Experiences of Parenthood and the Child with an Intellectual Disability

Petra Boström

UNIVERSITY OF GOTHENBURG
DEPT OF PSYCHOLOGY

2012

© Petra Boström
Printed in Sweden by Ale Tryckteam
Department of Psychology
University of Gothenburg, 2012

ISBN 978-91-628-8591-5
ISSN 1101-718X
ISRN GU/PSYK/AVH--267--SE

Abstract

Boström, P. (2012). *Experiences of Parenthood and the Child with an Intellectual Disability*. Department of Psychology, University of Gothenburg, Sweden.

When a child is diagnosed with an intellectual disability (ID) the experience of parenthood is affected and parents' descriptions tend to vary, containing a wide spectrum of emotions that may change over time. In the present thesis, empirically-based knowledge about parents of children with ID and their particular circumstances in Sweden is described within the theoretical framework of Bronfenbrenners' ecological model (1977). The individual children and their closest relationships are at the centre of the ecological model, surrounded by spheres of environmental factors that interact with their development directly and indirectly. Parents are affected by the disability in terms of mental health as increased levels of stress and depression have been found among parents of children with ID. The impairment in parental mental health is not, however, simply explained by the severity of the disability or developmental delay, but is related to a number of risk and protective factors in parents and children. Parents' descriptions and experiences of parenthood are not only of interest from a mental health point of view. They also offer information about the parent's motivational system to provide care and protection for the child described within attachment theory (Mayseless, 2006a).

To explore the diversity of parents' experiences, the four studies presented in this thesis aimed to investigate parents' descriptions and experiences of their child with ID during five years from two different perspectives. In studies I and II, parents' descriptions of child temperament were analysed and explored in relation to positive and negative impact of the child. Results from studies I and II indicated that children with ID differ from typically developing children in terms of temperament. Two unique temperament profiles (disruptive and passive/withdrawn temperament) were found only among children with ID and turned out to predict negative impact on mothers. In studies III and IV, interviews with parents exploring their subjective experiences of the child and the parent-child relationship were analysed. Most parents in study III described their child in both positive (affectionate/loving) and negative terms, indicating a balanced experience of their child. In contrast, a few parents' narratives were more limited, offering a less nuanced picture. Experiences varied between acceptance of and preoccupation with the disability. Parent's narratives varied in time orientation in terms of tense and flexibility. In study IV, fathers explicitly described how receiving the diagnosis of the child had affected them as persons in the theme *an interrupted path - no longer taking things for granted.* Fathers mostly described themselves as *being a good father.* The process of integrating, managing and living with the insight of the child's diagnosis was described in the theme *dealing with the unexpected* containing the subthemes *vulnerable openness, contained openness,* and *avoiding the unexpected.*

The four studies show that children with ID constitute a highly heterogeneous group evoking equally diverse reactions from their parents. Results indicate that parents are affected by the variety in child temperament, and also by the support and constrains of their environments. The different perspectives may provide important information about parents' emotions towards and experiences of the child that may affect parents' well-being and parenting behaviour.

Key words: Intellectual disability, parents, fathers, family impact, temperament, risk and protective factors

---

Petra Boström, Department of Psychology, University of Gothenburg, Box 500, 405 30 Göteborg, Sweden. Phone: +49 31 786 4294, E-mail: petra.bostrom@psy.gu.se

List of papers

The dissertation is based on the following studies, which will be referred to by their Roman numerals in the text:

I. Boström, P., Broberg, M., & Hwang, C. P. (2010). Different, difficult or distinct? Mothers' and fathers' perceptions of temperament in children with and without intellectual disabilities. *Journal of Intellectual Disability Research, 54*(9), 806-819.

II. Boström, P. K., Broberg, M., & Bodin, L. (2011). Child's positive and negative impacts on parents - A person-oriented approach to understanding temperament in preschool children with intellectual disabilities. *Research in Developmental Disabilities, 32*(5), 1860-1871.

III. Boström, P. K., Broberg, M., & Hwang, P. (2010). Parents' descriptions and experiences of young children recently diagnosed with intellectual disability. *Child Care, Health and Development, 36,* 93–100.

IV. Boström, P. K., Broberg, M. (Submitted). Openness and Avoidance – A Longitudinal Study of Fathers of Children with Intellectual Disability.

Svensk sammanfattning

Att få barn och bli förälder kan innebära stora förändringar av livsituationen. Uppgiften att ta hand om ett litet barn kan vara krävande och leder ofta till att både livsstil och identitet påverkas. Att vara förälder innebär inte bara att vara en vuxen individ utan också att stå i särskilda relationer till andra individer och institutioner i samhället. Upptäckten att ens barn har ett intellektuellt funktionshinder påverkar upplevelsen av föräldraskapet, men också tankar och förväntningar kring barnets och familjens framtid. De fyra studier som ingår i avhandlingen avsåg att undersöka hur föräldrars tankar och känslor inför barnet och upplevelsen av föräldraskapet påverkas av att barnet har ett intellektuellt funktionshinder.

När föräldrar till ett barn med intellektuellt funktionshinder beskriver upplevelsen av sitt föräldraskap skiljer sig berättelserna åt sinsemellan och kan förändras över tid. Vid diagnostillfället och under den närmast tiden därefter, befinner sig många föräldrar i chock och kan exempelvis känna misstro inför eller förneka barnets diagnos. Även om känslorna inför barnet och diagnosen utvecklas och förändras efterhand, så fortsätter många av föräldrarna att ägna mycket tankar åt att hantera det faktum att barnet har ett funktionshinder då de fortsätter att möta nya utmaningar. Hos en del föräldrar, framför allt mammor till barn med intellektuella funktionshinder, påverkas den psykiska hälsan negativt. De är något mer stressade och deprimerade än föräldrar till barn med typisk utveckling.

Flera faktorer påverkar dessa föräldrars upplevelser. Exempelvis kan förälderns tidigare föreställningar om vad det kan innebära att vara förälder i denna speciella situation vara negativa. Dessa bilder och föreställningar är ofta påverkade av värderingar i samhället och de möjligheter till stöd som samhället erbjuder. Internationellt har man funnit att exempelvis ekonomiska svårigheter, vilka ofta drabbar familjer till barn med intellektuella funktionshinder på grund av extra kostnader och inkomstbortfall, kan leda till ökad stress. Egenskaper hos barnet och föräldern påverka också förälderns hälsa i både positiv och negativ riktning. Beteendeproblem är mer vanligt förekommande hos barn med intellektuella funktionshinder än hos typiskt utvecklade barn. Det finns en koppling mellan dessa svårigheter och den ökade stress och depression som deras föräldrar upplever. Förälderns personlighetsdrag såsom hög nivå av optimism och låg nivå av neuroticism, samt förmågan att acceptera den situation man befinner sig i, är faktorer som är relaterade till god psykisk hälsa i denna grupp.

I avhandlingen presenteras teorier och modeller för att integrera empirisk kunskap och förklara hur olika faktorer påverkar varandra. Bronfenbrenners ekologiska

modell ger en övergripande bild av hur medlemmar i familjen påverkas av olika risk och skyddsfaktorer, medan samspel mellan barn och förälder beskrivs inom ramen för anknytningsteori. Likheter och olikheter i beteende hos barn med och utan intellektuella funktionshinder beskrivs i termer av temperament.

Ett område som hittills studerats lite är hur föräldrars inre föreställningar av barnet påverkas av diagnosen. Däremot vet vi att föräldrars känslor och tankar inför typiskt utvecklade barn påverkar förälderns lyhördhet och beteende gentemot barnet, vilket är av avgörande betydelse för barnets utveckling och välbefinnande. Därför är det intressant att studera föräldrars inre föreställningar kring sina barn med funktionshinder. I fyra delstudier undersöks föräldrars tankar och känslor inför barnet och hur upplevelsen av föräldraskap påverkas av att barnet har ett intellektuellt funktionshinder. Studie I och II undersökte via enkäter relationen mellan barnets temperament och barnets positiva och negativa påverkan på föräldern. Studie III och IV undersökte mammors och pappors subjektiva upplevelser av barnet och föräldraskapet genom intervjuer.

