

Mothers and fathers of children with developmental disabilities

Co-parenting, well-being and empowerment

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*When we choose to love,
we choose to move against fear,
against alienation and separation.*

*The choice to love is a choice to connect,
to find ourselves in the other.*

bell hooks

Abstract

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Parents of children with developmental disabilities (DD) generally experience more stress and poorer well-being than other parents. However, there is considerable individual variation in parental adaptation. The general aim of this thesis was to further the understanding of the adaptation of Swedish parents of children with DD. It investigated factors regarding the individual and the couple that may affect parents of children with DD and evaluated an intervention for families of children with rare diseases. **Study I** focused on couple relationship and individual well-being in parents of children with DD. Parents of children with intellectual disabilities (ID) (N = 83) and control parents (N = 319) responded to surveys including questions about their well-being and relation with the child's other parent. Data was collected on two occasions 12 months apart. Well-being was predicted by marital quality, economic risk, parent gender and child ID status. Prospective well-being was most strongly predicted by baseline well-being, followed by co-parenting quality. Mothers of children with ID reported poorer well-being than control mothers. Parents of children with ID reported more severe child behaviour problems than controls. **Study II** investigated parents' propensity to use harsh parenting practices (HPP; e.g. hitting, slapping or yelling). Both parents (N = 44) of children with a wide range of DD, and who were entitled to special support services, and control parents (N = 170) responded to a web survey examining the prevalence of HPP. Parents of children with DD did not indicate higher HPP propensity than controls after controlling for parent sex and child age. The parents of children with DD reported more child behaviour problems than controls. Within the group of parents of children with DD, child behavioural problems positively predicted HPP propensity. **Study III** evaluated parent outcomes of a brief intensive intervention for families of children with rare diseases aimed to increase parent competence. Parents (N = 124) answered self-report surveys prior to and three months after participation in the intervention. At baseline, mothers reported higher levels of parenting stress, depressive symptoms and anxiety, relative to fathers. Only fathers' responses indicated a change over time: reports by fathers of empowerment and child-related marital stress increased slightly between baseline and follow-up. Additionally, parents found the intervention beneficial, especially through sharing experiences with other parents, meeting other children with the same diagnosis and increasing their knowledge about the diagnosis. Taken together, the results indicate that parents of children with DD experience additional strain compared with the general parent population. The risk for negative outcomes is higher for mothers than fathers. Although the presence of a child with DD does not imply a poorer couple relationship for parents, there is an association between relationship quality and individual parental well-being. In addition, parents of children with DD are more exposed to child behaviours that may be difficult to handle, and those behaviours are associated with a higher risk of harsh parenting practices. Finally, parents of children with DD value other parents in the same situation as a source of support and knowledge.

Keywords: parental well-being, child disability, intellectual disability, developmental disability, couple relations, harsh parenting, rare diseases

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List of papers

This thesis consists of a summary and the following three papers, which are referred to by their roman numerals:

- I. Norlin, D., & Broberg, M. (2013). Parents of children with and without intellectual disability: couple relationship and individual well-being: Couple relationship and individual well-being. *Journal of Intellectual Disability Research*, 57, 552–566.
- II. Norlin, D., Axberg, U., & Broberg, M. (2014). Predictors of harsh parenting practices in parents of children with disabilities. *Early Child Development and Care*, 184, 1472–1484.
- III. Norlin, D., Starke, M., & Broberg, M. (2017). A brief intensive intervention for families of children with rare diseases. Manuscript.

Förord

Att skriva en avhandling framstår kanske som ett ensamt arbete. Samtidigt är det väldigt socialt. Under min tid som doktorand har jag hela tiden varit omgiven av personer som delar min fascination inför oss människor och hur vi fungerar tillsammans. Därför vill jag uppmärksamma några av dem som varit med mig på denna fleråriga resa.

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Introduction

The overall aim of this doctoral thesis is to study the life situation and psychological adaptation for parents of children with disabilities. It is based on three empirical studies. The first study investigates the psychological well-being in parents of children with developmental disabilities, using parents of typically developing children for comparison. The second study investigates parents' inclination to use harsh parenting practices, comparing parents of children with any of a wide range of disabilities with parents of typically developing children. The third study evaluates an intervention delivered to parents of children with rare diseases, designed to increase participants' sense of competence in their role as a parent of a child with a rare disease.

In addressing the overall aim, the thesis is divided into five chapters. The first provides an introduction to child disability and the support system. The second provides a background to the subject of parents of children with disabilities, as well as theories used in understanding their adaptation. The third provides a review of existing literature on the adaptation of parents of children with disabilities. The fourth presents the three empirical studies. The fifth and final chapter offers a discussion of the results and their implications, in light of previous research.

Child disability and support

Definitions of disability

According to the first article of the United Nations' Convention on the Rights of Persons with Disabilities, 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (UN General Assembly, 2007). This definition reflects a socio-ecological model of disability, where a key distinction is drawn between impairment and disability. *Impairment* represents a functional limitation within the individual. A *disability* however, is not a quality in the person, but rather the consequence of a misalignment between him or her and the environment. Thus, people with the same functional limitations but living in different societies will experience different kinds of disability. It is not the *person* who *is disabled*; it is society that *disables* him or her. The socio-ecological model of disability emerged as a reaction to the earlier dominating paradigm, the medical model of disability. The medical model is concerned with deficits and deviations from optimal or normal functioning of the human body, often treating normality as a natural category. It therefore entails a tendency to identify problems, and possible solutions, as situated in the individual (Rothman, 2010).

A further way of looking at disability is represented by the supports paradigm (Thompson & Viriyangkura, 2013). Here, it is not the deficits in people, but rather their support needs, that are emphasised. Efforts by service systems are not primarily directed at overcoming functional limitations. Instead, the person should be allowed to define the lifestyle they desire and the environments they want to access. Then, services are tailored to effectively address these formulated needs on an individual basis, enabling a self-determined and meaningful way of life. The key point to identifying disability is not in levels of functionality, but in the differences in support needs between people.

Persons with disabilities can be further divided into subcategories, and this is often done from a medical perspective, according to individual characteristics, disorders or deficits. A coarse distinction is that between physical and neurodevelopmental disabilities (Houtrow, Larson, Olson, Newacheck, & Halfon, 2014), although there are conditions, e.g. cerebral palsy, that often lead to impairments in motor function as well as cognition. The American Individuals with Disabilities Education Act (IDEA) lists 13 categories under which children and adolescents may be entitled to special education and related services: autism; deaf-blindness; deafness; emotional disturbance; hearing impairment; intellectual disability; multiple disabilities; orthopaedic impairment; other health impairment; specific learning disability; speech or language impairment; traumatic brain injury; and visual impairment (National Dissemination Center for Children with Disabilities, 2012).

Rare diseases

In Sweden, rare diseases are defined as those that affect less than 1 in 10 000 people and that lead to disability (Swedish National Board of Health and Welfare, 2016). In the EU, a disease is classified as rare when it affects less than 5 in 10 000 people (EURORDIS, 2009). In the US, the definition of rare diseases commonly used is taken from the Orphan Drug Act of 1983. Orphan drugs are so named since their development risks being abandoned by the pharmaceutical industry as a consequence of the very limited outlet potential. The Orphan Drug Act defines a rare disease as one that affects less than 200 000 US patients (Wellman-Labadie & Zhou, 2010).

Most rare diseases have a genetic aetiology and are often chronic, progressive and sometimes life-threatening. Many of them predispose their carriers to developmental disorders or intellectual disability (Roubertoux & de Vries, 2011; Wästfelt, Fadeel, & Henter, 2006).

Rare diseases are actually not that rare. Although each disease by definition has a very low prevalence, the number of rare diseases is large; in 2008, the US National Institute of Health listed 6 819 different rare diagnoses (Seoane-Vazquez, Rodriguez-Monguio, Szeinbach, & Visaria, 2008). With ongoing advances in biotechnology and an increasing understanding of the underlying molecular mechanisms, the number of defined diagnoses continues to grow at a rate of around 250 per year (Wästfelt et al., 2006). As the number of identified and named genetic syndromes increases, children who have earlier received an unspecified diagnosis are nowadays instead often diagnosed with a rare disease.

A good example of this is the TBCK-related ID syndrome (Bhoj et al., 2016), where a common pattern of mutations in a specific gene was discovered in 13 children from different families through an international multi-centre collaboration. The children all belonged to a phenotype that presents with intellectual disability, hypotonia and seizures, but the aetiology of their condition was previously unknown.

Prevalence of child disability

The prevalence of disability depends on the definition of disability used and the measures used to identify cases (Bethell, Read, Blumberg, & Newacheck, 2008). In the US National Health Interview Survey (NHIS), the disability measure used is designed to identify children who experience limitations in developmentally appropriate activities, e.g. walking, playing with peers, attending regular schooling, remembering and independent personal care. The prevalence of such limitations in children under 18 was 7.7% in 2008–2009 (Halfon, Houtrow, Larson, & Newacheck, 2012). A similar prevalence figure of 7.3% is reported for British children in 2004–2005 (Blackburn, Spencer, & Read, 2010). In this case, the disability measure was based on the definition set forth by the UK Disability Discrimination Act. Children were defined as disabled if they had a limiting illness, disability or infirmity and experienced one or more significant difficulties or health problems, or would have such difficulties or problems if they did not take medications.

No similar prevalence statistics based on a measure of disability have been found for Sweden. However, in a study of preschool children, teachers reported that 3.7% of the children were diagnosed with a disability belonging to the traditional categories, and an additional 13.6% were undiagnosed but needed special support due to functional difficulties (Lillvist & Granlund, 2010). In a national Swedish survey (Statens folkhälsoinstitut, 2011) on the psychological health of 6th graders (12–13 years old), children were asked whether they had a disability, and 14% indicated ‘yes’. The survey item included an explanatory note: ‘Disability is here understood as e.g. motor disability, dyslexia, impaired vision or hearing. It can also include ADHD, epilepsy or diabetes.’

Another indication of the prevalence of child disability is the number of children who receive support according to the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (LSS). On October 1, 2011, 19 752 children received such support (Riksrevisionen, 2011). Combined with census data from 2011 (Statistiska centralbyrån, 2017), this cor-

responds to 0.78% of Swedish children. It should be noted that this group of children is only a subgroup of the children diagnosed with a disability, as not all types of disability confer the right to support according to the LSS Act. Children with undiagnosed disabilities, diagnosed children not entitled to support according to LSS, and children entitled to, but not currently receiving, support according to LSS are all excluded from the 0.78%.

Around 15 million people in the US (Roubertoux & de Vries, 2011) and 30 million in Europe (EURORDIS, 2009) are estimated to be affected by a rare disease. However, to my knowledge, there is no data on the number of children in Sweden affected by rare diseases.

Sweden from a child disability perspective

Psychology is not isolated from society. Human lives take place within an ecological context, and the economic, political and ideological structures of society affect an individual's psychological well-being (Bronfenbrenner, 1979). A good example of this is presented in a study by Hatton and Emerson (2009), where differences in socio-economic position between families with a child with and without intellectual disabilities substantially accounted for differences in child and parent psychopathology.

Much of the research on families and parents of children with disabilities has been conducted in the US and UK, whereas the current thesis is based on data from Swedish participants. Sweden has sometimes been described as the model example of a social democratic welfare state, and there are important differences in public policies that set it apart from the US and UK welfare systems (Svallfors, 2004). In terms of income inequalities expressed with the Gini coefficient, Sweden (0.281) scores lower than both the UK (0.358) and the US (0.394) (OECD, 2017).

Sweden features public health insurance, public social security insurance, public childcare and free public education. Some insurance systems are income based, but in those cases a minimum level of benefits is guaranteed. Children up to 18 years of age are entitled to free primary and specialised health care. Support and services to children with disabilities are almost exclusively funded by the state or local governments. Parents of children with disabilities can apply for services including free or highly subsidised transportation; free wheelchairs, lifts etc.; respite care; and financial assistance (M. B. Olsson & Hwang, 2003). Children with disabilities are also entitled to free health care at child habilitation centres.

The LSS Act ('Lag om stöd och service till vissa funktionshindrade,' 1993) is a Swedish law passed in 1993, which entitles persons with significant and long-term functional disabilities to specific support measures. These support measures are supplementary and shall not replace the general support system available to all citizens. The law applies to: 1) persons with intellectual disabilities and people with autism or conditions similar to autism, 2) persons with significant and permanent intellectual functional disabilities following brain damage as an adult, and 3) persons, who as a result of other serious and permanent functional disabilities, which are clearly not the result of normal ageing, have considerable difficulties in everyday life and a great need for support or service. The stated objective of the LSS Act is to promote equality in living conditions and full participation in the life of the community, so that the individual can live as others do. The support measures shall be based on respect for the individual's right to self-determination and privacy, and in cases where the individual is a child, special consideration shall be given to the child's best interest.

As seen in the formulation of the LSS Act, the entitled persons are identified by diagnosis, but also by level of difficulties and support needs. It could therefore be argued that the legislator has been guided by both a medical and a support needs perspective. The objectives are stated not in terms of overcoming individual deficiencies, but in terms of equitable living conditions and participation in the community, in alignment with a support need perspective.

Parents of children with disabilities

Becoming and being a parent

For most adults, having a child is an overwhelming experience. Childbirth, especially if it is the first child, is a rite of passage that marks a dramatic transition in life. Besides engaging emotionally and practically in the emergent relation with his/her child, the 'newborn' parent also has to accommodate a host of changes affecting virtually all areas of life, such as self-image, the couple relationship, extended family, professional career and social life. The adaptation is not guaranteed to be smooth and effortless. Mothers and fathers frequently experience mood swings, self-doubt, anxiety and interpersonal conflict during the process (Barimani, Vikström, Rosander, Forslund Frykedal, & Berlin, 2017).

The transition to parenthood may be stressful regardless of child characteristics. For couples, the two individuals must function both as romantic partners and as a parenting team, a reorganisation that demands a lot of flexibility and renegotiation and that may be challenging to many new parents (Emery & Tuer, 1993). Even in the absence of disability in a child, becoming a parent implies an increased risk for depression around and after birth, for both women and men (Paulson & Bazemore, 2010), and for a couple it is often associated with role conflicts, restriction of freedom and decreased satisfaction with the relationship (Twenge, Campbell, & Foster, 2003).

Despite the fact that things will never be quite the same again, soon-to-be parents are not venturing into completely uncharted territory. The arrival of the child is implicitly expected to follow a common and fairly well-known trajectory. Most people have vicarious experiences and accounts of parenthood to draw on, involving for example their own parents, friends and relatives, or cultural depictions of parent-child relations. Future parents' expectations for their family are

also shaped by societal institutions. In industrialised countries, during pregnancy, childbirth and early childhood, maternity and child-health services are provided to support the transition to parenthood.

When the child is affected by a disability or disease, this often runs counter to parents' expectations. Becoming the parent of a child with special needs is an event that most parents meet completely unprepared, and for many it will precipitate a personal crisis of some magnitude as well as the experience of emotional distress (Nelson Goff et al., 2013; Poslawsky, Naber, Daalen, & Engeland, 2014; Schuengel et al., 2009). Despite these overwhelming initial reactions, a majority of parents of children with disabilities learn to adapt to their situation and are able to meet their child's needs, enabling a positive development within the constraints imposed by the disability (Trute, Benzies, Worthington, Reddon, & Moore, 2010). Moreover, when comparing parents who have children with a disability by birth with those who knowingly have a child with a disability through adoption, despite higher depression scores in the former group during the child's infancy, the long-term adaptation is very similar (Flaherty & Masters Glidden, 2000). Such findings suggest that early crisis reactions are not formative, but that parents generally move on and are able to adjust well to daily life with their children.

