions of support and their interactions with professionals and agencies. Disability policy provides parents of children with disabilities with the opportunity to apply for support services for their child, giving them a chance to participate in the community and to live as others in accordance with the CRC and CRPD. However, since the responsibility to apply for these support services lies with the person with disability and/or their caregivers, it creates a tighter dependency within the microsystem between a child and his/her parents.

Another way to trace the manifestation of the macrosystem is by investigating the interaction between children with disabilities, their parents, and professionals. The results from Study I and Study II also indicates that the macrosystem in Sweden has minimized the gap in the equal distribution of rights for children with disabilities and their parents to a certain extent. However, the two studies also show that plenty of work still needs to be done within the exosystem and mesosystem. Examples are: making information about support services more available, simplifying the process of receiving support services, improving collaboration between children-professionals-parents, and increasing children’s direct participation as these may influence parent-professional relations and parents’ trust on the existing support system.

Due to the cumulative effects (acquired over time), factors related to parents (e.g. gender and country of origin), and responsive environment (e.g. adequate support, interaction within the mesosystem) parents’ needs for support can be different at different times during the child’s life and/or the parents’ own life. Parents of children with disabilities may be interested in specific information on support services that are beneficial to their child’s and their current and particular needs. Parents’ needs for information about their child’s diagnosis, for instance, might be crucial during the period after assessment to enable them to understand further, how a certain diagnosis might impact the life of their child, the daily challenges that might come with the child’s impairments and determine the type of early interventions that are available for their child. Over time, parents’ needs for support might take a different discourse, such as needing support finding respite care or needing emotional support to manage the daily challenges of parenting. It is also worth highlighting that a parent's need for support can be short-term or long term. Parents, for instance might need support to help their child develop into an active citizen. This type of support might be stretched throughout the child's lifespan and might increase in level of complexity. Parents might need special support in different stages of their child's life such as when finding employment opportunities for their son/daughter when they transition into adulthood. At the same time, parents might also need support if a crisis arises; this type of support might be short-term and vary in frequency depending on each parent's individual situation.

Methodological and ethical considerations

Study II and III was approved by the Regional Ethical Review Board in Gothenburg, Sweden (Dnr: 682-11). Study I and IV was conducted in accordance to the Swedish Research Council.

The studies included in this thesis explore parents' perception of support in relation to having a child with disabilities. All studies included in this thesis used interviews as the data collection method. For instance, parents' perception of received support was collected through semi-structured interviews, conducted face-to face with the parents in Study I and IV. While in Study II and III parents' perception of their support needs and the opportunity for their child to participate in decision making processes were collected through structured telephone interviews. This method relies heavily on the interviewees' subjective verbal report and is limited to what they are willing to and/or are requested to report (Kvale & Brinkman, 1997). However, interview approaches could be useful in acquiring deep, detailed information (Kvale & Brinkman, 1997).

In Study I, the author was the interviewer. This provided an opportunity for the author to explore and dig deeper into questions that were closely related for the research questions. In Study II and III, professionals, working for the municipalities, as well as the author were involved in interviewing the parents. The professionals responsible for interviews with the parents were selected by the head of the municipalities they work in. One of the conditions of the interviewer selection process was for the individual not to have the power of approving/disapproving applications for support to the respective parents. It is worth mentioning that the interviewers stated that participating parents were thankful and appreciated the opportunity to share their experiences. While the involvement of professionals working in the service delivery agencies might bring positive aspects such as direct feedback from the parents, a few ethical considerations need to be considered. First, parents were interviewed by professionals with whom they were not familiar with but who worked within the municipalities that the parents lived in. To minimize the risk of the parents misunderstanding the role of the interviewer, a protocol clarifying the aim of the research project was used. This was done to ensure that all the interviewers introduced themselves and explained their role in the municipalities and their involvement in the research project. The protocol also included thanking the parents for sharing their experience and devoting time to take part in the research project, and the parents were offered a digital copy of the final report written in Swedish using relatively easy language. Second, using professionals from different municipalities might also increase the risk of interviewer error. To minimize this risk, all the interviewers underwent to three-hours of training provided by the research group. All interviewers were provided with standard transcript about the research project that they were obliged to read to the parents and instructed to provide neutral probes such as rereading the questions, when parents did not understand what was being asked. Interviewers were also encouraged to mail the research group directly about the instances they perceived as difficult during the interview and when unsure of their probing approach.