I **studie I** fanns tre syften: 1) att undersöka skillnader och likheter i föräldrars skattningar av temperament hos barn med och utan intellektuella funktionshinder, 2) att jämföra föräldrars skattningar av barns temperament i olika diagnosgrupper och barnets påverkan på föräldern, 3) att utforska skillnader och överensstämmelser mellan mammors och pappors skattningar av temperament hos barn med och utan intellektuella funktionshinder. Mammor och pappor, till 183 barn med typisk utveckling och 55 barn med intellektuella funktionshinder i åldrarna 0-5 år, skattade sina barns temperament. Några av barnen hade dessutom diagnosen autismspetrumstörning, Downs syndrom, Cerebral Pares, motoriska funktionshinder eller andra mer ovanliga diagnoser. Formuläret EASI användes, vilket mäter barns negativa emotionalitet, aktivitetsnivå, blyghet, sociala förmåga och impulsivitet. Föräldrarna skattade också barnets positiva och negativa påverkan på föräldern. Barn med intellektuella funktionshinder visade sig vara mindre aktiva och sociala, och mer blyga och impulsiva än barn utan diagnos. Vad gäller emotionalitet fanns det ingen signifikant skillnad. Det visade sig också att barn med intellektuella funktionshinder påverkade sina föräldrar mer negativt och mindre positivt än barn utan diagnos. Skillnader i temperament och negativ påverkan fanns mellan olika diagnosgrupper, medan det inte fanns någon skillnad i positiv påverkan. Överensstämmelsen mellan mammors och pappors skattningar var hög både bland föräldrar till barn med och utan diagnos.

I **studie II** fanns följande syften: 1) att finna meningsfulla temperamentsprofiler bland barn med intellektuella funktionshinder, 2) att validera dessa profiler i relation till andra mått på barnens beteende, 3) att undersöka relationen mellan barns temperamentsprofil och positiv och negativ påverkan på föräldrar, 4) att jämföra temperamentsprofiler funna bland barn med och utan intellektuella funktionshinder. Mammor och pappor till 49 barn med och 82 barn utan intellektuella funktionshinder i åldrarna 4-6 år skattade barnens temperament och beteendeproblem, samt positiv och negativ påverkan på föräldern. I gruppen barn med diagnos formades tre kluster: *aktiv/utåtriktad*, *besvärlig* och *passiv/tillbakadragen*. Temperamentet hos barn med aktiv/utåtriktad profil liknade de kluster som fanns bland barn med typisk utveckling. De två klustren besvärlig och passiv/tillbakadragen utgjorde unika temperamentsprofiler som bara fanns bland barn med intellektuella funktionshinder. Barnets temperament verkar påverka föräldrar starkt, då barn med besvärligt temperament och beteendeproblem har mer negativ och mindre positiv påverkan på sin mamma än övriga barn.

Syftet med **Studie III** var att undersöka föräldrars beskrivningar och upplevelser av sitt barn som nyligen fått diagnosen intellektuellt funktionshinder. Åtta mammor och nio pappor till nio barn med intellektuellt funktionshinder (varav några hade en mer specifik diagnos) intervjuades om sitt vardagsliv med barnet. Intervjuns innehåll och berättarstil analyserades. I alla intervjuerna fanns tre gemensamma teman; 1) *känslor inför barnet* – som varierade mellan balanserat (både positiva och negativa känslor) och begränsat (övervägande positiva eller negativa känslor), 2) *upplevelsen av funktionshindret* – som varierade mellan upptagenhet och acceptans, samt 3) *tidsorientering* – tidsmässig flexibilitet eller huvudfokus på dåtid, nutid eller framtid hos varje förälder. Resultaten från studie III visar att föräldrars syn på sitt barn med ett intellektuellt funktionshinder påverkas negativt av diagnosen, men att de flesta föräldrar också har starkt positiva känslor och upplevelser i relation till barnet som tycks balansera upp de svårigheter som diagnosen medför. Det är inte ovanligt att en förälder bär på motsägelsefulla känslor och å ena sidan älskar barnet precis som det är, men å andra sidan önskar att barnet skall botas från funktionshindret. Att de flesta föräldrar var upptagna av diagnosen är inte överraskande med tanke på att de nyligen fått veta sitt barns diagnos.

Studie IV undersökte pappors upplevelser av föräldraskap och barnet med intellektuellt funktionshinder under fem års tid. Samma pappor som deltog i studie III intervjuades första gången när de fått reda på barnets diagnos och ytterligare två gånger under de följande åren. Syftet var att undersöka 1) hur pappors upplevelser utvecklas över tid från diagnos och fem år framåt, 2) hur pappor tillskriver mening till upplevelsen av att vara förälder till ett barn med intellektuellt funktionshinder, 3) hur pappors upplevelser kan förstås ur ett teoretiskt perspektiv. I pappornas berättelser fanns tre teman: *en avbruten väg - att inte längre kunna ta saker för givet*, *att vara en bra pappa*, samt *att hantera det oväntade*. Det sista temat innehöll tre underteman: *sårbar öppenhet*, *behärskad öppenhet* och *undvikande av det oväntade*. De flesta pappor beskrev hur deras sätt att förhålla sig till oväntade upplevelser som var relaterade till diagnosen förändrades över tid. Flera pappor reagerade till en början på den känsla av avbrott som barnets diagnos orsakade med en sårbar öppenhet eller försök att undvika det oväntade. En behärskad öppenhet blev mer framträdande i de senare intervjuerna. Ett undvikande förhållningssätt till svårigheterna verkade sammanfalla med en viss distans i relation till barnet om en nära relation inte byggts upp före diagnostillfället. Känslan av att vara en bra pappa fanns återkommande hos alla pappor.

Resultat från de fyra studierna klargör och stärker ytterligare förståelsen för hur föräldrar upplever och påverkas av att ha ett barn med intellektuellt funktionshinder. Egenskaper hos barnet, som kan vara relaterade till diagnosen, men som också påverkas av det bemötande barnet får från sin omvärld, är viktiga faktorer som påverkar förälderns vardag. Dessutom är förälderns möte med samhället genom olika nära eller mer avlägsna relationer av stor betydelse för hur det specifika föräldraskapet kommer att upplevas.

Acknowledgements

Without the contribution and support from many people, the writing of this dissertation would not have been possible. I sincerely hope that you will all know that I think about you with genuine gratitude even though only a few will be mentioned by name.

I would like to thank all the parents, who participated in the Vafoo project, for communicating their perspectives on parenthood despite being busy parents of infants or young children.

I would like to express my sincere gratitude to my two supervisors: Associate Professor Malin Broberg; thank you for believing in me and always encouraging me to keep going! I would like to thank you especially for all the support you have granted me on my long journey over these years which has sometimes included challenges other than just research and writing. You are both a great role model on how to balance work and family, and a friend! Professor Philip Hwang; thank you for guiding my work with great commitment and interest! You have always examined my work thoroughly with great competence, offering both criticism and encouragement, all which I believe has been important to improve my research and to shape my way of thinking.

I would like to thank all the wonderful people in the Department of Psychology who make me feel at home by offering their friendship and support - always willing to listen and discuss ideas. I am especially grateful to my friends who have been there with me all the way! Leif, Jan, Jesper and others who have helped me resolve methodological problems – thank you for your generosity!

I would also like to express my gratitude to Professor Mats Granlund for carefully reviewing this dissertation and for suggesting valuable improvements.

To my parents, Anders and Kristin, for making me believe that it is always worth trying, and for listening and discussing ideas with me. Many thanks!

I am particularly grateful to Johan, my husband, and to my children Ruben and Noomi for always being there for me, making my life joyful!

This research was carried out with the financial support from the Swedish Council for Working Life and Social Research, Stiftelsen Sunnerdahls Handikappfond and Petter Silfverskiölds Minnesfond.

Göteborg, Oktober, 2012
Petra Boström

Contents

Experiences of Parenthood and the Child with an Intellectual Disability

Introduction

For most parents, the birth of their first child is a major transition in life that involves the new challenge of caring for an infant, and major changes in life-style and sense of identity (Michaels & Goldberg, 1988; Rutter, 1996). With the arrival of each new child in the family further changes will take place (Stern, 1995). Being a parent does not only mean being an individual adult, but it involves holding a particular position in relation to other individuals and to society. When a child is diagnosed with an intellectual disability (ID) the experience of parenthood is affected, and expectations with regard to the child and the future may have to be revised. In four studies included in this dissertation, the aim was to examine parental experiences and parents' emotions towards children who do not follow the typical developmental trajectory.