Many of the impairments and rare diseases that lead to disability in a child are detectable during pregnancy or in early infancy. However, disability can be also be diagnosed later during childhood or adolescence. For example, the *Diagnostic and Statistical Manual of Mental Disorders*, issued by the American Psychiatric Association (DSM-5; 2013), defines intellectual disability as a disorder with onset during the developmental period, meaning brain injuries sustained before 18 years of age can be included. For autism, one of the most prevalent diagnoses among children who receive support from disability services, the DSM-5 criteria state that symptoms must be present in early childhood. However, the time between the first signs and a professional assessment and diagnosis is often long, and in a study of European children with autism, an age of five at diagnosis was not uncommon (Salomone, Charman, McConachie, & Warreyn, 2016). Thus, for a parent, the birth of a child and the initiation of a new role as parent of a child with a disability do not necessarily coincide. In this context, it should be noted that there is considerable variation in terms of both child age and time elapsed since the child received a diagnosis among the participants in the studies presented in the current thesis.

Parents of children with disabilities often experience more pronounced day-to-day challenges of parenting than parents of typically developing children.

Time constraints, difficult or physically demanding caregiving tasks and challenging or unresponsive child behaviour are all factors that may heighten parents' experience of stress (Plant & Sanders, 2007). Other sources of stress are not directly related to the child's impairment, but to the family's societal context. Our Western societies value qualities such as intelligence, productivity and independence. Within this system of values, the birth of a child with an impairment is often regarded as a highly negative event (Kearney & Griffin, 2001). Having to deal with one's own and other people's negative attitudes to disability or maintaining contact within a poorly coordinated service delivery system are obligations that may cause emotional distress in parents (Green, 2007). When chronic stress and exhaustion are experienced by caregivers, it may adversely affect not only their psychological well-being (Singer, 2006) but also their physical health (Miodrag & Hodapp, 2010).

The child with a disability may have difficulties in the areas of social behaviour, communication, cognition and emotional regulation, which make interaction more challenging or less rewarding for the parent, and this may have limiting effects on the child's opportunities for learning and development. These challenges also come with the implication that the child has bigger needs than a typically developing child for a developmentally supportive environment. For example, Landry, Smith, Swank, Assel and Vellet (2001) found that biologically at-risk children were more negatively affected than other children when their parents displayed low-responsive behaviour in interactions with the child. Thus, compared with parents of typically developing children, previous research suggests that parents of children with disabilities not only have a more difficult role to fulfil, but also have to deal with higher costs of shortcomings in terms of compromising effects on child development.

When presenting the available body of research on outcomes for parents of children with disabilities, there is a risk of painting a bleak picture. Granted, there is a heightened risk of negative outcomes in parents of children with disabilities. For example, mothers in particular display elevated depression scores as a group (Singer, 2006). However, it should be pointed out that there is great individual variation in parents' adaptation. In fact, a majority of parents of children with disabilities report well-being within the normative range (Baker, Blacher, & Olsson, 2005; M. B. Olsson, Larsman, & Hwang, 2008).

Not only are the negative outcomes for parents of children with disabilities a more complex matter than simple group comparisons are able to truthfully capture. There is also the potential for positive perceptions and experiences (Hastings & Taunt, 2002). It has long been established that positive and negative

affect are relatively independent dimensions of self-rated mood (Watson, Clark, & Tellegen, 1988). If daily life for parents of children with disabilities contains both challenges and rewards, researchers who use instruments that only measure negative outcomes run the risk of finding what they are looking for, while missing the bigger picture. Some 20 years ago, Helff and Glidden (1998) pointed out that research on family adjustment was written in a negative tone, focusing on measuring the difficulties that families encounter and being relatively silent about positive outcomes. A decade later, the literature had not changed in any remarkable way; although the vocabulary used to present study results was changing from pessimistic to more neutral, the instruments used to collect data were often the same as before (Turnbull, Summers, Lee, & Kyzar, 2007).

Blacher, Baker and Berkovits (2013) identify three different levels of positive impact of a child with disability on his or her family. The first level defines positive outcomes as an absence of negative outcomes. However, this may be overly simplistic, as studies have found that individuals often experience positive and negative emotions alongside each other. The second level, which Blacher and colleagues call the 'common benefits' view, holds that parents of children with disabilities have the same positive experiences that other parents have with their children, and that it is those experiences that are to be measured. The third level, the 'special benefits' view, looks for the positive perceptions and experiences that may be attributed to the child's disability.

Conceptualising parental adjustment

Risk and protective factors

Parents' adaptation in their role as caregivers is the result of a complex interplay between the environment and the individual over time. This is no less true for parents of children with disabilities than for parents of typically developing children. The well-being of the parent is not simply a product of certain child characteristics, such as a diagnosis or level of functionality.

Parents of children with disabilities face challenges of various kinds and also draw on a range of resources to handle these challenges. Wallander and Varni (1998) proposed a conceptual model to organise the range of different risk and resilience factors for parental adjustment in families of children with disabilities. They identify two broad areas of risk factors:

- *Disease parameters and functional care strain.* This area represents factors directly related to the child's impairment and associated care. It includes the type of diagnosis, severity and prognosis, and the amount of daily care that parents have to provide beyond the child's age-typical needs.
- *Psychosocial stress.* This area includes disability-related events that can cause stress for the parents. Examples are medical or legal issues, the child's school-related problems, and loss of career opportunities for the parent.

The authors further identify three areas of resilience factors:

- *Parental stress processing.* This relates to how parents appraise and cope with stressful events, e.g. whether an emotion-focused or an adaptive problem-focused coping style is used.
- *Intrapersonal factors.* Parents display different general cognitive and affective behavioural patterns, such as self-confidence, dispositional optimism and problem-solving ability.
- *Socio-ecological factors.* Practical resources, marital satisfaction, the social support network, service utilisation and health care service characteristics.

Wallander and Varni's model was commented on and further developed by Olsson (2008). One of her critical comments is that it is difficult to draw a clear-cut line between risk and resilience factors. For example, socio-economic resource level can represent both. Poverty, obviously, is a risk factor, whereas affluence can mitigate the effects of the child's impairment when it secures access to costly medical and social care. Olsson therefore proposes a model where risk and protective factors are not separated, but where different factors affecting parental adaptation are placed within three broad areas:

- Child- and disability-related factors
 - Child behaviour (especially behavioural problems)
 - Different diagnoses (familiarity, support group availability, time of diagnosis, diagnostic procedure)
 - Objectively and subjectively measured burden of care
 - Daily hassles, time demands, disruption of daily life
 - Restrictions in life

- Intrapersonal factors
 - Personality (e.g. neuroticism)
 - Problem-solving strategies and skills
 - Coping style
 - Locus of control
 - Optimism
 - Self-efficacy
 - Sense of coherence

- Socio-ecological factors
 - Spouse relationship (satisfaction, conflict)
 - Social support (partner, family, social network, leisure activities)
 - Formal support (health care, habilitation services, respite care)
 - Parenting support (parent education, interventions)
 - Socio-economic situation (financial resources, education, employment)

Transactional and ecological perspectives

Research on individual parent and child characteristics has proven useful in explaining variation in parental well-being (Baker et al., 2005; Glidden, Billings, & Jobe, 2006) and parenting behaviour (Fenning, Baker, Baker, & Crnic, 2014). Thereby it provides vital information on some of the determinants of family functioning. However, when conceptualising the factors thought to affect parental well-being, it is important to note that parents' adaptation is a complex process that is influenced by interplay with processes in the individual's context over time.

As theorised by the transactional model (Sameroff, 2009), child development takes place not in terms of a malleable child interacting with and adapting to a certain static environment, but rather the child and the environment exert a mutual influence on each other and reorganise in increasingly complex patterns. To exemplify, in an ideal situation, a child's gains in cognitive and linguistic abilities prompt the adult to employ correspondingly more elaborate communicative strategies, which in turn provide new learning experiences for the child. In the case of children with impairments, the establishment of such virtuous circles may sometimes be in jeopardy. A study of mother-baby dyads involving both children with Down syndrome and a control group of typically developing children (Slonims, McConachie, & Abbeduto, 2006) provides an illustration. The mothers and babies were filmed during play in a laboratory setting, and

then their interactive behaviour was rated by the researchers. Eight weeks old, the children with Down syndrome were less communicative than their typically developing peers, but their mothers' behaviour was similar to that of mothers in the control group. However, at a second point in time when the babies were 20 weeks old, something had happened, as the mothers of the children with Down syndrome were rated as less responsive than control mothers. The authors interpret their findings as an indication that it is the infants, rather than the mothers, who shape the interaction.

The transactional perspective suggests that parents' adaptation is not the sum of a number of risk and protective factors. Rather, it could be viewed as a process that takes place over time, and does so within the framework of a number of significant relationships that evolve and get shaped by their unique history.

The situation for families with children with disabilities is also highly dependent on contextual factors such as formal support systems, social networks and societal attitudes and values. Ecological systems theory (Bronfenbrenner, 1979) describes individual development as embedded within a multi-layered hierarchy of systems ranging from the most direct interpersonal influences to the most distant factors at a societal or cultural level. The microsystem includes the family, school, health services and other institutions that directly impact the child's development. The mesosystem is described as the interconnections between different factors in the microsystem, for example the relation between school and family. The exosystem involves links between the individual's micro- and mesosystems and the larger social system in which the child is not functioning directly, such as the parent's workplace. The macrosystem describes the society and the culture that individuals live in, their socioeconomic status and ethnicity. It also encompasses societal values and attitudes, for example those relating to parenting, normality and disability.

In many settings, people with disabilities are perceived as different from the dominant majority. They do not fit the socially constructed expectations about how they should look and behave, and often encounter stigma and prejudice. Being closely associated with a person with disability can also be stigmatising. Parents of children with disabilities often need to cope with negative attitudes and stereotypes. Parents of children with autism describe how they avoid public situations since they often receive glares and unwelcome advice on parenting from strangers when their child's behaviour is socially inappropriate (Farrugia, 2009). In situations where a child is labelled with a medical diagnosis, the child's atypical behaviour or appearance is less attributed to parental shortcomings in childrearing. However, parents, and mothers in particular, are still faced with the

stigma of having a body that has produced a child seen as 'deficient' (Davis & Manago, 2016), and may experience feelings of guilt (Chapple, May, & Champion, 1995). In a study of parents of children with Proteus syndrome (Turner, Biesecker, Leib, Biesecker, & Peters, 2007), a rare congenital syndrome that involves visual deformity, many of the informants reported exposure to intrusive inquiries, staring and devaluing remarks. A smaller portion had also experienced social withdrawal of family and friends. Just as the individuality of children with disabilities is often overlooked due to a focus on their impairment, parents' lived experiences are often framed within a limiting 'tragedy discourse' where they are expected to feel sad because of their child's disability (Broberg, 2011).

Families where a child has a disability need to negotiate and relate to factors across all levels of the ecological systems model. For example, parents' experience of time pressure may be related to their access to respite care. Stress related to this time pressure may affect their ability to react with patience and creativity when the child displays behavioural problems. The availability of respite care may in turn be a consequence of a society's norms regarding the responsibilities of the parent and the community.

A factor in Olsson's (2008) updated version of Wallander and Varni's model, which warrants further elaboration in the light of ecological systems theory (Bronfenbrenner, 1979), includes financial problems. Poverty and disability show a consistent association (Fujiura & Yamaki, 2000), and exposure to poverty is associated with negative outcomes for children with disabilities, including behavioural problems and being at risk of significant harm (Emerson & Brigham, 2014). The family stress model of economic hardship (Conger & Donnellan, 2007a) proposes that when parents experience economic hardship, they are at increased risk of emotional distress, marital conflict and reduced marital warmth, which may in turn deteriorate parental nurturance and involvement in relation to their children. There is also evidence from research on families with children with disabilities suggesting that the link between low socioeconomic position and child well-being is at least partially mediated by parenting difficulties; living under poor conditions may have a negative influence on parents' mental health and relationship quality, hampering their ability to engage in consistent and effective parenting behaviour (Emerson & Brigham, 2014). It is well known that socioeconomic factors play an important role in the family processes related to child development. However, empirical research has mainly been grounded within a psychological framework centring on individual factors (Turnbull et al., 2007), and leading scholars in the field of intellectual and devel-

opmental disabilities recommend that future research take into account families' broader social context (IASSIDD, 2012).

Review of empirical research on parental adaptation

This chapter gives a review of existing research on the adaptation of parents of children with disabilities. The review is intended to provide a background to the research questions and findings presented in the empirical studies. It will present previous research on the general population of parents and on parents of children with disabilities, addressing the following perspectives on parental adaptation: psychological well-being, couple relationship, harsh parenting practices and parent empowerment.

Psychological well-being in parents of children with disabilities

The existing research on parents' adaptation to a child's disability can be divided into two strands focusing on different times in the child's life. Some research aims to understand the reactions to the discovery or establishment of a diagnosis in the child, and the ways parents cope and adapt to a situation for which they are mostly unprepared. Other studies are more concerned with the long-term processes of adaptation of parents in the presence of risk and protective factors pertaining to their daily life with their child.

Reactions to becoming a parent of a child with a developmental disability

For some conditions, such as Down syndrome, parents often come to the realisation that the child has a disability already during prenatal screenings or imme-

diately after childbirth. For others, such as autism, the establishment of the disability includes a series of assessments and the parents have to live through a period of uncertainty during the time lag between first noticing that the child is different and receiving the diagnosis (Poslawsky et al., 2014). The diagnostic process and the certainty or uncertainty of the diagnosis have great influence on parents' experience of the situation (Graungaard & Skov, 2007).

Parents display different reactions to the diagnosis of their child's disability, but some themes are common in the literature. Parents often describe a pain in realising that the dreams and images they had of the child's future would have to be abandoned or radically adjusted, and that the emotional reactions associated with this loss were intense and could take on qualities of sorrow, anger, fear and guilt (Nelson Goff et al., 2013). Many also experience the unforeseen situation after a diagnosis as a call for action, and thus parents feel a need for information about the impairment, the prognosis and what they can do to help their child. In this process, the relations with health professionals are critical; however, parents are often disappointed when the professionals focus on symptoms and limitations rather than seeing the child's personality and potentials (Graungaard & Skov, 2007). Despite initial emotional difficulty, a majority of parents are able to come to terms with the child's diagnosis and reorient to address in constructive ways the needs actualised by the new situation (Poslawsky et al., 2014; Rentinck, Ketelaar, Jongmans, Lindeman, & Gorter, 2009).

Marvin and Pianta (1996) propose an attachment-theoretical framework for understanding the reactions that parents display when receiving a diagnosis for their child. Attachment theory (Bowlby, 1982) describes how humans, together with other species, possess evolutionary based behaviour systems that are activated in the child to protect it from danger by seeking and maintaining proximity to the caregiver when frightened, sick or otherwise in distress. The adult has access to a corresponding caregiving system, which in optimal circumstances operates conjointly with the child's attachment system, such that the child uses the adult as a 'secure base' from which exploration of the world can be endeavoured without relinquishing predictability or security. Problems within the attachment relation, such as caregiver insensitivity to child attachment behaviour, different forms of abuse or the loss of an attachment figure, may overwhelm the child's attachment system. The child may in such cases either inhibit the attachment system, acting avoidant, or overactivate it, whereby anxiety about the availability of the attachment figure impedes exploration (Bowlby, 1982). These insecure attachment patterns may increase the risk of difficulties in parenting as the child eventually becomes a parent, and the idea of such a transmission over

generations has also received empirical support (Shah, Fonagy, & Strathearn, 2010).

The experience of receiving the child's diagnosis has been likened to the 'loss of the perfect child', and the parent is faced with a challenge that bears similarity to an attachment-related loss or other trauma (Marvin & Pianta, 1996). The parent has to revise and reconstruct his or her internal working models when facing experiences that are incompatible with existing expectations and perceptions, a process described as resolution. When the parent has reached resolution and moved past the initial crisis, he or she is oriented to the present reality and the concrete demands implicated in caring for the child with a disability. An unresolved parent, however, is often preoccupied with the diagnosis and its possible causes and finds difficulty in creating a representation of the child that integrates the disability, and this limits his or her ability to relate emotionally and respond sensitively to the actual child (Feniger-Schaal & Oppenheim, 2013).

In their seminal work, Marvin and Pianta (1996) did not find that the severity of a child's disability or the time passed since diagnosis were associated with parents' resolution of reactions to the diagnosis. However, other researchers have found that less severe impairment and longer time since diagnosis were predictive of higher rates of resolution among parents (Schuengel et al., 2009). The proportion of parents who achieve resolution also varies in the existing research, with one study finding a resolution rate of 28% (Feniger-Schaal & Oppenheim, 2013) and another a rate of over 80% (Schuengel et al., 2009).