The material in Study IV, however, derived from interviews conducted by two social workers employed by an NGO. The original aim for these interviews was to evaluate parents’ experience of support from a specific intervention. The author did a secondary analysis of the material with a slightly different aim and had no possibility of asking clarifying questions to go deeper into themes that were raised. On the other hand, by using this method, the risk of influencing the parents’ specific thinking regarding a particular subject before the interview was conducted, such as their experience before and after the received support, was reduced.

Limitations

The present thesis also has some limitations influencing the generalization of the results that need to be addressed. First, most of the parents who participated in the studies were mothers. Although the involvement of fathers in the daily life of their child with DD has increased, their participation in research studies is still underrepresented (MacDonald & Hastings, 2010). Second, this thesis does not include certain factors such as informal support that could also be considered important in parents' experience of parenthood. Third, parents included in this thesis had children with different diagnoses and levels of impairments due to which parents might receive different kinds of support from the community, which in turn may also affect parents' experience and expectation of services.

There are also a few limitations in the specific studies worth mentioning. First, the number of participants needs to be considered in study I. Despite the small number of participants, the findings are in accordance with other studies and even in this very small study group some experiences are consistent with the results from previous research, making it reasonable to suggest that other parents may also share these experiences. Second, Chi-square analyses were used in Study II, other non-parametrical analysis might be more appropriate as the parents themselves were not selected randomly. This should be considered in the interpretation and generalization of the results. Third, the sub-analysis in Study III needs to be interpreted with caution. Although, according to Cohen's d 0.1 - 0.2 is considered a small effect, Ferguson (2009) argued that in social science research results of those with d 0.1 - 0.4 were below the minimum effect size representing a "practically" significant effect. This suggests that although some of the results are significant, the effect of the results may be too small to be practically meaningful, indicating a need for further investigation in the matter. One limitation that may lead to knowledge gaps and generalization problems in Study IV is that it only includes parents of youth aged youth with disabilities who attend the special upper secondary education. The experience of parents of youth with disabilities whose children are not included in the National upper secondary school program such as those enrolled in the regular upper secondary school program is not represented in this study.

Practical implications

The issue of social barriers such as lack of information may potentially be improved by making the service system easier to navigate or for the municipalities to have support coordinators, who can help parents to navigate the available support within the agency. National strategies aiming to improve accessibilities might also need to include specific strategies to improve access to information about rights and support to parents/caregivers of children with disabilities. Municipalities could create information center or information meeting for parents/individual with disabilities which aim to provide information about the different support available. Another way is for a change of routine that increase interaction between the mesosystem. For instance, for supervisors within the municipalities to have a face-to-face meeting with parents and children/young adults when parents initiate their need for support or a regular network meeting between professionals providing support for parents and their child with disabilities.

Professionals cannot be expected to support parents in providing information on how their life with their child with disabilities will look like. However, professionals may be able to support parents by creating, for example, parents network groups so that parents can share information and experience with each other.

As most children with disabilities will be impaired for life, continuation of support is critical in parenting development. Yet it is also critical to keep in mind that parents' needs for support are not only determined by the factors related to their child but also to factors related to them as individuals and to the organization of the support system. As parents' role is vital to their child, especially children with disabilities, the importance of supporting parents in their parenting and well-being cannot be overestimated.

To increase accessibility of support, we need better bridging between the different stages in the child's life as well as a more flexibility and collaborative system structures. Agencies may not be able to provide support to fulfill the needs for all family members, but all agencies might be able to collaborate with other agencies that provide support for parents and inform parents that those supports are available to them. Parents might or might not utilize the service; nevertheless, they might feel supported by knowing that support is available for them when they need it. Support focusing on the need of the whole family, therefore, needs to be implemented.

Time is a vital element within the PPCT model. Thus, there is a need to monitor how ongoing changes in policy and support systems affected the daily life of parents of children with disabilities and their parental experience. Lastly, the results of this thesis indicate that the presence of a child with disabilities does not necessarily mean that parents need the same type and amount of support. Thus, decisions about support require careful assessment and should be based on the individual parent and/or family need.

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