When parents are asked about their experiences of parenthood in relation to a child with ID descriptions tend to vary, containing a wide spectrum of emotions that may change with time. Parents' initial reactions to the child's diagnosis have been described as a crisis often characterised by shock, denial or disbelief (Blacher, 1984). However, many parents express a wide range of emotions (Larson, 1998). Feelings of love and affection towards the child, just the way she or he is, coexist with wishes for a miraculous cure of the disability. Conflicting emotions may exist within the parent, but also between individual parents, as they tend to react to the situation in a wide variety of ways–some are managing well, while others experience great difficulty.

A parent is a closely entangled part of a larger system, including other family and extended family members, as well as persons and institutions in the immediate neighbourhood and larger society. Through interaction with members of this system the parent will affect other members of the system, and will in turn be affected by others. In the present thesis, parents of children with ID will be described within the theoretical context of developmental psychology, as that is where theories of parenthood tend to be found. The ecological model described by Bronfenbrenner (1977) will serve as a basic framework for depicting how parents and their children with ID may be affected by their environment in a Swedish context. The individual children and their closest relationships are at the centre of the ecological model, surrounded by spheres of environmental factors that influence their development directly and indirectly. The transactional model (Sameroff, 2009) offers a theoretical structure for the reciprocal relationships within the ecological model, emphasising how events in the family and characteristics of the child may trigger reactions in parents and influence parental behaviour, which in turn may affect the child's emotions and behaviour. The complex interplay between parent and child and how they affect one another has been described in more detail in the theories of emotional availability (Biringen, 2000; Easterbrooks & Biringen, 2005), and attachment and caregiving (Bowlby, 1980). When asked to describe their child, parents will also provide information about their emotional experiences of the child and the nature of the parent-child relationship. Parents' experiences of their child affect parental sensitivity and caregiving behaviour, which in turn may have consequences for the child's feeling of security and organisation of attachment (Zeanah & Benoit, 1995). The above-mentioned theories will serve as a framework for merging and understanding empirically-based knowledge about families of children with ID and their particular circumstances in Sweden.

Following the introduction of a theoretical framework, characteristics of children with ID and their parents will be described. Parents of children with ID are not considered to be different from parents in general, except for the special circumstances related to the disability (Olsson, 2008). What makes this experience of parenthood unique will be described in terms of characteristics of the child with ID, but also in terms of how the disability may affect the parent indirectly through the family's access to support or experienced distress in relation to the surrounding environment. Children with ID have in common significant limitations both in intellectual functioning and in adaptive behaviour, which affect their everyday social and practical skills and the caring demands on their parents. However, as studies I-IV show, children with ID constitute a highly heterogeneous group evoking equally diverse reactions from their parents.

Parents are commonly used as informants of child characteristics in research. It is, however, known that parents are biased when describing their own child, and their reports are influenced by the special relationship between parent and child. The value of parents' perspectives on their children will be discussed in the context of results from the four studies included in the dissertation. Two studies (I & II) consider parents' reports of their child's behaviour in terms of temperament, and two studies (III & IV) explore parents' subjective descriptions of their child regarded as internal representations of the child. Both these perspectives may provide important information about parents' emotions towards and experiences of the child that may affect their own well-being and behaviour.

Theories of Parenthood

Parenthood can be described as a state or a position an individual enters and maintains as he or she becomes a father or mother of a child. It is a role that implies certain responsibilities and relationships to other individuals. The special relationships that constitute parenthood are primarily to one or several children, but may also involve relations to a spouse, grandparents of the child, friends, neighbourhood, and societal institutions (child care, schools, health services, etc.) and are characterised by the functional and social characteristics of parenthood. Once a child is born, the adult responsible for the child (biological, adoptive or fostered) attains a new position in society that involves various responsibilities as prescribed by the particular cultural, historical and socio-economic setting. Studies of parents may investigate the individual adult from the perspective of personality, mental health, psychobiology, cognitive or other major perspectives in psychology, but they also go beyond the study of the individual. To understand the specifics of the parental role, which are important parts of the adult's experience and the child's environment throughout development, we need to look at the system within which parenthood is constituted.

An Ecological System

Theories of parenthood can be found embedded in models of child development, perhaps due to the view of the parent's functional role in relation to child development. Bronfenbrenner (1977) created an ecological model of relationships as a multi-layered system affecting individual development. This ecological model includes factors ranging from the immediate environment, with direct influence on the person, to more distant societal factors that have an indirect influence on child development. The *microsystem* includes the most proximal relationships between the developing person and other persons in the environment who engage in activities in particular roles (such as parent, child, employee, etc.) in a specific place and time setting. The second layer of the ecological model, the *mesosystem,* is described as a system of microsystems. In the mesosystem factors in the microsystem interact and affect development. For instance, the flexibility of the parents' workplace and willingness of employers to accommodate the family's needs in relation to the child's school and social activities may affect both parent and child indirectly.

Other more distant relations that affect the child and the parent indirectly are found in the *exosystem* which includes not only larger social institutions such as community support and health services, but also other structures such as the world of work and mass media that operate on the local layer. The *macrosystem*, the outermost layer of the ecological system, refers to institutional patterns or structures of a culture. It includes cultural values, societal regulations and resources that interact and have an indirect effect on the individual. Factors in the macrosystem may include societal policies for child care that provide important support for families. For instance, parents' allowance may enable parents to stay at home with the child during infancy and later access to child care outside the home may promote the child's social and language development and allow for parents to participate in working life.

An important characteristic of the relationships on the different layers of the ecological system is that they are reciprocal, for example the behaviour of the child will have an effect on the behaviour of parents, friends, child care staff, etc. and their behaviours will affect the child. Parenting behaviour, which is considered to be shaped by both the individual characteristics and experiences of the parent, and by child characteristics and behaviour, is thought to have major effects on development, as the child will be exposed to this on a daily basis. A child displaying a disruptive or aggressive behaviour is more likely to elicit restrictive or punishing parenting behaviour, while a friendly and attentive child is more likely to evoke positive reactions from the environment (Sameroff & Fiese, 2000).

As implied by Bronfenbrenner's model, a number of factors both in the near and the distant environment may have positive or negative effects on child development, and the importance of various factors have been debated and explored. In support of Bronfenbrenner's model, longitudinal analyses of factors representing all the system layers of the ecological model have indicated that there may not be one specific environmental factor that is more important in determining the developmental outcome in individual children, but rather the number of negative influences in a child's environment in combination with the number of positive factors (Furstenberg, Cook, Eccles, Elder, & Sameroff, 1999).

Transactions within the Ecological System

Although parents are not at the centre of the ecological model, they are tightly entangled within the system and may be put into focus in their own right. This thesis describes the situation of parents of children with ID in Sweden from the perspective of Bronfenbrenner's ecological model. First, theories that attempt to describe the complex interaction between parents and children are expanded upon in further detail, with explication of the *transactional model* described by Sameroff (2009) and Sameroff and Fiese (2000). While the main focus of the ecological model is on environmental factors, the transactional model emphasises and expands the understanding of the bidirectional influence between an individual and the environment.

A transaction differs from an interaction in that it is more than just an episode of social exchange because the participants are affected and changed in some way by the interaction (Sameroff, 2009). A child's characteristics do not only influence behavioural responses from parents, siblings and other close relations, they also determine to what extent environmental characteristics will influence that child depending upon the child's susceptibility to those influences. The transactional model describes the interplay between child and environment over time and emphasises environmental factors in the culture, the family and the individual parent. Particular childrearing and educational practices are communicated through cultural codes. Family codes are transmitted via family belief systems as memorised representations across generations. These will guide family behaviour through rituals and daily practices, and shape expectations on family members.