Even though parents' ability to come to terms with a child's diagnosis may have long-standing effects on their individual well-being and family relations (Sheeran, Marvin, & Pianta, 1997), there are also a host of other individual and contextual factors that are relevant to discuss in relation to their adaptation over time.

Long-term well-being of parents of children with disabilities

Previous research indicates that parents of children with disabilities, as a group, experience higher levels of stress than parents of children without disabilities (Florian & Findler, 2001; Gerstein, Crnic, Blacher, & Baker, 2009). The heightened stress levels affect parents' physical and psychological health (Miodrag & Hodapp, 2010). Parents, especially mothers, of children with disabilities are at higher risk of depression (Singer, 2006), although it should be noted that only a minority reach levels of depression outside of the normative range (Baker et al., 2005). Thus, there is great individual variation among parents of children with disabilities (Singer, 2006), and researchers have focused on investigating the

factors that are associated with resilience or vulnerability to negative emotional outcomes.

First, it should be noted that the prevalence of depression among parents of children with disabilities display gendered patterns that have parallels in the general population. Mothers of children with disabilities are more affected by depression than fathers (M. B. Olsson & Hwang, 2001), a finding that mirrors the finding that women are twice as likely as men to experience depression (Kessler, 2003). Despite the development of a strong gender equity discourse in Western societies as we enter the 21st century, the division of care responsibilities is still often highly asymmetric between the two parents in heterosexual couples (Bianchi & Milkie, 2010; Crompton, Lewis, & Lyonette, 2007), which suggests that stressors associated with caring for a child with a disability may affect mothers to a greater extent than fathers. Mothers of children perceived as vulnerable, such as children with a disability, may also experience stress because of an intensified pressure to conform to the socially constructed idea of the 'good mother', i.e. someone who devotes her time and energy to her child's needs, always leaving personal self-interest aside (Knight, 2012; Sousa, 2011).

Another important dimension to consider is socioeconomic position and economic hardship. People who experience hardship are at higher risk of depression (Butterworth, Rodgers, & Windsor, 2009). In the US, families where a child has a disability are more likely to live in poverty (Fujiura & Yamaki, 2000). Evidence from a British study suggests that the link between poverty and depression is valid for parents of children with disabilities, and that differences in socioeconomic circumstances may actually account for a substantial part of the increased risk for poor mental health among parents of children with disabilities (Hatton & Emerson, 2009).

When it comes to personal characteristics relevant to the development of poor emotional well-being, we can note that people tend to use a variety of strategies to cope with difficulties. Some strategies are more effective than others, and people who seek help or focus on their own opportunities in order to change the situation are often better off than those who try to escape unpleasant feelings through wishful thinking and avoidance (Noojin & Wallander, 1997). For mothers of children with developmental disabilities, the use of confrontational efforts to alter the situation is associated with lower depression scores, whereas behavioural efforts to escape or avoid the problem are associated with higher scores (Glidden et al., 2006). A feeling of being in control of the situation likely increases the chance that the parent will try to deal with things actively rather than making unsuccessful attempts at avoiding them. Self-mastery, the

view that life circumstances are within one's control rather than determined by fate, was associated with greater overall mental health in a study of mothers of children with cerebral palsy (Florian & Findler, 2001). Another characteristic that may influence parental well-being both directly and through its effect on the use of coping strategies is personality. This applies in particular to the dimension neuroticism, which describes a proneness to emotional instability, a low tolerance for stress and a tendency to experience negative emotions such as anger, sadness or frustration (Glidden & Natcher, 2009).

One of the most robust findings in the existing research is that child behaviour problems are associated with lower parental well-being (Baker et al., 2005; Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011). There is also evidence to suggest that parents of children with autism fare less well emotionally than parents of children with other types of developmental disorders, especially Down syndrome (D. B. Bailey, Golden, Roberts, & Ford, 2007; Hartley, Seltzer, Head, & Abbeduto, 2012). Researchers have attributed this difference between diagnostic groups to the higher prevalence of behaviour problems in individuals with autism, and to the higher level of adaptive behaviour often found in individuals with Down syndrome (Totsika et al., 2011). Plant and Sanders (2007) found that what parents experienced as most stressful in their daily life caring for a child with a developmental disability was difficult child behaviour during specific caregiving tasks, such as helping the child with eating, going to bed or going to the toilet.

Aside from interaction with the child, most parents of children with disabilities encounter additional disability-related demands, such as the coordination of healthcare, treatment, transportation and special education (Green, 2007). Mothers of children with autism who feel rushed and pressured by time constraints report more mental health problems (Sawyer et al., 2010), but the availability of informal social support from partners, relatives and friends may act as a protective factor for maternal well-being (Boyd, 2002; Bromley, Hare, Davison, & Emerson, 2004; Horton & Wallander, 2001; Sawyer et al., 2010).

In a depressed emotional state, the parent's capacity to respond sensitively to the child's needs may be compromised. Parental depression has a detrimental effect on children's emotional development, and has been observed to increase the risk of both internalising and externalising behavioural problems in community samples of children (Dawson et al., 2003; Fanti, Panayiotou, & Fanti, 2013; Weinfield, Ingerski, & Moreau, 2009). Low maternal well-being has been linked to increases in behavioural problems in children with autism (Totsika et al., 2013) although the directionality of the link between child behaviour problems

and parental well-being is subject to discussion (Hastings et al., 2005). It may be hypothesised that as children with disabilities may be more sensitive to low responsiveness in parents (Landry et al., 2001), and as their own behaviour provides fewer or weaker cues for interaction with the parent (Slonims et al., 2006), they are perhaps more vulnerable than other children to the negative effects of parental depression.

Although there is a great deal of research documenting the risk factors for negative outcomes in parents of children with disabilities, it is important to note the considerable individual variation that exists (M. B. Olsson, 2008). To illustrate, we can look at the data for mothers of 3-year-olds reported by Neece, Green and Baker (2012). The difference in parental stress scores between mothers of children with developmental delay and mothers of typically developing children was significant at the .001 level. However, we can also express this group difference as a probability: if we pick one mother out of each group at random and compare their stress levels, what is the chance of finding that the mother of a child with developmental delay reports *less* stress than the mother of a typically developing child? It turns out to be around 32%, which does differ from the 50% probability for two equal groups, but still it is far from zero.

Parents of children with disabilities are no different from other parents in the respect that stress and worries can coexist with joy and hope. An indication that the positive and the negative are not mutually exclusive is provided by a literature review by Horsley and Oliver (2015). In the included articles on parents of children with intellectual disabilities, the general finding was that mothers reported lower well-being but also higher positive perceptions, compared with fathers.

Raising a child with a disability also has the potential to exert a positive influence on the family (Blacher et al., 2013). Special benefits that parents may derive from their child with a disability include: an opportunity to learn and develop, a strengthened marriage, an increased sense of purpose in life, increased personal strength and a changed perspective on life (Hastings & Taunt, 2002). In a study of parents of children with Williams syndrome, Scallan, Joyce and Colin (2011) found distinctly positive experiences that were directly related to the child's disability. Participants described how their family was brought closer together, that their patience and tolerance had increased, and that their outlook on life had become less materialistic.

The couple relationship

Marital quality

Here, terms referring to marriage are used because they are established in family research literature. They refer to the nature of the relationship rather than specific legal arrangements. Thus, cohabiting parents are not excluded from the following reasoning.

There is a widespread conception that raising a child with a disability inevitably takes a hard toll on the marriage, and that separation or divorce is much more common in the families concerned (Williams, 2014). However, this idea is not based on empirical evidence, which instead suggests that the divorce rates are either in the average range (Lundeby & Tøssebro, 2008; Urbano, Hodapp, & Floyd, 2007) or only slightly higher (Hartley et al., 2010). In a study of UK parents of preschool children, children with cognitive delay were more likely to experience changes in family composition during their first five years in life, but this difference disappeared when socio-economic circumstances were controlled for (Hatton, Emerson, Graham, Blacher, & Llewellyn, 2010). The birth of a child, whether it has a disability or not, implies that the parent assumes a new social role that may compete or conflict with other important roles. There is also less freedom to pursue individual goals as children demand a lot of time and attention, and parenthood generally has a negative effect on marital satisfaction (Twenge et al., 2003).

Although the stereotypic image of a couple in distress because of their child's disability does not stand up to scrutiny, the couple relationship between parents of children with disabilities does deserve further investigation because of its relation to parents' personal well-being and their fulfilment of the parenting role. A couple operates within two family subsystems, i.e. the partner subsystem and the parental subsystem, and the boundary between them needs to be flexible and adaptive; the couple needs to maintain a protected space for intimacy, but also has to let the two subsystems nourish and support each other (Young, Negash, & Long, 2009). While most parents of children with disabilities do well, many are exposed to heightened levels of stress, and if the couple relationship is characterised by agreement over important issues, expression of affection, shared interests and low levels of conflict, it can function as a source of strength and energy when child-related stress puts strain on the individual (Gerstein et al., 2009).

From the general marital relations literature, there is evidence that poor marital quality predicts lower individual well-being (Whisman & Uebelacker, 2009) and that hostile marital interactions may precipitate depressive symptoms (Proulx, Buehler, & Helms, 2009). In a study of mothers of children with autism, higher marital quality predicted better subjective well-being and less depressed mood (Benson & Kersh, 2011). Moreover, the effects of marital quality are not limited to the psychological well-being of the individual. There is evidence to suggest that there are also effects on physical health (Robles, Slatcher, Trombello, & McGinn, 2014).

A strained marital relation may have negative spillover effects on parents' capability to interact with their child in positive ways that promote child development (Sturge-Apple, Davies, & Cummings, 2006). Given the reported negative consequences of parenthood on marital quality, there is of course the possibility that the associations found between poor relationship quality and negative parenting behaviour can be attributed to the child's impact on the couple relationship. However, a study where couples were assessed prior to the birth of the first child, and child negativity was controlled for, yielded results supporting the hypothesis that it is marital adjustment that precedes and influences parenting behaviour (Tanner Stapleton & Bradbury, 2012).

Informal social support is an important protective factor for the adaptation of parents of children with disabilities (Bromley et al., 2004; White & Hastings, 2004). An intimate relationship between the parents has the potential to function as an accessible and important source of such informal social support, which promotes parental adjustment. Supporting this line of reasoning, Kersh and colleagues (2006) found that in parents of children with disabilities, greater marital quality predicted lower parenting stress and also, for mothers, higher parenting efficacy.

Co-parenting

Marital quality has received much attention by family researchers. It has been successfully operationalised in empirical research and proven useful to explain differences between families in terms of child outcomes, parental psychological well-being and other variables. However, it does not directly tap the qualities of the relation between two adults that pertain to their parental functioning, what is called the *parenting subsystem* in family systems theory (Minuchin, 1985). The marital quality concept focuses on the couple dyad, regardless of whether they have a child or not. This limitation is similar to the way a large share of child psy-

chology research historically has restricted its focus to the processes within the dyadic relation between mother and child (Mchale, 2007).

Addressing this theoretical gap, the co-parenting concept is an attempt at theorising and measuring the relation between two adults who are jointly responsible for the care of a child. It includes but goes beyond the issue of sharing child care labour. Rather, it reflects a view of parenting together as an alliance characterised by mutual collaboration, affirmation and support (McHale, Kuersten-Hogan, & Rao, 2004). While there is, as one would expect, a link between marital quality and co-parenting quality in intact families (Bonds & Gondoli, 2007), co-parenting is conceptually distinct from the romantic relationship. It is thus useful not only for the investigation of parents living together or who are romantically involved, but applies to any comparable constellation of adults who share the responsibility for a child's upbringing. For example, co-parenting has been used as a measure in research on divorced couples (Dush, Kotila, & Schoppe-Sullivan, 2011) and families where the mother and the grandmother jointly take on the childrearing tasks (Goodman & Silverstein, 2002).

Harsh parenting practices

As its name implies, harsh parenting practices is a term used to describe parenting behaviours that are different from normative parenting practices. For comparison, an attempt to summarise succinctly parenting practices beneficial to child development comes from a book titled *The Circle of Security Intervention* (Marvin, Cooper, Hoffman, & Powell, 2002), where parents attending the intervention receive the admonishment to 'always be bigger, stronger, wiser, and kind' (p. 110). Harsh parenting could then be described as those things parents do when their size and strength gain the upper hand over their wisdom and kindness. Although there is no consensus on a definition of harsh parenting, researchers generally tend to include parenting behaviours situated on a continuum from mildly hostile to abusive, where the common denominator is physical, verbal or psychological aggression towards the child. Examples of ways to operationalise harsh parenting include 'spanking, threatening, yelling, or screaming' (J. A. Bailey, Hill, Oesterle, & Hawkins, 2009, p. 1215), 'spanking or slapping the child, throwing something at the child, pushing or shoving the child, or grabbing the child' (Martorell & Bugental, 2006, p. 643) and observer ratings of 'hostility (i.e., harsh, angry, and rejecting behaviours), escalate hostile (i.e., parents' intensification of their own hostile behaviour toward the child), reciprocate hostile (i.e., parents' responses to child's anger with hostility), angry-coercion

(i.e., attempts to control child's behaviour in an angry or threatening manner), antisocial (i.e., disruptive, age-inappropriate behaviour), and physical attack (i.e., hitting, pushing, or slapping) behaviours toward the child' (Scaramella, Neppl, Ontai, & Conger, 2008, p. 729).

Harsh parenting is not uncommon in US studies on families. In a study using data from the 2000 National Survey of Early Childhood Health, out of parents of children aged 19 to 35 months, 26% reported frequent spanking and 67% reported frequent yelling (Regalado, Sareen, Inkelas, Wissow, & Halfon, 2004). However, there are differences among parents, differences that researchers have found to be associated with their age, gender, ethnicity, mental health, socioeconomic circumstances and own exposure to violence (P. W. Jansen et al., 2012; Rhoades et al., 2011; Scaramella et al., 2008). Parents who perceive themselves as helpless when confronted with difficult child behaviour that they interpret as intentional seem to be particularly at risk for using harsh parenting practices (Martorell & Bugental, 2006; Sturge-Apple et al., 2006).

A number of negative developmental outcomes in children have been linked to parents' use of harsh parenting practices, including low mental development scores in preschool children (Berlin et al., 2009), aggression in early school age (Herrenkohl & Russo, 2001), low emotion regulation capacity in adolescence (Sarıtaş, Grusec, & Gençöz, 2013), poor physical and psychological health in adolescence (Brody et al., 2014), juvenile delinquency (Hoeve et al., 2009), adolescent conduct problems (Wang & Kenny, 2014) and perpetration of intimate partner violence when reaching adulthood (Swinford, DeMaris, Cernkovich, & Giordano, 2000). Researchers have found child effects of exposure to harsh parenting, not only as assessed by self-reported symptom levels, but also when measured through immune system bio-markers (Brody et al., 2014) and brain morphology (Tomoda et al., 2009). Moreover, physically harsh parenting exerts its negative psychological effects even when it takes place within an otherwise warm emotional climate (Lansford et al., 2014). Besides being harmful, harsh parenting practices seem to be ineffective. Control over the child's behaviour, the outcome most probably intended by the parent, does not extend beyond the immediate event (Gershoff, 2002).

Harsh parenting and child disability

Researchers have repeatedly reported that children with disabilities are more exposed to harsh parenting than their peers without disability (Brown, McIntyre, Crnic, Baker, & Blacher, 2011; Jones et al., 2012; Svensson, Bornehag, & Janson, 2011). One possible explanation for the observed increase in the risk of harsh

parenting practices is that when parents try to manage the behaviour of their child with a disability, they are more prone to resort to harsh strategies because less aggressive strategies have been found to be ineffective (Greenwald, Bank, Reid, & Knutson, 1997). For example, mothers of profoundly deaf children were more likely than mothers of hearing children to escalate to physical violence if their child did not comply, which the authors interpret in light of communication difficulties due to the hearing impairment (Knutson, Johnson, & Sullivan, 2004). Similarly, parents of children with speech-language delay report using more punitive parenting strategies than parents of typically developing children (Carson, Carson, Klee, & Jackman-Brown, 2007). If a child is able to behave well in some situations but misbehaves in others, parents may perceive their child's misbehaviour as intentional, which increases the risk of harsh parenting practices (Helton & Cross, 2011).

Parents of children with disabilities tend to experience situations where the child behaves in ways that obstruct daily caregiving tasks, which predicts heightened levels of parenting stress (Plant & Sanders, 2007), and one may hypothesise that this in turn increases the risk of harsh parenting practices. In an in-depth interview study, Swedish parents of children with disabilities disclosed feeling exhausted, frustrated and powerless in situations where their child's behaviour made daily caregiving tasks difficult to handle; the parents also reported that interaction with non-disabled siblings did not elicit their anger to the same extent (Svensson, Eriksson, & Janson, 2013).

The prevalence of behavioural problems is higher among children with intellectual disabilities than in the general child population (Emerson & Hatton, 2007). At the child level, the presence of behavioural problems is associated with an increased risk of harsh parenting (Emerson, Einfeld, & Stancliffe, 2011) as well as an increase in the risk of physical abuse that may be as big as seven-fold (Sullivan & Knutson, 2000). Exposure to harsh parenting is also associated with the persistence of behavioural problems in children with intellectual disabilities (Emerson et al., 2011).

The results of a national cross-sectional study of children in Sweden (Svensson et al., 2011) indicated that children with chronic health conditions including disability were more likely than other children to be exposed to physical abuse, and that there was an interaction effect such that in unfavourable socio-economic circumstances, this difference became even more pronounced. One possible explanation for this socio-economic effect is offered by the family stress model of economic hardship (Conger & Donnellan, 2007b), which predicts that parents under economic pressure will be at increased risk of emotional

distress, drug use and antisocial behaviour, which in turn leads to less affective and more irritable and inconsistent parenting practices.

For children with disabilities who are exposed to abuse, there may be obstacles to discovering it and appropriately intervening. Children with disabilities sometimes have motor, cognitive or communicative challenges that limit their ability to avoid perilous situations or to get help from others (Sobsey, 2002). In a Swedish study, parents reported that their discussions with professionals were marked by a feeling of taboo surrounding child abuse (Svensson et al., 2013). Swedish health care professionals working with children with disabilities and their parents further report that they experience difficulties in reporting suspected abuse or neglect to Social Services, because of a perceived closeness to the families and a desire to keep a cooperative relation with the parents, who are crucial to children's access to treatment (Mallén, 2011). Another Swedish study reported that legal representatives did not know how to assess credibility in children with intellectual disabilities, and doubted their capacity to testify in court (Cederborg & Gumpert, 2010).

Harsh parenting in a Swedish context

The United Nations Convention on the Rights of the Child (UNCRC; UN General Assembly, 1989) obliges its signatory states to protect children from 'all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse'. All UN members except USA and South Sudan have signed the UNCRC. Nevertheless, the use of corporal punishment against children remains legal in most countries (Global Initiative to End All Corporal Punishment of Children, 2014), and childrearing practices involving violence remain common (MacKenzie, Nicklas, Waldfoegel, & Brooks-Gunn, 2013).

While some US scholars and professionals continue to debate over the existence of negative consequences of disciplinary violence (Baumrind, Larzelere, & Cowan, 2002), and how to best use it in childrearing (Dobson, 2017), the efforts of Swedish researchers are targeted entirely at investigating prevalence and attitudes and at designing policy measures to minimise the acceptance of violence as an option for parents (Jansson, Jernbro, & Långberg, 2011).

With its decision to prohibit all disciplinary violence in 1979, Sweden took a legislative step without prior example. The law has been used primarily as an instrument to drive public attitudes and encourage identification of children at risk, and not to prosecute minor infractions (Durrant, 2000). The ban seems to be an effective measure to lower the prevalence of disciplinary violence; from

1980 to 2000, the proportion of Swedish parents who admitted to spanking their children dropped from 28% to 1.1% (Jansson et al., 2011). The current generation of parents, who were themselves children when the law went into effect, or who were born after 1979, have been socialised to disapprove of disciplinary violence (Durrant, 2000). At present, the attitudes to disciplinary violence are overwhelmingly negative, with 92% of Swedish parents subscribing to the idea that slapping or spanking the child is never justified (Jansson et al., 2011).

The differences between Sweden and the US and UK are also relevant to the measurement of parenting practices. The behaviours commonly used to operationalise harsh parenting may have different status in different judicial systems. According to one line of reasoning commonly applied by US legislators and authorities, physical punishment is reasonable within certain limits, but turns into physical abuse when it causes physical injury that harms the child or impairs the child's health (Coleman, Dodge, & Campbell, 2010). In Sweden, however, the law prohibits all corporal punishment or other injurious or humiliating treatment (Durrant, 2000). Thus, some of the behaviours used to measure harsh parenting practices, such as spanking (used by J. A. Bailey et al., 2009; Martorell & Bugental, 2006), are actually considered abuse by Swedish standards.

Abuse of children with disabilities is likely both underreported and underestimated (Cooke & Standen, 2002). It would therefore require a very large sample to arrive at reasonable numbers of families admitting they use violence. Furthermore, admitting to using violence against a child with a disability is likely difficult for parents, and there is a great risk of social desirability bias, a risk that may be aggravated as a consequence of the Swedish legislation. The harsh parenting instrument employed in this thesis framed the questions in a discipline context and included behaviours that may be less stigmatising to admit, such as yelling at the child. These are behaviours that are likely to occur more frequently in the population than physical abuse, making the items thus more likely to be answered honestly by parents.

Parent empowerment and information needs

When faced with challenges, it is of critical importance whether the individual approaches the situation with a feeling of mastery or one of hopelessness. An important aspect of parents' psychological adaptation to life with a child with a disability is their perceived sense of control and ability to proactively produce positive change for their family. The term *empowerment* has been used in the liter-

ature to describe people's understanding of the environment, beliefs about their own competence and efforts to control their environment (Nachshen & Minnes, 2005). It is generally understood to encompass a set of attitudes and behaviours that include self-efficacy, participation and collaboration, sense of control, meeting personal needs, understanding the environment, access to resources and personal action (Dempsey & Dunst, 2004).

Family-centred support (Dempsey & Dunst, 2004; Dunst & Dempsey, 2007; Trute, 2007) is a caregiving philosophy that is closely related to parent empowerment. It reflects an approach where professionals seek to establish a respectful and collaborative working alliance with families, focus on family strengths and capacity building, and commit to information sharing in order to facilitate family decision making in relation to family-identified service needs. The family-centred support paradigm has received much attention from both researchers and policy makers and is often considered best-practice in early intervention and other support measures for children with disabilities. Research on family-centred support suggests that it promotes positive outcomes for children, parents and families (Dunst & Trivette, 2009). An objective set by Swedish policy makers is that support measures offered to children with disabilities should be tailored to fit the needs of the family as a whole, by creating individualised solutions where service providers cooperate (Riksrevisionen, 2011). The principles recognised within the family-centred paradigm also correspond well with qualities that parents rate as important in formal support (S. L. G. Jansen, van der Putten, & Vlaskamp, 2013).

As parents are viewed less as passive recipients of support and more as equal partners, their responsibility also increases. In a discourse analytic study (Hallberg A, Lindbladh E, Petersson K, Råstam L, & Håkansson A, 2005) of Swedish official documents about the development of child health care during the period 1930–2000, the researchers found that the focus has gradually shifted from paternalistic institutions towards seeing the parents as capable agents, such that professionals are increasingly tasked with supporting parents to cope with their difficulties independently. An important goal for service providers is therefore to strengthen parents' competence and sense of control (Dunst & Dempsey, 2007).

When parents are involved more and more as partners in joint decision-making with professionals, their information needs become pertinent (Alsem et al., 2017). Reliable, correct and useful information is crucial for parents to make good decisions for their child, and to enhance their sense of mastery. Parents of children with disabilities are striving to handle a complex life situation, and in-

formation seeking is described as a positive coping strategy that enables parents to manage their child's condition, gives them more control over their family life and facilitates access to the right services (Davies & Hall, 2005). Information is useful for parents as it helps them understand and accept their child, be better prepared for the future and cope emotionally (Pain, 1999). Parents' need for information is often accentuated during transitions in the life of the child or the family (Alsem et al., 2017).

The Internet is an important source of information for parents of children with disabilities. However, although there is an abundance of information online, it is often difficult to sift through, evaluate, absorb and put to practical use (Mathiesen, Frost, Dent, & Feldkamp, 2012). The information available online often fails to meet quality criteria (Pauer et al., 2017), and there are indications that online information searches may actually serve to increase parents' anxiety (Tozzi et al., 2013). Despite these problems associated with online health information, parents seldom bring facts found on the Internet up for discussion with professionals (Alsem et al., 2017).

Parents' access to information is vital to their ability to make competent therapeutic and educational decisions for their child, and therefore a key ingredient in professionals' help-giving practices (Fordham, Gibson, & Bowes, 2012). However, parents themselves are not always aware of what information they need at a particular time, or may not know what to ask to obtain it (Pain, 1999). Therefore, the challenge for professionals is to tailor information provision to the individual needs of the family as they change over time (Alsem et al., 2017).

Whereas meetings with professionals and online material from institutions are perceived as sources of reliable medical information, other parents play an important role as providers of experience-based knowledge (Alsem et al., 2017). Sharing ideas and meeting other families coping with a similar disability can give parents hope and increase their confidence (Davies & Hall, 2005). Parents educate each other by sharing stories about their children's development and their experiences with the support system, and when they gain more knowledge their chances of gaining access to appropriate services are increased (I. Olsson & Roll-Petterson, 2012).

Parents' experiences and satisfaction with support systems

The special needs that children with disabilities have across various life domains often make families dependent on formal support delivered by professionals.

These professionals typically represent a range of public service providers including habilitation centres, school or childcare, general healthcare, specialised medical care, social services and social security insurance offices. Parents of children with disabilities thus need to maintain a significantly larger formal support network than parents of typically developing children (M. B. Olsson & Hwang, 2003), and the quality of these relations with professionals is of importance to a range of child and family outcomes (Dunst, Trivette, & Hamby, 2007).

Swedish parents of children with disabilities often express satisfaction with their relations with individual professionals and the quality of specific interventions (Broberg, Norlin, Nowak, & Starke, 2014; M. B. Olsson & Hwang, 2003). However, a finding that emerges in many studies is that both parents and professionals perceive a lack of coherence and coordination. No single instance within the service system has a clearly defined responsibility for ensuring that the support is efficiently orchestrated. Parents are thereby forced to assume several roles, i.e. advocate for their child, information hub and service coordinator, and this demands a great amount of time and effort on their part (Broberg et al., 2014; I. Olsson & Roll-Pettersson, 2012; Riksrevisionen, 2011).

Parents report that whereas the support needs directly related to the child's impairment are generally catered to, the psychological needs of parents are not sufficiently addressed. Parents express wishes for couple counselling, stress management interventions and support in their parenting role in order to cope better with their situation (Broberg et al., 2014).

In the cited Swedish studies, inequality is also mentioned as a concern. Parents and professionals express the view that the chances of obtaining services increase with the parent's acquaintance with the support system, knowledge of their entitlements, ability to argue convincingly for their child's cause and sheer perseverance (Broberg et al., 2014). Another problem is that whereas legislation and policies are national, most of the support measures for children with disabilities are funded, applied for, approved, and delivered at the municipal and county council levels, and a degree of spatial inequality is evident (Riksrevisionen, 2011).

Summary of the studies

The general aim of this thesis is to further the understanding of the adaptation of parents of children with disabilities. To this end, it investigates challenges at the individual and couple levels that may affect parents of children with disabilities, and evaluates an intervention for families of children with disabilities. Study I addresses the question of how aspects of the couple relationship may affect the adaptation of parents of children with intellectual disabilities. Study II addresses the questions of whether children with disabilities are more exposed to harsh parenting than typically developing children, and how this possibly increased exposure might be understood. Study III evaluates a brief intensive intervention for families of children with rare diseases, with parental empowerment and psychological well-being variables as outcome measures.

The three studies used different samples of families and different inclusion criteria. Study I recruited parents of children with intellectual disabilities attending habilitation service centres. Study II recruited parents of children with any kind of developmental disability from the population of children who had been approved for assistance pursuant to applicable Swedish disability entitlement law. Despite the different recruitment procedures, the composition of the respective samples, in terms of the child disability diagnoses represented, was rather similar in Studies I and II. Study III recruited parents of children with rare diseases who participated in the specific intervention.

Study I

Aims

Study I investigates parents' individual well-being, marital quality and co-parenting quality using data from two waves separated in time by one year. The first aim of the study was to compare parents of children with intellectual disability (ID) with other parents. The second aim was to examine how marital qual-

ity and co-parenting quality predict individual well-being when controlling for presence of child ID, economic risk, child behaviour problems and parenting stress. The following hypotheses were tested:

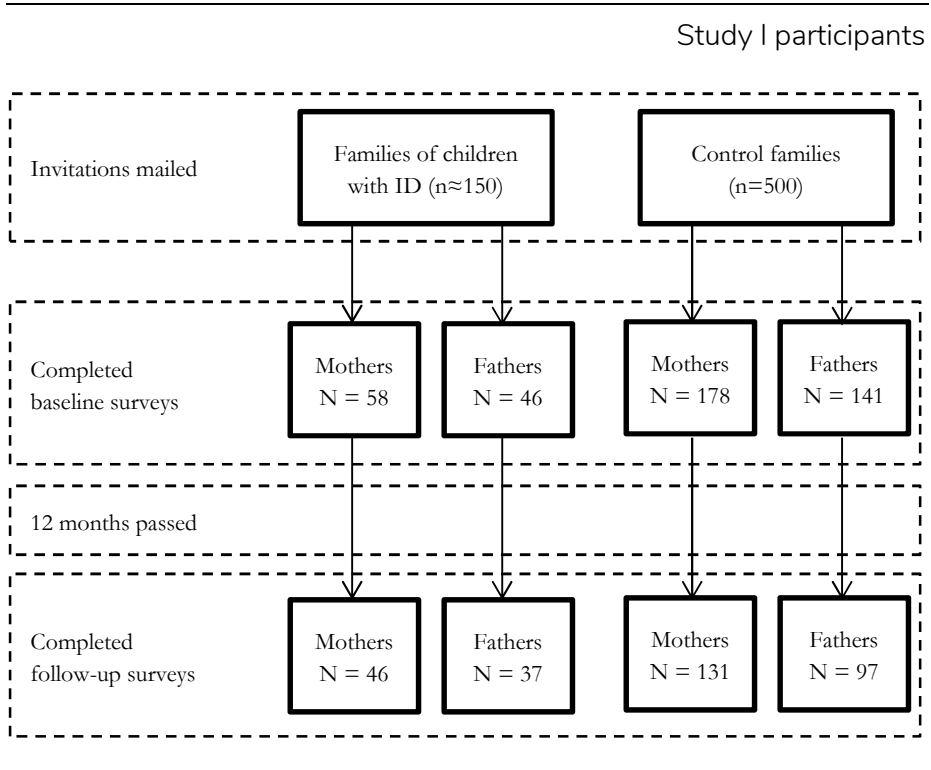
- 1) Parents of children with ID have lower well-being than control parents, and fathers have higher well-being than mothers.
- 2) Parents of children with ID have lower marital quality than control parents.
- 3) Parents of children with ID have lower co-parenting quality than control parents.
- 4) Marital quality and co-parenting quality will explain additional variance in parental well-being, when controlling for risk factors: parent gender, child ID status, child behaviour problems, parenting stress and economic risk.
- 5) Well-being at follow-up is associated with marital quality and co-parenting quality at baseline.