In addition to cultural and family codes, parenting behaviour is shaped by individual interpretations of these codes. Characteristics of the child and incidents in the family will be interpreted by the parent according to cultural, family and individual parenting codes. As an example, the birth of a child with a disability may elicit stress in a mother, who might have negative preconceptions of what life would be like parenting a child with a disability. The parenting stress may prevent this otherwise warm and sensitive mother from adequately interpreting the child's signals, which in turn could make the child difficult to soothe. The mother's experience of being unable to comfort her child may add to the stressful experience and may be interpreted by the mother as her inability to meet her child's needs, or evidence that her child has a difficult temperament. This experience could cause the mother to withdraw from interaction with the child who due to the disability requires extra stimulation, and may in turn have long-term negative effects on the child's social, emotional and language development (e.g., Warren et al., 2010).

To further understand the specifics of how parents are affected by previous experiences and by the interaction with the child, we will turn to the theoretical frameworks of attachment and emotional availability. Attachment theory describes two reciprocal behaviour systems in the relationship between parent and child: attachment and caregiving (Bowlby, 1980). Attachment refers to the motivational system of the child to receive care, and caregiving represents the parent's motivational system to provide care and protection for the child (Mayseless, 2006a). Caregiving consists of two sub-systems, *internal representations* and *patterns of behaviour*. The internal representations consist of inferences, attitudes, goals, plans, emotions, and defences that organise and regulate the functioning of the behavioural system (Pianta et al., 1996). Caregiving behaviour is considered to be triggered by the parent’s emotions about him/herself, the child and the parent-child relationship (Solomon & George, 1996). A connection between parental internal representations, parental responsiveness and the child’s attachment style has been established in numerous studies (reviewed in van Ijzendoorn, 1995). Over the past two decades, the theory and research on parental representations has expanded greatly, with new interview methods enabling assessment of parental representations (Mayseless, 2006b). The main focus when analysing parent interviews is on affective tone and narrative style, rather than on compiling content (Zeanah & Benoit, 1995). The parent’s perceptions, attributions and interpretations of the child’s specific behaviour have been found to be affected by the parent’s internal representations of the child and parent-child relationship in interaction with actual child behaviour (MacKenzie & McDonough, 2009).

While parental representations of the child remain an indirect means to study the parent–child relationship, direct observation of parent–child interactions provides information about the actual behaviour that forms the bridge between the parent’s internal representations and the child’s attachment style. Emotional availability is a concept that describes the quality of the relationship between parent and child and its emotional meaning (Biringen, 2000; Biringen, Fidler, Barrett, & Kubicek, 2005; Easterbrooks & Biringen, 2005; Pipp-Siegel & Biringen, 1998). Parenting behaviour is analysed in terms of the sensitivity of the emotional communication between parent and child, parental non-intrusive availability, structuring by supporting the child’s learning and exploration, and non-hostile behaviour. Two aspects of child behaviour are observed: the child’s responsiveness to the parent and inclination to involve the parent in interaction.

Applying the theoretical perspectives described above on families of children with ID may contribute important knowledge about the passage of transactions between parents and their children with ID, and how they affect each other. In many of these families parents experience stress related to the diagnosis and the responsibility of caring for a child with special needs. Many of these children are known to display atypical and sometimes challenging behaviour, which may affect parents’ representations of the child and perceptions of the child’s behaviour. From an ecological perspective, proximal or distant factors in the environment may also affect the experience of parenthood, and consequently the quality of the relationship between parent and child. For most children with ID, the family will remain an important part of the environment throughout childhood, adolescence and sometimes in adulthood due to the continuous dependence on support from adults.

Intellectual Disability in Children

Intellectual Disability (ID)

The common denominator of the parents participating in the four studies of the present dissertation was that their child was considered to have an intellectual disability. A brief summary of what characterises children with ID as a group follows to illustrate how parenthood of a child with an ID may differ from or resemble other parenthood experiences. The American Association on Intellectual and Developmental Disabilities (AAIDD) has defined intellectual disability as "a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18" (AAIDD, 2012). Intellectual functioning, or intelligence, refers to general mental capacity and includes abilities such as learning, reasoning, problem solving, etc. A score below 70-75 on an IQ-test can indicate limitations in intellectual functioning. Intellectual functioning can be assessed with tests such as the Wechsler Intelligence Scale for Children (Wechsler, 1991) or the Raven's Progressive Matrices (Raven, 1948). Adaptive behaviour, which can be tested with standardised tests such as the Vineland Adaptive Behavior Scales (Sparrow, Balla & Cincchetti, 1984), and include three types of skills as described by the AAIDD:

- Conceptual skills — language and literacy; money, time, and number concepts; and self-direction.
- Social skills — interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimised.
- Practical skills — activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

(AAIDD, 2012)

The parents participating in the four studies presented in this dissertation learned that their child had an intellectual disability within the child's first five years of life. Most of the children had an additional diagnosis to ID such as autism spectrum disorder (ASD), Down syndrome, Cerebral Palsy or other uncommon chromosomal abnormalities. In Europe, the most widely used classification system for diagnosing ID is the International Classification of

Diseases (ICD-10) followed by the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (World Health Organisation, 2007). The degree of the disability is commonly classified by using the International Classification of Functioning, Disability, and Health (ICF or ICF-CY for children and youth) or professional opinion (World Health Organization, 2007). The ICF-CY is an instrument that compiles a broad spectrum of impairments or delays in a person's bodily functions and structures. In some contexts the impairment may cause disability that restricts the person's abilities to participate in activities. The degree of the actual disability depends both on the cognitive or physical impairment and the environmental factors that may either compensate for those deficits or further limit participation (World Health Organization, 2010).

The criteria for diagnosing ID described by the AAIDD involve limitations in some skills that are not apparent or possible to assess during the pre-school years, and certainly not during infancy. Consequently, the diagnosis of young children is sometimes uncertain. To diagnose an infant or toddler with ID requires that he or she has a syndrome or chromosomal abnormality known to co-occur with ID, or severe ID. Syndromes that affect the appearance of a child, or are genetic syndromes previously known to the family, can generally be discovered and tested for around the time of birth, while autism or intellectual disability tend to be diagnosed at a later stage (Simonoff, Bolton, & Rutter, 1998).

As the children in the present sample grew older, a few children who had at first had an unknown or uncertain diagnosis to begin with turned out to have a developmental delay (DD) rather than ID. DD is a more general term that also includes less severe disabilities. DD is defined as a significant and ongoing delay in a child's development and may occur in any or all of the major areas of child development: social, language, or motor skills (Morrissette, 2012).

Even though ID is a clearly defined concept, it is also a social construct that has changed historically (Odom, Horner, Snell, & Blacher, 2007). For instance, prior to 1973 the AAIDD (formerly the American Association on Mental Retardation) included individuals with an IQ below 85 in the diagnostic criteria; lowering this cut-off to an IQ of 70 reduced the official prevalence significantly. This change had consequences for individuals with a previous diagnosis in terms of access to support etc. (Odom et al., 2007) — an example of how factors on the macro-level may affect a family within Bronfenbrenner's ecological model (1977). An important conceptual shift has taken place during the past two decades, moving away from the previously dominating concept of mental retardation to the current concept of ID. Previous definitions made assumptions about the disability existing within the person, more specifically within the mind, and was looked upon as a defect. The redefinition of the concept into ID involved a shift in perspective towards perceiving the disability as an impairment in “the fit between the person’s capacities (implied in that is limited capacity as a function of neural impairment) and the context in which the person functioned” (Wehmeyer et al., 2008, p. 314). This change of concept may be seen as an action to change how people with disabilities and their families tend to be perceived, which may in turn affect transactions on all levels of the ecological system. Other reasons for changing the concept from mental retardation into ID were to adjust to the changes in the disability concept made by the AAIDD and World Health Organization, (World Health Organization, 2011), and for it to be less offensive to people with disabilities (Schalock et al., 2007).

There is a powerful societal discourse that devalues people with disabilities in Western society (Green, 2007). Expectations tend to be low about the contribution that can be made to society by adults with ID, and their rights to receive care and to have a place in society is sometimes questioned (McKeever & Miller, 2004). In addition to the adverse effects that such negative perceptions may have on individuals with disabilities, they also create problems for parents of children with ID, as they often feel pitied by others and perceived as burdened by their child — an image that according to many parents does not correspond with their own experience (Green, 2007).

Dominant theories about ID or mental retardation over the past century have emphasised the *delay of development,* initially assuming that children with ID would follow a sequence of development similar to typically developing (TD) children, but at a slower pace (Burack, Hodapp, & Zigler, 1998). Some influential ideas have emerged suggesting that children with ID with no apparent organic damage could be matched with TD children in terms of “mental age” and that these groups should resemble one another in terms of developmental sequencing, as development in children with and without ID was considered to be organised in horizontal stages (Bennett-Gates & Zigler, 1998). However, other theories have put an emphasis on how environmental factors may impact and interact with the source of the disability. For instance, in the 1970s, Zigler (cited in Burack et al., 1998) highlighted the fact that the conditions of growing up often differed between children with ID and TD children. Children with ID commonly grew up in environments with low socio-economic status (SES) and spent greater part of their childhood years in institutions than those with TD (Burack et al., 1998).

To date there are no reliable data on the global distribution of ID as there is no consistent international approach to defining disabilities (World Health Organisation, 2011).

However, the prevalence of environmental risk factors known to cause developmental disabilities are more common in some regions of the world – particularly in countries and areas in which a large proportion of children live in poverty with higher risk for malnutrition and pre- and postnatal exposure to infections and toxins (Emerson, Fujiura, & Hatton, 2007). The direction of the relationship between adverse environmental factors such as low SES and exposure to malnourishment and diseases and an increased frequency of ID has been discussed, and it is likely that these factors interact (Horowitz & Haritos, 1998). Environmental factors may promote or constrain a child's opportunity to develop physically and psychologically. However, the disability may also affect the environment of the child. Family income may be reduced if one parent has to resign from work to look after the child full-time. Costs may increase due to special requirements of the child that may not be subsidised by the state. The lowered economic status of the family may force the family to move to an area with lower quality education, which may in turn have adverse effects on the child's future academic performance and development (Klingner, Blachett, & Harry, 2007). In some genetic syndromes, heritability may interact with environmental factors and parents may also have a diagnosed or undiagnosed disability that could have prevented them from educational and professional success (Simonoff, Bolton, & Rutter, 1998).

The prevalence of ID varies between regions, as shown in studies from various countries and regions (Raghavan & Small, 2004). For instance, a national Finnish study (Westerinen, Kaski, Virta, Almqvist, & Iivanainen, 2007) reported a prevalence of 0.7% of ID in the population, while 3% of children in a British national cohort study were considered to have ID (Emerson et al., 2007). This difference in prevalence may be due partly to the criteria for inclusion and definitions of ID used in each of the studies. Approximately one-third of all the children who are identified as having ID will also receive a more specific diagnosis (Verri et al., 2004).

Researchers have commonly divided children with ID into subgroups according to the etiology of the disability. When comparing children with or without an apparent organic cause of the disability, Zigler and Hodapp (1986) found that children within the mild or moderate range of ID without an organic cause more often came from families with low SES, belonged to a minority group, and had parents who scored low on IQ tests, indicating multi-factorial sources of the condition. Children with mild or moderate ID with no organic source is a large group, as they comprise about half of all children with ID (Zigler & Hodapp, 1986). Recent developments in genetic testing techniques have made the etiologies of disabilities with organic causes that co-occur with ID easier to establish. The most common initial sources of ID include genetic disorders, anoxia at birth and childhood meningitis (Hodapp, Burack, & Zigler, 1998).

The extent to which a child is affected by a disability varies extensively between individuals depending on degree of impairment and the extent to which environmental factors facilitate or limit the individual child (World Health Organization, 2010). The heterogeneous group of children with various genetic disorders have turned out not to follow common developmental sequences, which has led to extensive research attempting to establish developmental and behavioural profiles or phenotypes for many of the genetic disorders (Hodapp et al., 1998). Children with Down syndrome (DS) and their parents have been more extensively investigated than many other diagnostic groups, even though this is not the largest diagnostic group. This may be due to the possibility of an early and conclusive diagnosis of these children through chromosome testing. Other disorders, such as autism spectrum disorders (ASD), that are behaviourally defined are usually not diagnosed until the preschool years, and even then with a lower level of certainty (Baird, Cass, & Slonims, 2003).

Features related to certain diagnoses such as the appearance of the child (e.g., a friendly or hostile facial expression) may transact with the environment by evoking positive or negative reactions from other people. The prolonged diagnostic process common for children with ASD may be stressful for parents (Blacher & Hatton, 2007). A more severe disability has in some instances been found to contribute to parenting stress through increased demands on the parents due to high child dependency, management needs and behavioural problems (Burack, Hodapp, & Zigler, 1998). Other studies, however, have reported the opposite relationship, with parents of children with mild ID describing higher levels of stress (e.g., Bristol, 1984). Despite conflicting results, we may with some certainty expect behavioural characteristics of the child to affect parents and siblings, as well as other more distant relationships. Such behavioural characteristics could be described in terms of temperament.

Child Temperament

Attempts to describe and understand the behaviour of typically developing children in a systematic way has provided researchers with a challenge for at least six decades (Nigg, 2006), beginning with the pioneering work by Thomas and Chess (1977) in 1956. Initially the main focus was to describe *how* children behave. Later, temperament has been defined by one prominent theorist as ‘individual differences in emotional, motor, and attentional reactivity measured by latency, intensity, and recovery response, and self-regulation processes such as effortful control that modulate reactivity' (Rothbart, 2007, p. 207), but controversy continues over the definition of temperament.

Temperament is thought to be biological based, but is influenced by maturation (development) and experiences throughout life (environment). Temperament can already be observed in the newborn infant (Rothbart, 2007); at this stage it is influenced by heredity and the prenatal environment, but another important influence is immaturity of development (Nigg, 2006). In toddlerhood heredity of temperament becomes more obvious as the child matures, but at this age and in the years to follow, environmental influences also play an important role (Nigg, 2006). The factors believed to serve as a basis for temperament may be influenced directly or indirectly by the sources of ID. In children with ID, development is often delayed in one or several domains, which may affect temperament at different ages (e.g., Fidler, Most, Booth-LaForce, & Kelly, 2006). Disability with an organic etiology may influence a child's behaviour through both physical and psychological pathways, and certain characteristics have been related to specific syndromes (Kasari & Bauminger, 1998). Despite the fact that most children with ID today grow up in a family environment just like TD children, they are known to be exposed to more risk factors such as deprivation, stigma, and physical and sexual abuse (Greenbaum & Auerbach, 1998). Children are affected by their parents' behaviour and vice versa. Transactions between parental stress and child temperament have been found to be significant in the important developmental phases of infancy and early childhood (Pesonen et al., 2008). Characteristics of the child are known to influence the environment, which means that the environmental influence will always differ to some extent between individuals even in the same family (Sameroff, 2009).

Temperament is seen as a factor of vulnerability or protection, predicting both adult personality traits and risks for psychopathology (Nigg, 2006). Stability of temperament during the childhood years has also been under investigated. A strong emphasis on the biological basis of temperament would predict high stability over time, but when comparing measurements of temperament from one occasion to another, stability appears to be moderate with correlations between 0.4 and 0.6 (Sanson, Pedlow, Cann, Prior, & Oberklaid, 1996). Developmental aspects have been found to influence continuity, however, and temperament does not seem to change randomly. Instead it follows certain developmental paths and rarely changes from one extreme to another (Janson & Mathiesen, 2008; Komsi et al., 2006).

The most commonly used measures in the studies of temperament in children with ID are the Infant Behavior Questionnaire and the Children's Behavior Questionnaire (IBQ/CBQ) (Gartstein, Marmion, & Swanson, 2006; Klein-Tasman & Mervis, 2003;

Konstantareas & Stewart, 2006; Nygaard, Smith, & Torgersen, 2002; Shanahan, Roberts, Hatton, Reznick, & Goldsmith, 2008) developed by Rothbart (2001) for two different age groups (infants and 3 to 8 year-old children), and the EASI (Boström, Broberg, & Hwang, 2010; Boström, Broberg, & Bodin, 2011; Zion & Jenvey, 2006) developed by Buss & Plomin (1984) for children between 1 and 9 years of age, which was used in studies I and II. According to Buss and Plomin's (1984) rather conservative theory, there are two conditions for temperamental traits: 1) that the genetic factor makes an essential contribution through heredity; and 2) that temperament dimensions should present in the early childhood years. Temperament dimensions are considered to be broad descriptions of behaviour types with functional significance (Buss & Plomin, 1984). Rothbart's age-specific questionnaires IBQ and CBQ, are more extensive and cover all kinds of behaviour with an emphasis on emotional reactions and developmental aspects (Strelau, 1998).