Method

Study I used data from an ongoing longitudinal investigation of the adaptation of parents of children with ID in southwestern Sweden. Parents were recruited through habilitation service centres operated by the county council. These centres deliver support to children with ID, mobility impairments and multiple disabilities, as well as their families. Staff selected families where the child was nine years or younger, had been referred in the last six months and was either under evaluation or diagnosed with ID and/or autism. Around 150 families received offers to participate in the research by post. Completed surveys were obtained from 58 mothers and 46 fathers. A follow-up survey was sent out to the respondents after twelve months. It was completed by 46 mothers and 37 fathers, implying a response rate of 79.3% and 80.4%, respectively. The children included were diagnosed with autism ($n=13$), Down syndrome ($n=9$), ID of unknown aetiology ($n=5$) and other disorders, including cerebral palsy and muscular dystrophy ($n=22$). The remaining children were awaiting diagnosis ($n=9$). The children were between 0:5 and 9:3 years old.

As a control group, through random selection from census data, 500 families with a child under age seven and that lived in the same region were identified. The families were sent surveys by post, and completed surveys were obtained from 178 mothers and 141 fathers. Twelve-month follow-up surveys were obtained from 131 mothers and 97 fathers, implying a response rate of 73.6% and

68.8%, respectively. The control group was similar to the parents of children with ID with respect to child age, child gender distribution and parents' age and education.



For well-being, survey data from both baseline and follow-up was used. For all other measures, only baseline data was included in the analyses. The following measures were included in the survey:

Well-being. A modified version of the second edition of the Beck's Depression Inventory (BDI-II), called BDI-2r (Chow & Brenton, 2000), was used to measure parents' well-being. In addition to the four responses in the original BDI-II, the BDI-2r includes three positively worded responses for each of the 21 items. The result is a seven-point Likert scale ranging from depression to a state of intensely positive mood. Examples of extreme positive responses are 'I could not possibly be happier', 'I am more energised than ever to do anything' and 'I am very pleased with myself'. The new responses are scored with negative numbers from -3 to -1, such that the total score is extended to the range -63 to

63, with higher positive score indicating a more depressed mood. Cronbach's alpha for this scale was 0.87 at baseline and 0.87 at follow-up.

Child behaviour problems. Child behaviours were rated by the parents using the self-injury/stereotypic subscale of the Nisonger Child Behaviour Rating Form (NCBRF; Aman, Tassé, Rojahn, & Hammer, 1996). Ten different behaviours were rated for their prominence on a four-point scale from 0 (problem does not occur or is not a problem) to 3 (problem occurs a lot or is a severe problem), yielding total scores ranging from 0 to 30. Examples of items are 'Rocks body or head back and forth repetitively' and 'Gouges self, puts things in ears, nose etc., or eats inedible things'. Cronbach's alpha for this scale was 0.66.

Parenting stress. Parenting stress was measured using a subset of items from the Family Impact Questionnaire (FIQ; Donenberg & Baker, 1993). Ten items described the child's negative impact on social life, and six items concerned negative feelings towards the child. All items were scored from 0 (not at all) to 3 (very much), yielding total scores from 0 to 48. Cronbach's alpha for this scale was 0.86.

Economic risk. Economic risk was assessed by summing three different measures. The first measure was a list of six social activities and five clothing items (adapted after Emerson, Hatton, Llewellyn, Blacker, & Graham, 2006). For each list item, the parent scored 0 if they could afford it, 1 if they occasionally could not afford it and 2 if they could not afford it. The second measure was an indication of reliance on income support from Social Services, scored 0 if the family had not received it, 1 if they had so occasionally and 2 if they had so regularly. The third measure was a dichotomous variable scored 0 if the parent thought the family could raise €1 400 within a week to cover unforeseen expenses and 1 if they could not. The score for economic risk had a range from 0 to 25, but since few parents achieved high scores, a dummy variable for high economic risk was created, which was set to 1 if the economic risk score was 2 or higher.

Marital quality. Marital quality was measured with 15 items from the dyadic cohesion and dyadic satisfaction subscales of the Dyadic Adjustment Scale (DAS; Spanier & Thompson, 1982). Thirteen items had six-point Likert scale responses scored from 0 to 5. Two more items, similar to the others but with a five-point Likert scale scored 0 to 4, were rescaled to the same range as the others by multiplying them by 1.25. The 15 items were then summed, yielding a total score ranging from 0 to 75, with a higher score indicating a more cohesive and satisfying relationship. Cronbach's alpha for this scale was 0.89.

Co-parenting quality. Co-parenting quality was measured using the Parenting Alliance Measure (PAM; Konold & Abidin, 2001), comprising 20 questions about cooperation, support and mutual respect, each scored on a five-point scale from 0 to 4, yielding a total score range of 0 to 80, with a higher score indicating a better co-parenting relation. Cronbach's alpha for this scale was 0.95.

Results

Hypothesis 1 received partial support: mothers of children with ID scored lower on well-being than control mothers, but the corresponding difference was not found for fathers.

Hypotheses 2 and 3 did not receive support, as there were no differences on marital quality or co-parenting quality between parents of children with ID and control parents.

Hypothesis 4 received partial support. For the whole sample, well-being was predicted by marital quality, economic risk, parent gender and child ID status. Co-parenting quality, however, did not predict well-being. A similar pattern emerged in gender-separated analyses: For mothers, marital quality and child ID status predicted well-being; for fathers, marital quality, hardship and child behaviour problems predicted well-being.

Hypothesis 5 received partial support. For the combined sample, prospective well-being was most strongly predicted by baseline well-being, followed by co-parenting quality. Marital quality was not a significant predictor.

Regarding group differences, parents of children with ID rated their child's behaviour problems as more severe than control parents. There was no difference in economic risk between parents of children with disabilities and control parents.

Study II

Aims

Study II investigated parents' self-reported inclination to use harsh parenting practices. It had three aims:

- 1) To compare the inclination to use harsh parenting practices in parents of children with disabilities and a control group.

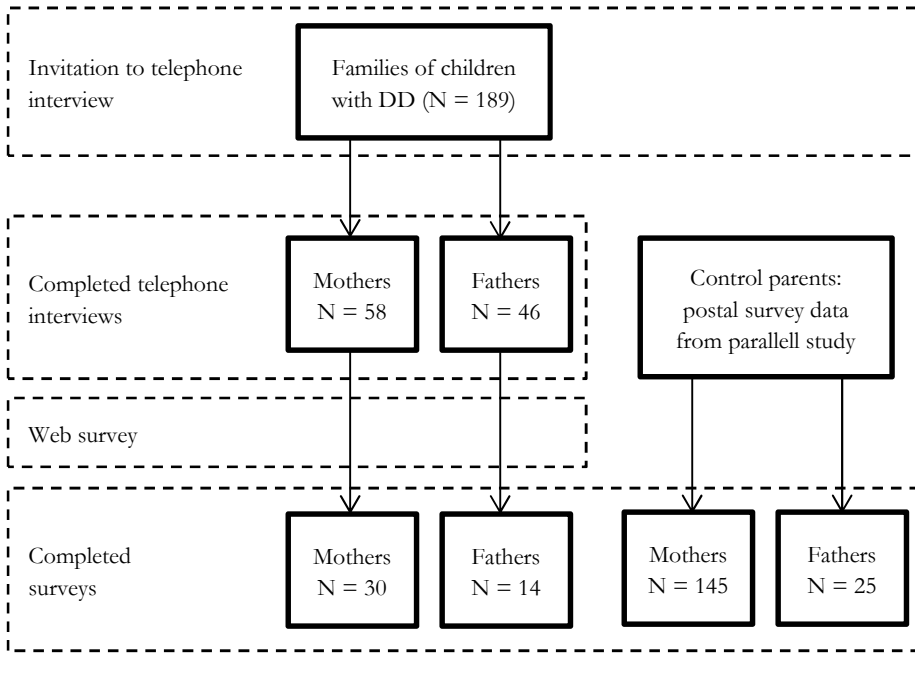
- 2) To examine, in the group of parents of children with disabilities, whether child behaviour problems and socioeconomic disadvantage predict the inclination to use harsh parenting practices.
- 3) To see whether our findings were similar to those reported in UK and US studies.

Method

For Study II, parents of children with disabilities were recruited with the help of the social service offices of three local governments in southwestern Sweden. Staff at twelve district offices listed all children in their records who had been approved for assistance pursuant to applicable Swedish disability entitlement law. Such approval implies that the child has been medically diagnosed with a condition entailing extensive and permanent functional impairment. From the compiled lists, a 15% subsample (189 children) was randomly selected. Each parent of the selected children received an information letter asking them to participate in a telephone interview. Ninety-seven mothers and 47 fathers accepted the request. During the telephone interview, the parents were also asked to participate in a web survey. Complete survey data was obtained from 45 parents from 37 families, representing 20% of the initially selected 189 families. After the removal of one outlier, 30 mothers and 14 fathers remained for analysis, representing 36 individual children. The parents participating in the web survey had higher average level of education than the parents who participated in the telephone interview only. Children were 3 to 18 years old and their primary diagnosis was autism ($n=16$), cerebral palsy ($n=5$), Down syndrome ($n=3$), intellectual disability ($n=2$), unspecified ($n=5$) and other disorders including specific genetic syndromes ($n=5$).

Control parents participated in a parallel study on general parent support. They were recruited by a random selection of parents from Swedish census data and received surveys by post. Completed surveys were obtained from 170 parents, 145 mothers and 25 fathers, of children aged 1 to 18.

Study II participants



The following measures were included in the survey:

Child behaviour problems. The Eyberg Child Behaviour Inventory (ECBI; Robinson, Eyberg, & Ross, 1980) was used. It comprises 36 items each describing a problematic behaviour, for example, 'Destroys toys and other objects', 'Is easily distracted' and 'Has temper tantrums'. For each behaviour, the parent scored how often it occurred, ranging from 1 (Never) to 7 (Always), with 4 representing 'Sometimes'. The sum of a subset of 22 items was used as a measure of intensity of child behaviour problems, with a range of 22–154.

Socioeconomic disadvantage. Socioeconomic disadvantage was assessed using the sum of three dummy variables: being in need of welfare benefits, having less than 12 years of schooling and being unemployed or retired on ill-health grounds. The range was 0–3.

Harsh parenting practices. The harsh discipline subscale of the Parenting Practices Interview (PPI; Webster-Stratton, 1998) was used. It consists of 14 items describing different parenting strategies that can be used in response to child transgressions. Examples were 'Give your child a spanking' and 'Raise your

voice (scold or yell)'. Responses indicated the probability and/or frequency with which the parent would use the strategy in question, scored on a seven-point scale from 1 (Never) to 7 (Always), with 4 representing 'About half the time'. The responses were summed to an index with a range of 14–98.

Violence. Using only the items from the PPI that indicated slapping or spanking, a dummy variable that was set to 1 for the parents who had indicated anything other than 'Never' on any of the items was created.

Results

In relation to the first aim, parents of children with disabilities did not indicate higher use of harsh parenting practices, controlling for parent sex and child age. However, a difference was found between fathers of children with disabilities and control fathers, in that the former to a greater extent admitted potential use of disciplinary violence more often than 'Never' (57% vs. 24%). There was no similar difference between mothers of children with disabilities (14%) and control mothers (8%). The children with disabilities had more reported behaviour problems: Parents who rated their child's behaviour problems as severe amounted to 36.4% and 7.7% in the parents of children with disabilities and the control group, respectively.

In relation to the second aim, in the group of parents of children with disabilities, more child behaviour problems predicted higher use of harsh parenting practices.

In relation to the third aim, the prevalence of harsh parenting practices suggested by the findings was lower than what is commonly reported in UK and US studies.

Study III

Aims

Study III investigated parents participating in a brief intensive intervention for families of children with rare diseases. Its first aim was to assess the effects of the intervention on the parents who participated. The second aim was to investigate differences between mothers and fathers, and the third was to explore whether socioeconomic status, parent gender or depressive symptoms predicted differences in effects of the intervention on the parents. The fourth aim was to describe how parents rated the perceived benefits of the intervention.

The following hypotheses were tested:

- 1) Before the intervention, compared with fathers, mothers would report higher levels of empowerment, parenting stress, depressive symptoms and anxiety.
- 2) After the intervention, mothers and fathers would report higher empowerment and lower depressive symptoms, anxiety and parental stress.
- 3) After the intervention, mothers and fathers would report lower child-related marital stress.

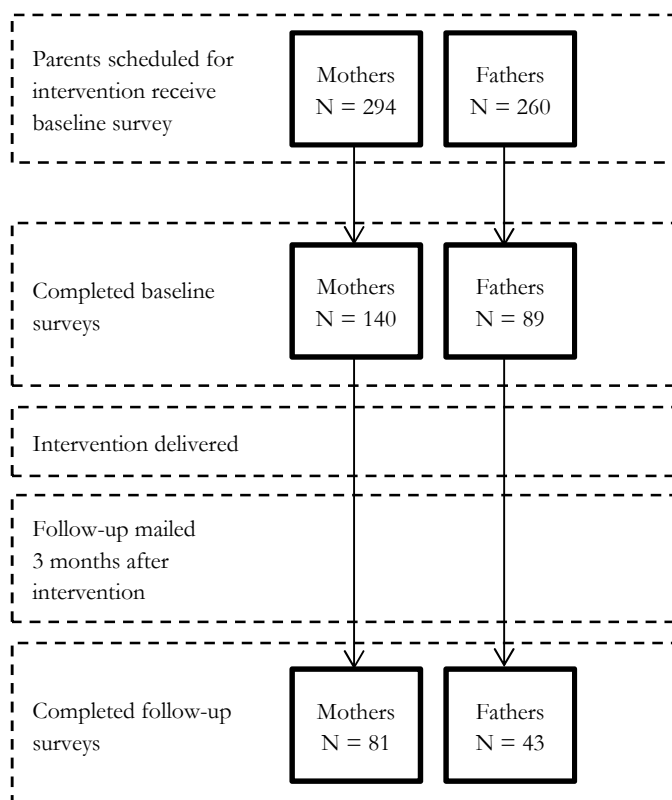
Method

The intervention studied in Study III was created and delivered by the National Competence Centre for Rare Diseases in Sweden. The intervention program was designed with the stated aim to increase parents' competence and self-efficacy in their role as parents of a child with a rare disease. On each occasion it is delivered, the intervention is tailored to a specific rare disease diagnosis. For five days, around ten families with a child who has the targeted diagnosis stay together at the Centre. As a general rule, all family members attend. The participants share meals, breaks and recreational time, giving them the opportunity to engage with and get acquainted with other families in a similar situation. For several rare diseases, the family intervention has been the occasion where parents have held a founding meeting to create a national advocacy group for the specific diagnosis. For parts of the day, parents and children have separate schedules. Parents participate in psychoeducational activities, classroom sessions where they are updated on medical information by experts on the respective diagnosis, and workshops with discussions around the psychological, social and family aspects of caring for a child with the diagnosis. Affected children take part in a program adapted to their age and abilities. Siblings to the diagnosed child also have some separate activities where they get to talk about their role in the family and how their life is affected.

During the recruitment period, i.e. March 2012 – November 2013, the intervention was delivered 31 times. Baseline surveys were sent or handed to all parents scheduled to participate in the intervention. Baseline data were obtained from 236 parents (140 mothers and 89 fathers). Follow-up surveys were sent out to the respondents by post three months after the intervention and data were obtained from 124 parents (81 mothers and 43 fathers), yielding a response rate of 52.5% (57.9% for mothers and 48.3% for fathers). These participants were the parents of 100 children, representing 23 different rare diseases. The largest

diagnostic groups were: narcolepsy following vaccination against the pandemic H1N1/09 virus ($n = 34$), dyskinetic cerebral palsy ($n = 8$) and achondroplasia ($n = 6$). The remaining children had various genetic syndromes or congenital disorders. Children were between 9 months and 17:9 years old at the start of the intervention, with a mean age 8.96 years ($SD = 4.65$). Fifty-one (51.0%) of them were boys, and eighty-eight children (88%) had siblings. For 26 children, responses were obtained from both the mother and the father, and for the other 74, only one parent's responses were available. No control group was used.

Study III participants



The following measures were included in the survey:

Socio-economic status was measured using the Hollingshead four factor index of social status (Broberg, 1992; Hollingshead, 1975), where level of education and

current occupation are used to calculate a one-dimensional index of socioeconomic status, ranging from 8 to 66. Since data from two parents were available only for a minority of the families, this index was calculated for each parent individually without taking into account the education and occupation of partners.