Despite their different theoretical backgrounds, different measures of temperament overlap substantially. The two systems EASI (Buss & Plomin, 1984) and IBQ/CBQ (Rothbart, 1981; Rothbart, Ahadi, Hersey, & Fisher, 2001) are similar in the following aspects: *emotionality* in EASI refers to 'distress, or the tendency to become upset easily and intensely' (Buss & Plomin, 1984, p. 54) which is comparable to *negative affectivity* in Rothbart's terminology. The three EASI-factors *activity* (intensity and speed of activity), *shyness* (being inhibited and feeling awkward in new social situations), and *impulsivity* (inhibitory control, decision time and persistence in ongoing tasks, and sensation seeking (Strelau, 1998)) are included in Rothbart's factor *extraversion/surgency*. Some of the characteristics of impulsivity are also found in Rothbart's *effortful control. Sociability* (seeking and preferring the presence of others to being alone, EASI) has no straightforward equivalence in the IBQ/CBQ (Hassall, Rose, & McDonald, 2005), although it could be seen as the reverse of EASI's shyness, as there is a negative correlation between those scales. Sociability (EASI) could also be related to *approach*, a subscale within extraversion/surgency in the IBQ/CBQ. The scales measuring impulsivity and shyness in the EASI were removed by Buss and Plomin (1984) because there was insufficient evidence of heredity for those qualities (Daniels & Plomin, 1985; Strelau, 1998). In studies I and II, all five scales of the EASI were included as shyness and impulsivity have been found to be related to externalising and internalising problems (Leve, Kim, & Pears, 2005; Schmitz et al., 1999), and children with ID as a group has been described to display higher than normal levels of behavioural problems (Hassall et al., 2005).

Temperament and ID

Attempts to map out which distinct characteristics are representative for each diagnostic group of children with ID is an ongoing project. Different diagnostic groups seem to vary both within and between groups and comparing and summarising results from different studies of temperament in children with ID is an intricate matter. Just like in studies of temperament in TD children the developmental dimension of temperament has to be taken into account. Straightforward comparisons, however, cannot be made since developmental delay is inherent to ID, but is not homogeneous within the larger group. In addition to children having different disabilities, studies include different age groups, comparison groups and different measures of temperament.

Of all ID subgroups most attention has so far been directed towards investigating temperament in children with Down syndrome, perhaps because of the possibility of a definitive and early and conclusive diagnosis of this group. There has also been a reaction against the stereotypical image of the child with DS as simply good-tempered and outgoing (Bridges & Cicchetti, 1982). Young children with DS show longer duration of attentional orientation during the first year compared to TD children (Gartstein et al., 2006). As they grow older the relationship seems to switch, as children with DS show lower levels of focused attention, persistence and inhibitory control, and appear to be more distractible (Bridges & Cicchetti, 1982; Nygaard et al., 2002). Children with DS generally appear to have lower levels of negative emotionality (Fidler, Most, Booth-LaForce, & Kelly, 2006) than children with mixed ID, and also a lower level of sadness (Nygaard et al., 2002) compared to TD children. The onset of difficult behaviour in children with DS seems to occur later in the developmental trajectory compared to children with mixed ID. When looking at children aged 12, 30 and 45 months, Fidler et al. (2006) found that children with DS showed less difficult behaviour at the age of 30 months, but that they seemed to have "caught up" at 45 months, displaying equal levels of difficult behaviour compared with the mixed ID group. Contrary to the findings by Fidler et al., Stoneman (2007) (using another measure of temperament) found 2- to 7-year-old children with DS to have less difficult temperament (activity and negative emotionality) than children with mixed ID.

Children with ID of mixed etiology have been used as a comparison group in some studies (Fidler et al., 2006; Stoneman, 2007) but have also been compared with TD children. Children in special classes display similar variability in temperament as children in regular classes of the same age (Zion & Jenvey, 2006). The only significant differences found were that parents rated their children attending special classes as lower in sociability, and teachers rated the same children as higher in negative emotionality.

Temperament in children with autism aged 3 to 10 years seems to be related to ASD specific characteristics (Konstantareas & Stewart, 2006). Compared to TD controls, children with autism were rated lower on all the scales effortful control, attentional focusing and shifting, inhibitory, and executive control. Konstantareas and Stewart (2006) also found that children with autism have higher levels of negative affectivity, as they are more difficult to soothe and appear to experience greater discomfort.

Three-year-old boys with Fragile X-Syndrome (FXS) appear to have less negative affectivity with lower levels of sadness and anger than TD children (Shanahan et al., 2008), and 3- to 8-year-old boys with FXS have higher levels of activity than IQ-matched children with mixed ID (Kau, Reider, Payne, Meyer, & Freund, 2000) and TD children (Bailey, Hatton, Mesibov, Ament, & Skinner, 2000). The temperament of children with FXS has been found to be similar to that in children with autism, including slowness to adapt, less persistence, and more social withdrawal than controls (Bailey, Hatton, Mesibov, Ament, & Skinner, 2000). Similarities between children with FXS and autism, as well as comorbidity between these types of disabilities, sometimes lead to an inaccuracy in diagnosis.

Children with Williams syndrome appear to be sociable and show an interest in faces already as infants. They score higher on sociability and empathy at age 8-10 years than children with mixed ID (Klein-Tasman & Mervis, 2003). Previously, children with Williams syndrome have been described as fearful in general, but the anxiety appears to be specifically related to social situations, which is common among individuals who are high in empathy (Klein-Tasman & Mervis, 2003).

“Difficult Temperament” and Behavioural Problems

The concept of difficult temperament has been questioned and processed extensively since it was first introduced by Thomas, Chess, Birch, Hertzig, and Korn (1963). According to the original definition, children with biological irregularity, withdrawal responses to new stimuli, difficulties in adapting to change, negative mood, and intense emotional reactions were considered to have a difficult temperament (Thomas & Chess, 1977). Difficult temperament was supposed to be a precursor of adult behaviour disorders. Later, Thomas and Chess were criticised for having failed to take into account factors such as cultural context, age and development of the child (Strelau, 1998). Thomas and Chess responded to the criticism by developing the construct of *goodness of fit.* According to this theory, parents’ reactions to the child's behaviour were seen as an essential mediator between difficult temperament and the development of behaviour disorders.

In studies of children with ID, level of difficult behaviour has been measured, but different studies use different definitions of difficult temperament. For example, Kasari and Sigman (1997) used the more traditional combination of low rhythmicity, high withdrawal, low adaptability, high intensity, and negative mood. Children with autism were found to have the highest level of difficult temperament when compared to children with DS, mixed ID and TD children (Kasari & Sigman, 1997).

Other studies explored the level of negative emotionality in combination with high activity (Mathiesen & Sanson, 2000; Stoneman, 2007). The idea of a fixed set of temperamental traits that would be experienced as difficult by parents has been challenged by Marcovitch, Goldberg, Lojkasek, and MacGregor (1987), who suggested that various combinations of temperamental traits may be experienced as particularly difficult by parents of children with disabilities. Marcovitch et al. (1987) found that children with ID that were considered difficult by their parents had a temperamental profile consisting of high activity and intensity, low adaptability and high approach, which diverges from what is generally perceived as difficult temperament. For instance, high approach is normally considered to be a positive trait, but for mothers of children with ID high approach in their child was experienced as stressful, perhaps because children approached new situations injudiciously.

The results found by Kasari and Sigman (1997) may help to disentangle and organise the somewhat incomprehensible amount of information about temperamental characteristics of children with specific diagnoses summarised above. When comparing preschool children with autism, DS and mixed ID with TD children on level of difficult temperament (specific combinations of rhythmicity, approach/withdrawal, adaptability, intensity, and mood) groups were ordered from highest to lowest level of difficult temperament in the following order: autism, mixed ID, DS, and TD children (Kasari & Sigman, 1997).