Empowerment was measured using the Psychological Empowerment Scale (PES; Akey et al., 2000), which consists of four subscales: attitudes of control and competence, cognitive appraisals of skills and knowledge, and formal and informal change-oriented behaviours respectively. In Study III, the formal change-oriented behaviours subscale was omitted, since those items did not translate well to the Swedish political and legal systems, yielding a total of 24 items. Items were translated to Swedish and then translated back to English by another person, and the outcome was compared with the original to ensure validity of the translation. Parents indicated their agreement with the items on a 5-point scale from 1 (= I do not agree) to 5 (= I agree completely), implying a total score ranging from 24 to 120. Examples of items include: 'I have control over decisions that are made concerning my child', 'I feel competent to meet my child's needs' and 'I try to act as an emotional support to other parents'. Cronbach's alpha was 0.97.

Parenting stress was measured using items from the Family Impact Questionnaire (FIQ; Donenberg & Baker, 1993). Parents were asked to compare their child with other children his or her age and estimate the child's impact on the family on a 4-point scale from 0 (= the behaviour did not occur or was not a problem) to 3 (= the problem occurred a lot or was a severe problem). Items indicating a negative impact of the child on the family's social life (8 items, e.g. 'My child's behaviour embarrasses me in public more') or negative feelings toward parenting (9 items, e.g. 'My child is more stressful') were used. Summation of items yielded a score ranging from 0 to 68. Cronbach's alpha was 0.91.

Child-related marital stress was measured using the marriage subscale of the FIQ, with seven items scored as above, indicating the child's negative impact on the relationship, e.g. 'My child causes more disagreements between my spouse and me'. Cronbach's alpha was 0.41.

Depressive symptoms and anxiety were measured using the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). The HADS is a brief measure of symptoms of anxiety and depression that is widely used in both healthcare and research. It has shown good performance in the general population, in general practice and in psychiatric patient populations (Bjelland, Dahl, Haug, & Neckelmann, 2002). Seven items are related to anxiety, e.g. 'I feel tense

or wound up' and 'I get sudden feelings of panic'. Seven items are related to depression, e.g. 'I can laugh and see the funny side of things' and 'I have lost interest in my appearance'. Each item was scored from 0 to 3, yielding one score for anxiety (HADS-A) and one for depression (HADS-D), both ranging from 0 to 21. For both scales, a cut-off of 8 is recommended for case-finding purposes in clinical settings (Bjelland et al., 2002). Cronbach's alpha was 0.81 for HADS-A and 0.81 for HADS-D.

Perceived benefit from the intervention. In the follow-up survey, in addition to the above scales, parents were asked to indicate the perceived benefit of the following aspects of the intervention: knowledge about the diagnosis, knowledge of available support measures, sharing experiences with other parents, meeting other children with the same diagnosis as one's own child, extending one's network, finding strategies to cope with daily life, finding strategies to handle contacts with service providers, finding strategies to handle contacts with school, finding strategies to handle other contacts with society and greater confidence in one's own parenting. The parents indicated their level of agreement on a 4-point scale: 1 (not at all), 2 (slightly), 3 (fairly) and 4 (fully).

Results

There were differences between the group of parents who responded to both the baseline and the follow-up surveys and the group that only responded to the baseline survey. Parents who responded to both surveys were more likely than those who did not return their follow-up survey to have a child with narcolepsy and more likely to have more than 12 years of schooling.

In relation to the first aim, regarding effects of the intervention, only fathers' responses indicated a change over time, i.e. fathers' empowerment and child-related marital stress increased between the baseline and follow-up surveys.

In relation to the second aim, regarding mother-father differences, it was observed that at baseline, mothers reported higher levels of parenting stress, depressive symptoms and anxiety. No difference was found for empowerment.

In relation to the third aim, regarding whether socio-economic status, parent gender or depressive symptoms predicted differences in effects of the intervention on the parents, hierarchical multiple regression was used to predict follow-up empowerment. Socio-economic status, parent gender and baseline depressive symptoms did not account for variation between parents when baseline empowerment was controlled for.

In relation to the fourth aim, regarding whether parents found the intervention beneficial, their highest ratings were given to the items: 'Sharing experiences

with other parents', 'Meeting other children with the same diagnosis' and 'Increased knowledge about the diagnosis'. A majority of participants agreed to the highest degree with the statements about the benefit of these intervention features.

Discussion

The general aim of the three studies was to investigate challenges that may affect parents of children with disabilities, and to evaluate an intervention for families of children with disabilities. Both Studies I and II indicate that, at group level, parents of children with disabilities experience additional strain compared with the general parent population. Replicating a substantial body of research, mothers of children with disabilities included in Study I reported more symptoms of depression than fathers. Both Studies I and II indicate that parents of children with disabilities are more exposed to child behaviours that may be difficult for parents to handle, and those child behaviours are associated with a higher likelihood of using harsh parenting practices. In Study I, the presence of child disability was associated with higher parenting stress, measured using questions about negative impact on the family's social life and negative feelings towards the child with a disability. In Study II, parents of children with DD were more likely than control parents to report severe behavioural problems in their child. Study III did not include a control group and therefore the association between child disability status and well-being could not be tested. However, the participants in Study III perceived the family intervention as helpful, and an increase in empowerment was observed in fathers between the baseline measurement and the follow-up measurement three months after the intervention.

In the introduction of the present text, Olsson's (2008) model of risk and resilience factors was used to provide a basic conceptual framework. The three empirical studies in the current thesis mainly address what the model refers to as child- and disability-related factors and socioecological factors. Taken together, the results of the studies emphasise that the child- and disability-related category in Olsson's (2008) model is relevant in explaining individual variations in parental well-being, but also that socioecological factors including financial resources and spouse relationship are of importance.

The results are compatible with a transactional process perspective on parental adaptation. In Study I, marital quality and co-parenting quality displayed as-

sociations with individual well-being, and previous research suggests that these links may be bidirectional, such that a person's psychological state is influenced by, but also shapes, the interactions with a partner (Whisman & Uebelacker, 2009). In Study II, children's display of behavioural problems was predictive of their parents' use of harsh parenting practices. The study used a cross-sectional design and did not measure change in variables over time, but again, there is evidence from the existing literature to suggest that child behaviour problems and parents' harsh parenting may form a vicious cycle (Emerson et al., 2011).

Elucidating and influencing these circular processes in families would be helped by a deeper understanding of how parents appraise a situation and the resources available to cope with it. None of the three studies considered variables belonging at the intrapersonal level of Olsson's model, such as parent personality, optimism or coping styles. These are variables that may moderate the relation between risk factors and parent adaptation and, thus, could explain additional individual variation (M. B. Olsson, 2008).

Gender in relation to parenting a child with a disability

In all three studies, a pattern of gender differences that mirrors findings in the existing literature was found. These group-level differences imply that in a heterosexual parent couple raising a child with a disability, there is a higher probability of observing negative consequences for the mother than for the father.

In Study III, mothers reported higher baseline levels of parenting stress, depressive symptoms and anxiety than fathers. In Study I, the presence of a child with a disability was a risk factor for individual well-being, but only when combined with female parent gender. Gender differences in depression in the general population is well known from previous research (Kessler, 2003), but the results from Study I suggest an interaction effect between parent gender and child disability status. This could reflect a pattern where women are more affected than men by strain related to childrearing, such as child disability. In a similar vein, the regression models tested in Study I were better at predicting mothers' well-being than fathers', replicating the findings of Hughes et al. (2004). This might reflect mothers' greater responsibility for childrearing and family, which could make them more vulnerable than fathers to negative effects of lacking support from the child's other parent.

Care work and responsibility for children are highly gendered domains. Even in Western societies such as Sweden, with a strong gender equality discourse,

traditional gender role ideologies still constrain women's ability to combine motherhood with other important roles. The fact that men, as a group, shoulder a disproportionately small share of the burden of care for their children is legitimised to the point of being normative (Bianchi & Milkie, 2010). Since the Second World War, Western women have entered the labour market on a large scale. In today's Sweden, women and men have virtually the same employment rate, but in most heterosexual couples with children, women continue to take care of most of the activities associated with the children and the household (Statistics Sweden, 2012). Arlie Hochschild (1997) coined the term *the second shift* to illustrate how a women's workday does not end when she comes home from work.

Thus, the conflict between work and family roles and the difficulties of negotiating work aspirations, personal fulfilment, couple relationship and child care demands are often more pronounced for women. However, it seems that this is even more the case for mothers of children with disabilities. In a previous Swedish study, there was a gendered impact of a child's disability on the parents, as it affected mothers' labour market participation and time for herself to a much larger extent than fathers' ditto (M. B. Olsson & Hwang, 2003). The unequal distribution of care work is likely to persist even when the child becomes an adult and is in continued need of support (Rowbotham, Carroll, & Cuskelly, 2011). The prevailing ideology of motherhood sets the expectation that a mother is the one who is ultimately responsible for her child's well-being, and that she should at all times put the needs of her child above her own (Christopher, 2012). It could be expected that this pressure is intensified when the child is perceived as vulnerable, for example due to a disability. As mothers of children with disabilities, women may have to justify their choices in relation to the idealised role of a selfless carer and ever-ready advocate for the child's needs. When identified as the one ultimately responsible for the child with a disability, mothers may also be more exposed than fathers to negative experiences of stigma associated with disability, as 'mothers work to reassert their child's personhood and their own identity as "good" mothers within a context that devalues both disability and themselves as mothers of a child with disability' (Knight, 2012, p. 665).

Study III indicates that after participation in the brief intensive family intervention, fathers reported higher child-related marital stress than before the intervention. This finding was puzzling as it ran contrary to the anticipated decrease in child-related marital stress. The related survey items include propositions about conflict and agreement about issues related to the child. Further-

more, in Study III, increased empowerment over time was observed in fathers, but not in mothers. A possible explanation for increased conflict could be that fathers who participate become more active in daily caregiving and service planning, and with increased involvement comes more opportunities for friction. Another possibility is that a shared understanding of the child's disability forces parents into a process of negotiating roles that were earlier assigned without explicit deliberation. The organisers of the intervention provided the author with stories about fathers who had left the intervention stunned by their realisation that they had up until then been oblivious to important aspects of the child's disability. Such instances of father unawareness are probably often compensated for by mothers' awareness, knowledge and sense of responsibility.

To connect again to the model of risk and protective factors proposed by Olsson (2008), the present results suggest that parent gender affects the way child- and disability-related risk factors impact individual parental adaptation. Firstly, some of these risk factors, such as burden of care, time demands and restrictions in life, may be different for two parents raising the same child as a consequence of gendered choices and practices in the household. Secondly, the impact of child- and disability-related risk factors on parental adaptation may be moderated by intrapersonal and socio-ecological factors that are themselves subject to gender differences. Cultural expectations on the role of the mother in the family likely influence women's self-image and appraisal of situations with their child.

Co-parenting

The view that the birth of a child with a disability must have tragic effects on the parents' couple relationship is not grounded in scientific observation. Study I found no group differences between the parents of children with disabilities and control parents in terms of marital quality and co-parenting quality. This adds to previous research where parents of children with disabilities have relationships that are as healthy and stable as those of a general parent population (Baker et al., 2005; Hatton et al., 2010; Lundeby & Tøssebro, 2008).

Even though the child's disability does not affect the couple relationship in any straightforward causal pattern, the couple relationship may be vital to the adaptation of parents of children with disabilities. The finding in Study I that co-parenting predicted prospective well-being better than all child- or disability-related variables included in the model suggests that the ability to maintain a positive relationship climate and good cooperation between parents is important

to the well-being of parents of children with disabilities. In a study of parents of preschool children with developmental disabilities, Plant and Sanders (2007) found that rather than child disability level, it was the difficulty of caregiving tasks and frustration with child behaviours that were associated with high levels of caregiving-related stress in parents. It could be hypothesised that such situations become easier to cope with when parents team up, validate each other's parenting efforts and look for solutions together. The finding in Study I, i.e. that co-parenting predicted parent well-being, may also be interpreted as a mirror image of previous research that found low levels of interpersonal support to be associated with high levels of psychological distress in mothers of children with autism (Bromley et al., 2004; Sawyer et al., 2010). These findings imply that the child's other parent has the potential to act as an important source of interpersonal support. Study I also points to the utility of studying marital quality and co-parenting quality as separate variables. Although closely related, these two concepts are theorised to capture different behaviours and cognitions in parents, behaviours and cognitions that may represent different dimensions of the interpersonal support that the child's other parent can provide.

The finding that co-parenting quality predicted prospective individual well-being for parents also underlines the applicability of a transactional perspective (Sameroff, 2009), in that intrapersonal and couple processes are intertwined. The parents' relationship also helps shape the emotional environment in which the child develops. Study I did not explore child behaviour or child-related parenting stress as outcome variables. However, there is evidence from family research to suggest that parents' couple relationship affects their parenting behaviour (Tanner Stapleton & Bradbury, 2012), and in a study of mothers of children with autism, researchers found that maternal psychological distress and lower life satisfaction were risk factors for later child behaviour problems (Totsika et al., 2013).

Harsh parenting

Just having a child with a disability does not mean that a parent will resort to yelling, spanking or similar behaviours. In Study II, child disability status did not predict harsh parenting practices. This supports the idea that it is not child disability in itself or associated parenting stress that leads to increased risk for harsh parenting. As pointed out in the literature (Sobsey, 2002), parental exhaustion does not seem to explain the increased vulnerability to negative parenting experienced by children with disabilities. Child behaviour problems, on the other

hand, was a predictor of harsh parenting in children with disabilities, which is in line with previous research linking child behaviour problems to a markedly increased risk for child abuse (Sullivan & Knutson, 2000). Of course, the present results are not enough to inform us on the causality of this association. There is evidence that harsh parenting practices increase the risk for child behaviour problems (Knerr, Gardner, & Cluver, 2013). Neece, Green and Baker (2012) also report a reciprocal relationship between child behaviour problems and parenting stress over time, but harsh parenting is only one of several possible mediators between parenting stress and child behaviour problems that they suggest. Even if it is hard to establish the causal direction of the association between harsh parenting practices and child behaviour problems, the present results indicate that when a child with a disability displays behavioural problems, there may be a heightened risk of exposure to harsh parenting, and clinicians should consider addressing the question of how parents handle difficult and stressful situations with their children.

A distinguishing feature of Swedish child-rearing practices is that corporal punishment is both illegal and denounced (Durrant, 2000). It can therefore be assumed that many acts of harsh parenting reported by Swedish parents are not premeditated but rather a result of the parent's inability to cope with a very stressful situation with the child. Therefore, the intrapersonal level of risk and resilience factors (M. B. Olsson, 2008) may be relevant in addressing the problem of harsh parenting in Sweden, for both scholars and support providers. Factors to consider for research and intervention include: parents' appraisal of the situation as a threat or as a positive challenge; parents' understanding of the child's disability and their interpretations of their child's behaviour as intentional or not; and whether parents' perceive themselves as competent or powerless.

When it comes to socio-economic circumstances, Studies I and II did not replicate findings from previous UK and US research on parents of children with disabilities. Study I found no difference in experiences of financial hardship attributable to the presence of a child with a disability in the family, and Study II did not show that socio-economic disadvantage predicts higher use of harsh parenting strategies.

There are differences between Sweden and the US, where much of the existing research on harsh parenting practices has been conducted, and these may partly explain the lack of findings to support an association between socio-economic adversity and harsh parenting. One important difference is the number of children born to young mothers as a result of an unintended pregnancy, where in 2012, 29.4 children were born to every 1 000 teenage girls in the US

(Centers for Disease Control and Prevention, 2014), while the corresponding figure for Sweden in 2011 was around 6 per 1 000 teenage girls (Folkhälsomyndigheten, 2014). Children born to teenage mothers are more likely to live under unfavourable socio-economic circumstances, and the men who father children of young mothers are less likely to be actively involved in parenting responsibilities and offer support to the mother. Furthermore, low maternal age is in itself a factor that increases the risk that the mother will use harsh parenting practices (Lee, 2009). Another difference between societies lies in the occurrence of poverty. The proportion of children who grow up in poverty is substantially higher in the US than in other industrialised Western countries, including Sweden (National Research Council [US] & Institute of Medicine [US], 2013). The studies presented in this thesis could thus be said to have a restriction of range problem compared with US studies, as they do not include data from families comparable to the poorest in population-based US samples. Besides structural differences in the distribution of wealth in society, there are differences related to the effects of child disability on families' financial situation. In Sweden, support to children with disabilities is provided free of charge with few exceptions. If families were to cover the expenses for medical treatments and habilitation programmes, their economic situation would be drastically affected. It may therefore be that the process where increased economic hardship leads to less involved and nurturing parenting (as outlined by Conger & Donnellan, 2007b) is less applicable to understand the effects of child disability on Swedish families.