Behavioural problems can be detected in children that are a few years old, but not before the age of 18 months. Parents' psychological ill-health has been found to be related to higher levels of behavioural problems of children with ID (Hassall, Rose, & McDonald, 2005; Hastings, 2002; Herring et al., 2006). However, the variation of temperament in the heterogeneous group of children with ID and its relation to parent well-being has been sparsely explored. Studies I and II investigated child temperament in relation to the diagnostic criteria (children with or without ID, and specific diagnosis) and with a person-oriented approach (cluster analysis). The specific temperamental profiles found were further explored in relation to positive and negative impact on parents.

Psychological Health of Children with ID

Results from international studies indicate that children with disabilities constitute a vulnerable group with a relatively high rate of symptoms of poor psychological health. All types of psychopathology are found in children with disabilities but at a higher rate. Studies show a three to seven-fold increase in externalising and internalising problems in children with ID over TD children (de Ruiter, Dekker, Verhulst, & Koot, 2007; Emerson & Einfeld, 2010). As many as 30-50% of children with ID fulfil the criteria for one or several psychiatric diagnoses (de Ruiter et al., 2007; Taggart & McMullan, 2007). Even if the symptoms of psychological ill-health do not differ substantially between children with or without ID, children with ID are seldom evaluated and diagnosed. Sometimes the symptoms are seen as a part of the disability or missed altogether, as children have difficulties in the areas of communication, locomotion or social relations.

It is likely that cognitive, verbal and diagnosis-specific factors of children with ID, in combination with relational and social factors, contribute to their increased vulnerability to psychopathology. Cognitive deficiencies may inhibit the child's ability to predict changes and to comprehend causalities, which may elicit fear, anxiety and outbursts in situations where other children would manage without such reactions (de Ruiter et al., 2007). Low verbal ability restricts children's ability to communicate personal needs and emotions, to develop self-regulating strategies, and to build social relationships (Koskentausta, Iivanainen, & Almqvist, 2007). The prevalence of such difficulties varies between different diagnostic groups, and certain diagnoses are known to be related to specific behavioural or psychological problems (Blacher & McIntyre, 2006; Dykens, 2000; Koskentausta et al., 2007). Children with ID with behavioural problems and difficulties to communicate are also known to be a group at risk for being exposed to neglect and physical and psychological abuse (Sullivan & Knutson, 2000; Svensson, Bornehag, & Janson, 2011). Sullivan and Knutson's population-based study (2000) in Nebraska showed that children were at particular risk of being exposed to neglect and physical and emotional abuse by a member of the immediate family, while sexual abuse was more commonly committed by someone outside the family.

Parenting a Child with ID

The scientific research on families of children with ID has a relatively short history, as the first studies were published in the 1940s in the American Journal of Mental Retardation (Blacher & Baker, 2002) The late onset and limited interest in family research may be related to the widespread separation of children with ID from their families, as individuals with ID commonly were brought up and spent their lives in institutions. With the realisation of the benefits for children to grow up in a family environment an extensive deinstitutionalisation took place in most Western countries, resulting in families of children with ID becoming increasingly important. As the scientific interest in these families increased, the main focus was initially on how parents, and mothers in particular, were able to cope with and adjust to the difficulties related to bringing up a child with ID. Only recently, researchers have focused their attention on the dynamic interaction between positive and negative factors involved in the experience of bringing up a child with ID, as well as the individual resources of parents and their environments (Blacher & Hatton, 2007).

As argued in the introduction, to further understand the experience of parenthood when the child has ID, we need to take a look at the system that surrounds and interacts with the individual parent. Environmental factors and circumstances that may be of relevance to the experience of the parents participating in the four studies of the present dissertation will be presented. In addition to the child factors that have been described above, factors in the exo- and macrosystems such as cultural and political values, which may be communicated to families through the welfare system, will be described. Furthermore, formal and informal relationships that are part of the more proximal micro- and mesosystems, will also be considered as they may affect and be affected by parents.

Effects of the Child's Diagnosis on Parents' Mental Health

In 1953, the psychiatrist Leo Kanner (1953), previously known for his pioneer work on autism and in child psychiatry, described the reactions and experiences of parents to their child's intellectual disability in a study with results that still seem highly relevant. Four couples were presented as typical cases of the parents that Kanner met during diagnostic examinations of children with ID. One reaction to the child's diagnosis was for parents to deny the child's delay in development with attempts to correct or remove symptoms by forcing the child to go through painful medical and surgical procedures that often turned out to be ineffective. Other parents were burdened by a sense of guilt, or feelings of shame towards their environment because of the deficits of the child. Some parents described that people in their environment would treat them without sympathy. Although our knowledge about intellectual disability has largely increased, parents are still engaged in many of the same questions that Kanner found to be central. Parents asked questions concerning the origins of the disability, its heritability and the probability that siblings would develop similar problems, how siblings would be affected psychologically, how to inform the child about his or her condition, how parents may support the child's development positively, and how development could be expected to proceed. Another interesting aspect of parenting that Kanner noted was the fathers' distance or absence in these children's lives, leaving much responsibility for child care and rehabilitation to mothers. It is striking how similar the experiences that parents describe today are to those of Kanner's clients almost 60 years ago. Numerous studies of mothers' experiences and well-being have followed after Kanner's informative description. However, fathers did not become the focus of researchers' attention until the 1980s.

Today it is fairly well established that on a group level, the mental health of parents, and mothers in particular, is affected by having a child with an ID. In a meta-analysis, Singer (2006) concluded that mothers of children with ID showed mild but significantly elevated levels of depression in comparison with mothers of TD children, but that approximately 70% of this population did not suffer from depression. Parental stress has been a recurring topic of research, and high parental stress has been found to be related to depression (Secco et al., 2006). Higher levels of parental stress and depression have repeatedly been found to be related to child behavioural problems (Hassall, Rose, & McDonald, 2005; Hastings, 2002; Herring et al., 2006), while the severity of the disability or developmental delay does not explain elevated levels of stress or depression (Beck, Hastings, Daley, & Stevenson, 2004; Blacher, Neece, & Paczkowski, 2005; Hastings, 2002). Certain groups of parents, such as parents of children with autism seem to be particularly vulnerable to stress and depression (Eisenhower, Baker, & Blacher, 2005; Olsson & Hwang, 2001). The relatively high level of behavioural problems among children with autism has been suggested to predict these impairments in parents' psychological health.

Increased stress and depression related to child behaviour problems appear to persist and sometimes escalate as the child grows older (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001). It has been suggested that parental stress and child behavioural problems may have a reinforcing effect on each other (Hastings, 2002), which is consistent with the transactional process described by Sameroff (2009). Discovering that your child behaves differently from the norm — perhaps by being more active, less social and more impulsive —

may trigger stress in parents. The experience of parenting stress may in turn affect parenting behaviour, or parenting style, in a way that will further reinforce the child's difficult behaviour. Family dysfunction, a factor which includes parenting stress, is a known predictor of harsh parenting behaviour (Jansen et al., 2012). Although harsh parenting may not seem as detrimental as child abuse, it constitutes a risk factor for and is related to emotional and behavioural problems, as well as psychiatric disorders (MacMillan et al., 1999; Prinzie, Onghena, & Hellinckx, 2006; Taylor, Manganello, Lee, & Rice, 2010).

Although elevated levels of stress and depression in this group of parents are of great concern, it is also important to note how many parents appear to manage well and describe positive experiences in relation to their child's disability. There has been some controversy about the aim of research on parenting a child with ID (Scorgie & Sobsey, 2000). The main focus has tended to be on negative aspects and reactions to the diagnosis and its consequences, while some researchers argue that negative aspects have been overemphasised and that positive aspects need to be put forward (Scorgie & Sobsey, 2000). Parents' well-being has often been defined as the absence of mental health problems (e.g., Herring et al., 2006). However, scales measuring the positive spectrum of well-being, such as the level of positive affect and life-satisfaction, have also been used (e.g., Olsson & Hwang, 2006). Positive characteristics of the child, such as pro-social behaviour, and certain personality factors in parents (e.g., low neuroticism and high optimism) have a positive relation to well-being (Baker, Blacher, & Olsson, 2005; Beck, Hastings et al., 2004; Hassall et al., 2005; Olsson & Hwang, 2002). While there is a lack of support for the relationship between parents' level of stress and objective factors such as severity of the child's condition or caretaking demands (Hassall et al., 2005; Lecavalier, Leone, & Wiltz, 2006; Luescher, Dede, Gitten, Fennell, & Maria, 1999), there is some evidence for parents' subjective experiences and appraisal of the disability's effect on daily life to affect the level of parental stress (Beckman, 1991; Plant & Sanders, 2007). Psychological variables such as parental self-efficacy (Kuhn & Carter, 2006), self-esteem (Hassall et al., 2005), and general acceptance (Lloyd & Hastings, 2008) are related to lower levels of parental stress.