Interventions for parents of children with disabilities

The evaluation of a brief intensive family intervention in Study III did not yield evidence of changes in parents' levels of parenting stress, depressive symptoms or anxiety. However, there was a slight positive change in fathers' empowerment over time. The other outcome measures used in Study III, i.e. depressive symptoms, anxiety and parenting stress, are adaptation measures that are not directly associated with the content of the intervention. Empowerment, on the other hand, encompasses abilities and attitudes that are more closely related to the intended goals of the intervention, namely parent competence and self-efficacy. This echoes a common finding in medical research, namely that outcome measures that are conceptually distant from the actual treatment are more affected by uncontrollable confounders and present smaller changes (Brenner, Curbow, & Legro, 1995).

Based on Olsson's (M. B. Olsson, 2008) model of parental adaptation, it could be argued that the intervention did not have parental adaptation as its primary goal. Rather, the intervention addressed problem-solving skills and self-efficacy, which are protective factors for parental adaptation that belong to the area of intrapersonal factors. Therefore, parental adaptation outcomes can be anticipated as secondary, rather than primary, effects of the intervention. Previous research on interventions for parents of children with disabilities suggests that secondary effects are generally small (IASSIDD, 2012).

An important result from Study III was that parents reported that the intervention had increased their knowledge about the diagnosis in ways that were useful to them. This suggests that even a brief intervention can be beneficial for parents of children with disabilities. Parents also appreciated meeting other families where a child had the same diagnosis. This adds to the evidence that sharing experiences with other families in a similar situation may provide unique benefits to parents of children with disabilities (Davies & Hall, 2005; Shilling et al., 2013). Since the parents participating in Study III had children with rare diseases, they most likely had even more limited access to other families with similar experiences than parents of children with disabilities of more prevalent types. The intervention may therefore serve to facilitate the development of informal networks where parents provide social support to each other.

Implications for practice

The studies presented in this thesis illustrate that the risk and protective factors that affect parents of children with disabilities do not exist as independent entities exerting unidirectional causal influence on the family as a developmental environment for the child. Rather, the present findings support the idea that these factors are interconnected and have to be considered together.

Parents' couple relationship and psychological support

The associations between individual well-being and couple variables, i.e. marital quality and co-parenting quality, suggest that problems in the couple relationship between the parents or in their mutual confidence and ability to cooperate around childrearing should not be left unattended. Regardless of what causes what, low marital quality serves as an indication that parental well-being may be at risk and that in turn there may be negative consequences for the child with a disability. The findings also serve as a reminder to practitioners that couples who raise a child with a disability are not distinctively different from others; just

because child disability has consequences for the family, it is not the sole determinant of parents' adaptation and emotional well-being.

In a survey on support to parents of children with disabilities in western Sweden, both professionals and parents described a lack of preventive psychological support for parents, including couple counselling (Broberg et al., 2014). A lack of appropriate services to carers of people with disabilities is noted in a report by the Swedish National Audit Office (2011), despite a 2009 change in legislation that makes delivery of such services mandatory for Social Services. In theory, the support system should be family centred and tailored to suit the whole family so that the parents can provide for the needs of the child with a disability. However, there seems to remain obstacles to parents' access to interventions that are not directly related to the child's diagnosis, such as couple counselling.

As noted in the introduction and in Study I, the concept of co-parenting provides a fruitful tool to operationalise the quality of those aspects of the parents' relation that pertain to their shared care of the child. Since parents of children with disabilities have divorce rates comparable to those of other parent couples, many of them live apart but have joint responsibility for the child's care. Whether or not the parents live together, raising a child with disabilities often puts high demands on their communication, cooperation and organisation of everyday activities. Parents of children with disabilities who have a strained co-parenting relation should be offered assistance in establishing a working partnership where the child's needs are the main priority.

Identifying and preventing risk for harsh parenting practices

To identify circumstances where children may be at risk for harsh parenting practices, it is important to address situations where parents experience heightened stress and frustration stemming from their child's behaviour. Further, the parent's appraisal of the situation must be explored, as instances where the child's behaviour is construed as intentional and controllable may imply an increased risk for parent hostility (Helton & Cross, 2011). If parents perceive themselves as powerless and underprepared for meeting the situations with positive disciplinary behaviour, they may resort to physical force or otherwise harsh strategies in their efforts to control the child's behaviour.

Consistent with previous research (e.g. Sullivan & Knutson, 2000), Study II indicated that children with disruptive behaviour problems were at higher risk of being exposed to harsh parenting practices. Therefore, in meetings with parents rearing a child with any of the diagnoses commonly associated with child behav-

their problems, attention should be given to the available disciplining strategies and their efficacy. Reflecting with parents on the chain of events leading to situations where they need to manage their child will also be helpful, as it may affect their interpretation of the child's behaviour, leading them away from attributions of hostile intent on the part of the child, attributions that increase the risk for harsh parenting (Del Vecchio, Pochtar, & Rhoades, 2014).

Professionals should acknowledge the challenges that exist in families and assist parents in finding constructive alternatives when their repertoire of positive disciplining strategies is exhausted. One possibility to discuss with parents lies in the various parenting support interventions that are delivered by schools, social service agencies, and child and adolescent psychiatry clinics. A national evaluation of the programmes Cope, Komet, Connect and The Incredible Years showed that parents who participated displayed decreases in stress, depressive symptoms and negative reactions to child behaviour, and in addition child behaviour problems diminished (Socialstyrelsen, 2014). Although the programmes are primarily designed for children with conduct problems or attention deficit disorder, they have showed positive effects for families of children with autism or learning disabilities (Kleve et al., 2011).

Parents' behaviour towards their children in emotionally demanding conflict situations is a delicate matter, the exploration of which must be carried out respectfully without intrusion and judgment, as there is a sense of taboo surrounding these issues (Svensson et al., 2013). One may hypothesise that feelings of shame, guilt and failure in parents who resort to harsh parenting practices are accentuated in societies like Sweden, where the public discourse on disciplinary violence is almost unequivocally condemning. Therefore, professionals have a responsibility to break the silence about harsh parenting practices in a non-judgmental manner. Otherwise they may fail to protect children with disabilities from physical and emotional abuse. However, habilitation professionals experience difficulties in bringing up suspected abuse with parents or reporting it to social services, especially when their team colleagues disagree on what action to take (Mallén, 2011). Service provision organisations may need to improve support to their staff in decision-making processes, e.g. by providing reflective supervision, so that they are guided by the best interests of the child only. One way to facilitate asking parents about negative parenting practices might be to promote the use of standardised instruments such as the Brief Child Abuse Potential Inventory (BCAP; Ondersma, Chaffin, Mullins, & LeBreton, 2005).

Improved prevention of harsh parenting and child maltreatment relies on raised awareness among professionals of the increased risk that children with

disabilities are exposed to. By acknowledging and addressing this risk in activities such as parent education groups, professionals can help create a climate where parents feel that negative parenting practices are not a taboo subject.

The importance of other parents

Other parents in similar situations represent an important source of informal support for parents of children with disabilities, as suggested by Study III. The presence of other parents can provide a source of experience-based knowledge and emotional support, decrease parents' feelings of isolation and provide an environment where they feel that their families are 'normal' (Davies & Hall, 2005; Kerr & McIntosh, 2000; Shilling et al., 2013). Parents of children with disabilities generally prefer homogenous parent support groups, where they meet parents of children with the same diagnosis as their own (Broberg et al., 2014). Professionals should be aware of the unique benefits parents can derive from meeting others whose experiences and challenges are similar to their own, and may assist them in finding or forming peer support networks.

Coordination of support

Children with disabilities require the services of a wide range of professionals, representing authorities at the municipal, regional and national levels. Parents often feel overwhelmed as they negotiate multiple service delivery systems and struggle with service fragmentation and inefficiency. When services are insufficiently integrated and coordinated, access to needed resources and appropriate support is stifled. Service coordination is a prerequisite for the efficient delivery of support to children with disabilities and their families, and improved coordination is crucial to enable service development according to the implications for practice provided above. Well-coordinated services form helping networks where recipients are linked to services (Trute, Hiebert-Murphy, & Wright, 2008), which reduces the risk that certain family needs fall between the cracks because of organisational boundaries between service providers. With tighter cooperation between educational, health care and social service systems, professionals will hopefully feel more confident in reporting suspected abuse and helping parents get access to preventive family support services.

Limitations and methodological considerations

All three presented studies are limited by relatively low response rates and small sample sizes, resulting in reduced statistical power. This poses a problem especially in cases where the findings do not support the hypotheses, since power could be expressed as the probability of detecting an effect that is actually present. The lower the statistical power, the higher the risk of a true effect hiding behind a nonsignificant test result. As a generally accepted rule, the power level should be at least 80%. A crucial parameter when reasoning about statistical power is expressed by the question ‘what is the smallest true effect that we can accept to fail to detect?’ The answer is given as an effect size, such as Cohens d , which expresses the difference between two group means, not in absolute numbers, but in relation to the observed variation of the variable.

In Study I, it was hypothesised that parents of children with disabilities would report lower marital satisfaction than control parents. Assuming that failure to detect effects smaller than $d = 0.5$ (an effect size threshold often used as a rule of thumb for ‘medium’ effects) can be tolerated, at least 64 participants would be needed for each one of the two groups in order to achieve 80% power (Soper, 2017). With 104 parents of children with disabilities, and 319 control parents, this particular null result could then be interpreted as not caused by insufficient sample size.

Study II made a similar comparison between groups as Study I, and would also need 64 participants in each group to detect a difference with a ‘medium’ effect. However, only 44 parents of children with disabilities participated, so the finding that there was no difference in the use of harsh parenting practices between parents of children with disabilities and control parents should not be interpreted as an indication that no such difference exists. Instead, the null result in Study II could be contrasted with the amount of evidence in the existing literature suggesting an elevated risk of maltreatment for children with disabilities, both in Sweden and elsewhere (Sullivan, 2009; Svensson et al., 2011).

For Study III, a determination of the power of the pre-post test is difficult, since an estimate of the variance of the change score is needed for each outcome measure, and previous data for psychological empowerment measured repeatedly at 3-month intervals was not available, to the researchers’ knowledge. With a lack of prior knowledge about the study variables from similar research, one can utilise precomputed tables that provide rules-of-thumb for various designs. A statistics handbook reports that for a related samples t-test, 80% power

to detect a medium effect size ($d = 0.5$) requires a total sample size of 34, and 80% power to detect a small effect size ($d = 0.2$) requires one of 200 (Wilson & Joye, 2017, p. 373). Study III had 124 participants. Thus, presuming that the assumptions made by Wilson and Joye also hold for the variables in Study III, setting the power level at 80%, Study III was able to detect a change over time representing an effect with a size above a limit located somewhere between $d = 0.2$ and $d = 0.5$.

Post-hoc power calculation is the practice of entering observed data into formulas for calculating the power of a test, thus giving an estimate of the power of a statistical test after the fact. While this may seem attractive to the researcher, it has been heavily criticised by statisticians, especially when used with data from tests yielding null results (Levine & Ensom, 2001). Since power is mathematically directly related to the p -value, the calculation of power using the same data that was used to obtain a p -value does not produce any new information (Hoenig & Heisey, 2001). Simply put: if the result was statistically non-significant, there was not enough power.

To increase the sample sizes and statistical power, the recruitment process needs to acknowledge and anticipate a low response rate, and a substantial over-recruitment is probably warranted. However, the sample size should not be excessively large, as this is a misuse of resources and of participants' time. The sample size required is related to statistical power, which in turn is related to the desired detectable effect size. How big must a difference or a change be to be meaningful, cost-effective or relevant to the population studied? A discussion of what constitutes a clinically relevant effect size is needed, as this may vary between the variables studied (Keefe et al., 2013). Given that the variables in Studies I–III are all related to individual well-being, it could be argued that changes or differences must be discernible by the persons involved in order for them to be of scientific interest.

The low response rate further raises the question of recruitment bias. In Study II, the parents who agreed to participate in the web survey were better educated than those who declined. In Study III, a similar difference in education level was found between participants who dropped out after the baseline survey and those who went on to complete the follow-up survey. However, the association between attrition rate and data bias is contingent upon a correlation between attrition propensity and the estimated variable. In other words, attrition is only a problem when the factors that cause participants to drop out also would affect their responses. Education level could be assumed to influence not only willingness or ability to respond, but also survey responses, e.g. on empower-

ment. In a Finnish study (Vuorenmaa, Halme, Åstedt-Kurki, Kaunonen, & Perälä, 2014), parents' education level was associated with their reported behaviour, knowledge and attitudes related to negotiating the service system and advocating for their child.

Another limitation concerns the inclusion of a very wide range of intellectual, developmental and physical disability diagnoses in the present studies, and moreover they lack measurements of the presumably wide variation in communicative and cognitive abilities that can exist even within diagnostic groups. Treating all parents of children with disabilities as one group may obscure variation between families that is attributable to differences in the children's conditions. On the other hand, grouping parents according to their children's diagnosis would yield much smaller samples. A trade-off solution would be to treat the parents as one group but include an overall measure of the degree of the child's impairment as a control variable in the statistical analyses. One such measure has been devised by Wendelborg and Tøssebro (2008) and is a sum of the parent's ratings of severity of impairment, visibility of impairment, expressive communication, language comprehension, restrictions in mobility and need of assistance during meals. A strength of Study I and II, however, is the inclusion of parents' reports of behavioural problems in the child, since the presence of such problems is the variable most strongly associated with parenting stress in previous research (Plant & Sanders, 2007; Totsika et al., 2011).

All studies rely on self-report data from parents only. When parents are expected to report on their child's behaviour, or their own for that matter, an extra layer of interpretation is present but out of the researchers' control. In a European study of children with cerebral palsy and their parents (White-Koning et al., 2007), parents and children only agreed to 25–40% in most domains in their responses to items concerning the child's health-related quality of life. Self-report data may also be mood-state dependent, which reduces reliability. Responses to questions on marital quality or severity of a child's behavioural problems may be influenced by the parent's psychological state in the minutes during which he or she completes the survey. As an example of the consequences, associations found between self-reported parental depression and parent-reported child behaviour problems could be an effect of either actual behavioural mechanisms in the family or depressed parents judging their child's behaviour as more problematic. When different variables are measured using the same method, systematic measurement error may introduce spurious relationships between them, and such *common method variance* is a potential threat to validity (Podsakoff, MacKenzie, Lee, & Podsakoff, 2003).

Improved validity can be achieved through the use of multiple informants or by means of observational methods. Children are surrounded by adults in their daily life, and these individuals can provide additional data beyond parents' reports. Several instruments exist in separate teacher and parent versions, where items describe behaviours likely to occur in a school or home setting, respectively. For child behaviour problems, there are observational measures such as the Disruptive Behaviour Diagnostic Observation Schedule (DB-DOS; Wakschlag et al., 2007), where children are observed during structured activities in a laboratory setting. However, a possible obstacle to the use of such standardised methods for research on parents of children with disabilities is that children with disabilities may have impairments that affect their ability to understand the situation as intended, engage in the assigned tasks or perform the behaviours that are scored.

The issue of self-report versus observation also comes into play when considering the subject matters of the studies in the current thesis. All three are concerned with family interaction or interaction between parents and professionals. Study I investigates associations between child behaviour, marital or co-parenting relations and parental individual well-being. Study II focuses on parents' use of certain parenting practices. Study III explores parental empowerment, which does encompass attitudes and feelings, but also change-oriented behaviours and interactions with professionals. Moreover, one of the findings in Study III suggests that child-related marital stress increased over time. In each study, human interaction is at the core of the investigated processes, and it could be argued that observation, in either a laboratory or a naturalistic home environment, would yield a more accurate and rich account of this interaction than self-reported survey data. Indeed, there is evidence to suggest that researcher observation of a child's disruptive behaviour during a laboratory visit can add unique variance, beyond reports of child behaviour collected through clinical interviews with the mother, to the prediction of the child's global level of functioning (Wakschlag et al., 2007). However, in some cases, observational methods may be more sensitive than self-report surveys to different types of bias. The researcher's presence, or the laboratory setting, may influence children's and parents' behaviour in unintended ways. It could be hypothesised that parents' display of harsh parenting practices might be moderated by the presence of an observer, and perhaps this social desirability bias is stronger with a researcher in the room than in the case where the parent ticks a box in an anonymous survey. The use of observational methods is expensive and time-consuming for both researchers and participants, and in practice the sample size must often be re-

duced, with lower statistical power as a consequence. Judicious use of observational methods involves identifying which study variables should be selected for direct observation and which can be measured using less labour-intensive methods.

Although the present studies capture some aspects of socio-economic disadvantage, they do not measure other types of unmet resource needs, including respite care, personal assistants and appropriate schooling for the child, which may be of utter importance to parents of children with disabilities. The relative importance of such non-financial needs may be especially big in a country like Sweden, where the economic inequality is relatively small and there is free access to health care. The Family Needs Survey (FNS; Krauss, 2000) is a tool that is used to assist in the drafting of service plans, but it has also been used by researchers to measure families' level of functional needs. Although qualified care and support services are available for Swedish children with disabilities, the problem of insufficient service coordination persists and gives rise to inequalities between families (Riksrevisionen, 2011). When asked open-ended questions, parents often point at overwhelming difficulties in negotiating multiple service providers within a fragmented system as a key cause of exhaustion and worry (Broberg et al., 2014). Trute and colleagues (2008) identified a subscale of the FNS referred to as *resource acquisition needs*, which they found useful as a family outcome measure in studies on family-centred service coordination. The researchers found that higher family-centredness in mothers' ratings of their service coordinator predicted reductions in the need for acquisition of psychosocial resources over time. The studies in the present thesis would likely be improved by the incorporation of a measure such as the resource acquisition needs subscale of the FNS. There is a possibility that frustrated access to psychosocial resources for the family, compared with socio-economic disadvantage, better explains the observed variation in parental adaptation.

A limitation of all studies in the current thesis is that many of the variables used to conceptualise parental adaptation are focused on the negative, rather than positive, experiences and behaviours that may occur in parents of children with disabilities. It could be held against the studies that they are not unmarked by the focus on pathology that continues to dominate the research field. As an attempt at a remedy to this problem, Study I used a modified depression scale, the BDI-2r, where the continuum has been extended with emotionally positive items that are scored with negative depression points. However, there is a debate as to whether positive and negative affect really are poles on the same axis or rather represent independent dimensions (Reich, Zautra, & Potter, 2001). As

mentioned in the introduction, parents of children with disabilities may experience strong positive and negative emotions at the same time (Blacher et al., 2013). In spite of this, a set of standardised, well-known instruments of stress, depression and anxiety continue to be used by researchers. One way to acknowledge the possible degree of independence between well-being and pathology is to have parents respond to both types of instruments. Glidden and colleagues (2006) incorporated both a depression scale and three different subjective well-being questions, e.g. 'how do you feel about how things are going right now?', rated by parents on a Likert scale ranging from 'delighted' to 'terrible'. As a more recent example, in a study of parents of persons with disabilities, Fianco and colleagues (2015) employed an even wider range of measures, which besides perceived burden and depression also included the Satisfaction with Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985), the Positive and Negative Affect Schedule (PANAS; Watson et al., 1988) and the Eudaimonic and Hedonic Happiness Investigation (EHHI; Delle Fave, Brdar, Freire, Vella-Brodrick, & Wissing, 2011). Of special interest in the context of this discussion is their finding that the best predictor of perceived burden was life satisfaction, whereas depression-related emotions did not contribute significantly. This serves to reinforce the notion that measures of subjective well-being can add crucial information about parental adaptation beyond that provided by depression scales.

When interpreting the results of Study II, one must consider the possible effects of social desirability when responding to questions about harsh parenting practices. As discussed above, this may prove difficult to remedy through the use of observational methods. A national Swedish survey (Jansson et al., 2011), had 31% of parents admitting to rough handling such as pushing or shaking their child in the preceding twelve months. Although the measures are not directly exchangeable, the figure of Jansson et al. (2011) suggests that Study II may provide an underestimate of the prevalence of violence in the population of parents of children with disabilities.

Study II did not include data from several points in time, and the cross-sectional design does not permit conclusions about the direction of the association between child behaviour problems and harsh parenting practices in families of children with disabilities.

Study III did use both baseline and follow-up surveys, but changes over time cannot with certainty be attributed to the intervention due to the lack of a control group. This limitation is related to inherent difficulties in the study of rare diseases. Since the number of affected children is minuscule, an intervention

that recurs with a few years' interval can practically absorb the total population of affected Swedish children, ruling out the creation of a control group. An alternative approach would be to use a multiple baseline design. However, this would entail repeated measurements over time, significantly increasing the demands on the participants and thus probably causing an even higher attrition rate.

Future research

The current studies suggest a number of questions to be addressed by future research.

As suggested by Studies I and III as well as previous research, informal support acts as a protective factor for parent well-being. It would be of interest to include a variety of sources of informal support in the investigation of the adaptation of parents of children with disabilities, and also to study how informal support may moderate the link between risk factors and adaptation.

The role of formal support for the adaptation of parents of children with disabilities should also be taken into account. Parents of children with disabilities often have to maintain a large number of contacts with professionals and there is often poor coordination between support services (Broberg et al., 2014). In fact, the negotiations and advocacy activities necessary to get access to support can actually be so draining for parents they present a risk factor for parental adaptation (Green, 2007; M. B. Olsson, 2008). Therefore, satisfaction with specific interventions or professional caregiving practices may not be sufficient to capture the impact of the service system on families. Not only must each service provider do their job well; they must also work smoothly and in concert in order to give optimal help to families. This global assessment of the quality of a family's 'support network' may prove useful in explaining variations in parental adaptation, and a first step for researchers could be to operationalise the concept and develop of instruments to measure it.

The investigation of harsh parenting practices raises questions about what situations and specific child behaviours are associated with a heightened risk that parents resort to such behaviour. Future studies could further explore sequences of events that lead up to hostile behaviour toward children with disabilities, and how parents appraise and cope with stressful situations with the child. Given that the risk for child behaviour problems varies with child diagnosis, the use of less heterogeneous samples could help researchers identify challenges that face specific populations, such as parents of children with autism.

The analysis of the situations and behaviours that constitute harsh parenting practices could be more detailed than in Study II. The risk factors for hostile parent behaviour that have been identified in previous research suggest the possibility of different subgroups among parents susceptible to harsh parenting practices. Consider an example with two groups: In one, parents experience emotional distress caused by financial hardship and lack of social support. In another, parents display an authoritarian parenting style, transmitted over generations, paired with dysfunctional attributions of their child's behaviour. The risk for harsh parenting practices will likely be elevated in both groups, but the timing, intention and accompanying emotions of the behaviours that the parents engage in may differ.

In studies of interventions for parents of children with DD, researchers need to theorise the associations between active components and outcome measures. An important consideration is whether outcome measures are primary or secondary in nature. Variables that tap parents' overall psychological health may represent behaviours and cognitions that are not directly tied to the skills that the intervention aims to foster, but susceptible to influence by confounding factors. In research on parenting competence interventions, qualitative studies are a good first step to elucidate mechanisms of action and identify appropriate outcome measures for quantitative evaluations.

Svensk sammanfattning

Föräldrar till barn med funktionsnedsättning har inte sällan en vardag som innehåller fler källor till påfrestningar än andra föräldrar. Det kan vara svårt att få tiden att räcka till, omvårdnaden av barnet kräver ofta mer insatser från föräldrarna, och barnet kan ha beteenden som är svårare att hantera jämfört med andra barn. Omgivningen kan också vara en källa till stress. Föräldrarna kan möta fördomar eller negativa attityder till funktionsnedsättning, och måste ofta hålla ordning på och samordna ett stort antal vårdkontakter. Sammantaget ökar dessa påfrestningar risken för stress och stressreaktioner hos föräldrarna. Det kan i sin tur riskera att påverka föräldraskapet negativt. Sedan tidigare är det känt att föräldrar till barn med funktionsnedsättning löper ökad risk för försämrat psykiskt välmående, och att denna risk är särskilt tydlig för mammor. Det finns också tecken på att barn med funktionsnedsättning som grupp är mer utsatta för negativa föräldrabetenden. Även om föräldrar till barn med funktionsnedsättning som grupp är mer utsatta för stress, finns det dock stor variation mellan individer. Tidigare forskning har visat att föräldrar till barn med funktionsnedsättning har stort behov av information om sitt barns hälsa och utveckling och att få reda på vilket stöd samhället kan erbjuda. Studier visar dock att det kan vara svårt för föräldrarna att få dessa behov tillgodosedda. Särskilt svårt att få information är det om barnet har en sällsynt diagnos, som professionella många gånger saknar erfarenhet av och kunskap om.

Studie I hade som mål att utforska föräldrars psykiska välmående och aspekter av parrelationen. Två aspekter av parrelationen studerades: dels tillfredsställelsen i parrelationen, dels det som på svenska kan kallas samföräldraskap (eng. *co-parenting*) vilket avser en känsla av samarbete, ömsesidig respekt och förtroende mellan föräldrarna, allt med avseende specifikt på deras gemensamma ansvar för sitt barnet. Medan tillfredsställelse i parrelationen undersöker den romantiska relationen föräldrarna är begreppet samföräldraskap relevant även för föräldrar som är separerade. Föräldrar rekryterades med hjälp av habiliteringsmottagningar i sydvästra delen av Sverige. Personalen gav information

om studien till föräldrar som uppfyllde följande kriterier: man hade fått kontakt med mottagningen under det senaste halvåret, barnet var under tio år och hade fått diagnosen utvecklingsstörning och/eller autism. En enkät skickades ut och svar erhöles från 58 mammor och 46 pappor. Efter ett år skickades en uppföljningsenkät ut som besvarades av 46 mammor och 37 pappor. Dessa föräldrar jämfördes med en kontrollgrupp ur den allmänna befolkningen som bestod av 178 mammor och 141 pappor till barn under sju år. Resultaten visade att mammor till barn med funktionsnedsättning hade lägre psykiskt välmående än mammor i kontrollgruppen. Någon sådan skillnad visade sig inte för papporna. Det fanns ingen skillnad mellan föräldrarna till barn med funktionsnedsättning och kontrollgrupp gällande parrelationens kvalitet. De variabler som visade ett samband med psykiskt välmående var tillfredsställelse i parrelationen, ekonomisk utsatthet, föräldrarnas kön och huruvida barnet hade en funktionsnedsättning.

Studie II hade som mål att utforska föräldrars inställning till att använda hårda uppfostringsstrategier. Med detta avsågs beteenden som att slå barnet, ruska om det, nypa det, skrika åt det eller komma med hotelser. Med hjälp av socialtjänstens handläggare i Göteborg och två kranskommuner rekryterades föräldrar till barn med insatser enligt LSS (Lag om stöd och service till vissa funktionshindrade). Ett slumpmässigt urval av de föräldrar som hade barn med LSS-insatser kontaktades och erbjöds att besvara en webbenkät. Svar från 30 mammor och 14 pappor kunde användas till studien. Barnen var mellan 3 och 18 år gamla och de vanligaste diagnoserna hos barnen var autism, cerebral pares och Downs syndrom. Som kontrollföräldrar rekryterades 145 mammor och 25 pappor med hjälp av folkbokföringen. Dessa bodde i samma geografiska område och hade barn mellan 1 och 18 år. Föräldrar till barn med funktionsnedsättning fick som grupp inte högre poäng på frågorna om hårda uppfostringsstrategier. För att undersöka risken för våld, användes specifikt svaren på de frågor som handlar om att kunna tänka sig att vara hårdhänt mot barnet (slå, ruska om, nypa eller vrida om armen). Hos papporna till barn med funktionsnedsättning var det vanligare att svara något annat än "aldrig" (57%) än hos papporna i kontrollgruppen (24%). För mammorna fanns ingen sådan statistiskt signifikant skillnad. Det var fler av föräldrarna till barn med funktionsnedsättning som angav att deras barn hade allvarliga beteendeproblem (36%) än det var i kontrollgruppen (8%). Inom gruppen föräldrar till barn med funktionsnedsättning var större förekomst av beteendeproblem hos barnet relaterad till större benägenhet till hårda uppfostringsstrategier. Socioekonomisk utsatthet bidrog

dock inte till att statistisk förklara variationen i benägenhet till hårda uppfostningsstrategier inom denna grupp.

Studie III hade som mål att utvärdera föräldrars nytta av en familjevistelse riktad till familjer där ett barn har en sällsynt diagnos. Familjevistelsen hölls på Ågrenska, nationellt kunskapscentrum för sällsynta diagnoser, och dess syfte var att öka familjens kompetens att bemästra sin livssituation. Ungefär tio familjer åt gången deltog i interventionen som skraddarsys för varje specifik sällsynt diagnos. Under fem dagar följde föräldrarna ett program som innehöll föreläsningar och diskussioner om medicinska rön, psykosociala aspekter och samhällets stöd. Föräldrar erbjöds att besvara enkäter strax före respektive tre månader efter sitt deltagande i familjevistelsen. Enkäten innehöll frågor om föräldrarnas psykiska välmående och deras *empowerment*. Empowerment (ungefärlig svensk översättning: 'bemyndigande') betecknar attityder och beteenden som underlättar positiv förändring. Det handlar bland annat om tilltro till sin egen förmåga och kunskap, aktiva försök att påverka sin situation och en känsla av kontroll och kompetens. Efter-enkäten innehöll dessutom frågor om hur föräldrarna upplevt familjevistelsen. Svar togs emot från 81 mammor och 43 pappor. Dessa föräldrar representerade 100 enskilda barn, vars diagnoser var narkolepsi, dyskinetisk CP (cerebral pares), akondroplasi eller andra genetiska eller medfödda syndrom. Barnen var mellan 9 månader och 17 år gamla. Före insatsen rapporterade mammorna högre föräldrastress, mer oro och mer depressionssymptom, jämfört med papporna. En förändring i utfallsvariabler mellan före och efter insatsen kunde avläsas hos pappor, men inte hos mammor. Papporna angav högre empowerment och högre barn-relaterad stress i parrelationen tre månader efter insatsen, jämfört med strax före. Dessa förändringar var dock små. Föräldrarna rapporterade att insatsen var till stor nytta för dem och att det betydde mycket att få träffa andra föräldrar och andra barn med samma diagnos som deras eget, samt att få ökad kunskap om sitt barns funktionsnedsättning.

Sammanfattningsvis visar de tre studierna att föräldrar till barn med funktionsnedsättningar som grupp möter fler utmaningar än andra föräldrar, och att särskilt mammor löper en ökad risk för försämrat psykiskt välmående. Det är dock inte förekomsten av funktionsnedsättning i sig som ensamt förklarar variationen i välmående mellan föräldrar, utan ett samspel mellan olika faktorer. Föräldrar kan ha nytta av psykologiskt stöd för att hantera sin vardag och vårda sin parrelation. Föräldrar kan också behöva möjlighet att samtala om hur man kan hantera barnets beteende i påfrestande situationer. Utvärderingen av familjevistelsen på Ågrenska tyder på att föräldrar upplever stor nytta av en insats där de får relevant och tydlig information tillsammans med andra familjer. Detta

pekar på att man också i annat arbete med föräldrar till barn med funktionsnedsättningar kan tillvarata de positiva möjligheter som finns i möten mellan föräldrar som befinner sig i livssituationer som liknar varandra.

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