Positive personal transformations may stem from challenges in one's life, although they are not the guaranteed outcomes of hard times. When looking for positive aspects of parenting a child with a disability, Scorgie and Sobseys (2000) selected parents who were considered as "good copers", dealing well with the situation of parenting a child with a disability. Positive experiences that parents themselves attributed to bringing up a child with ID were divided into three domains: personal growth, improved relations with others, and changes in philosophical or spiritual values (Scorgie & Sobsey, 2000). Parents described experiences of personal growth in terms of acquiring new roles due to their position as a parent of a child with ID. They would act as a speaker, advocate, group leader, advisor, and so on, sometimes challenging old patterns of living a more quiet life. They also acquired changes in personal traits such as increased compassion, personal strength and endurance, and reported less self-focus and sense of powerlessness. Some parents described how their relationships to other people, including family, friends and professionals, had both deepened and expanded. However, there were also descriptions of how challenges related to the disability could put extra strain on relationships. Changes in philosophical or spiritual values referred to changes in how parents viewed life in general as they became more present-minded and appreciative of life in general than before the arrival of the child. These new aspects took time to acquire, and many parents were driven by a desire to protect and support their child (Scoorgie & Sobsey, 2000).

The emphasis on and in-depth research of the negative aspects of parenting a child with ID may be rooted in researchers concern for the well-being of both parents and children who experience difficulties in relation to the disability, and who may consequently be at risk for developing psychological ill-health. One cannot deny the importance of identifying risk factors in those families to enable future prevention and strengthening of support and resources. However, as several studies have shown, positive aspects may coexist with the challenges experienced and may not constitute one end of a scale measuring positive versus negative experiences. The results from previous research may be interpreted as indicating that positive and negative experiences constitute separate variables, probably not completely unrelated, but most importantly not excluding each other. Investigating the full range of parents' experiences is important to enable parents to identify with the results of these studies without stereotyping them (Hastings & Taunt, 2002; Larson, 1998). Identifying positive aspects may be an important step in the process of finding ways to support families. By listening to how some parents have found ways of managing and appraising the often unexpected challenges that they have encountered may provide models for support that can be offered to families that are managing less well. When taking into account the consequences of the transformations involved in the interaction between parents and their children, parents' interpretations of child characteristics and behaviour become important.

Expectations versus Experiences

Parents whose child receives a diagnosis of ID are usually unaware that the child has a disability prior to childbirth. As with all parents, these parents have expectations and worries concerning the child that they are expecting. Parents' expectations about future parenthood and about the infant prior to the birth are generally positive (Harwood, McLean, & Durkin, 2007; Raphael-Leff, 1991). There also tends to be some thoughts about future difficulties and how these could be dealt with (Delmore-Ko, Pancer, Hunsberger, & Pratt, 2000). For most mothers postnatal experiences exceed expectations, but for about one-third of women expectations are overly optimistic relative to their actual experiences. This negative discrepancy is associated with postnatal depressed mood and poor relationship adjustment (Harwood et al., 2007). Women who report a negative discrepancy between expectations and experiences appear to encounter difficulties in adjusting to their new role as a mother. Another important aspect of the development of mothers' prenatal expectations of the child is that they tend to weaken and become less defined towards the end of pregnancy, making room for the "real child" to shape internal representations (Raphael-Leff, 1991; Stern, 1995) and possibly reduce the risk for negative discrepancies.

For most parents, realising that their child has an ID is a stressful experience (Graungaard & Skov, 2007). The most common initial reaction is characterised by shock, denial or disbelief (Blacher, 1984). Parents who find out that their child has ID could be expected to experience a negative discrepancy between prior expectations and actual experience that will require extensive revision of their expectations, and may contribute to difficulties in adjustment. Graungaard and Skov (2007) explored how parents coped with the diagnostic process and found that parents of infants with severe disability were negatively affected by uncertainty of diagnosis in terms of emotional stress. Being able to do something for their child was described as important. Equality and empathy in communication with health professionals was also experienced as a positive factor during this difficult initial phase.

Some aspects of having a child with ID are experienced as difficult. However, parents do not tend to describe the child as the reason for increased levels of stress and depression (Olsson, 2008). The emotional bond between parent and child, and the moments of joy that tend to be part of the parent-child interaction, have been suggested to work as protective factors for the well-being of both the parent and child (Beresford, 1996).

Reactions to Diagnosis

Comparisons between mothers' representations of children with ID and without diagnosis have concluded that these emotional experiences differ (Beck, Daley, Hastings, & Stevenson, 2004; Button et al., 2001; Hastings, Daley, Burns, & Beck, 2006). Mothers of children with ID describe more negative internal representations when speaking about their child than mothers of children with no diagnosis (Button, Pianta, & Marvin, 2001). Likewise, mothers express more negative emotions towards the child with ID compared to a sibling with no ID (Beck, Daley et al., 2004). In a review of studies investigating expressed emotion (for example criticism or emotional over-involvement) of parents of children with ID, Hastings and Lloyd (2007) concluded that expressed negative emotion (particularly criticism) was related to parental stress and caregiver burden, as well as child behavioural problems.

Several studies exploring parents' reactions to diagnosis and parental representations of the child (Button, Pianta, & Marvin, 2001; Marvin & Pianta, 1996; Oppenheim et al., 2007; Pianta, Marvin, Britner, & Borowitz, 1996) have their theoretical origin in attachment theory (Bowlby, 1980). The experience of receiving a diagnosis of one's child has been described as a metaphorical loss of the wished-for, typically developing child (Oppenheim et al., 2007). According to Bowlby (1980), such a loss is followed by stages of mourning, ending with a reorganisation that enables the person to adapt to the new circumstances — if the mourning process is successful. Reorganisation includes working through and leaving habitual patterns of thinking and acting which are related to the loss, and accepting that the loss is irreversible. Marvin and Pianta (1996) and Pianta et al. (1996) developed the "Reaction to diagnosis interview" (RDI) to assess whether parents were resolved versus unresolved in relation to a diagnosis (of CP or epilepsy) that was received months or years earlier and was considered to be experienced as a loss or trauma by parents.

Resolution was "characterized by elements reflecting integration of the experience of the diagnosis into parents' representations, which in turn allows for reorientation and refocus of attention and problem solving to present reality" (Pianta et al., 1996, p. 242). Parents who were classified as resolved demonstrated a recognition of emotional change since diagnosis, an assertion of moving on in life, suspension of the search for reason, an accurate representation of the child's abilities, and a balanced description of both positive and negative aspects of this experience. A lack of resolution was related to grieving and reflected "an underlying strategy of attempting to change, or alter, the reality of the experience" (Pianta et al., 1996, p. 243). Elements of lack of resolution were cognitive distortions of thoughts concerning the child, an active search for reasons, being stuck in the past, cut off from the experience of diagnosis, and confusion and mental disorganisation indicated by how the parent told the story. “These elements reflect the parents’ representational systems’ focus away from the reality of the child’s needs, feelings, and signals” (Pianta et al., 1996, pp. 243-244).

Approximately 50% of the mothers were classified as unresolved independent of type or severity of diagnosis, the child’s developmental age, or the amount of time that had passed since the diagnosis (Marvin & Pianta, 1996). The parent’s lack of resolution was found to be associated with insecure attachment of the child. Results from Marvin and Pianta’s research suggest that a substantial part of the group of parents was highly affected by the child’s diagnosis, and that resolution cannot be expected to occur spontaneously with the lapse of time.

Diverse results in terms of parents’ reactions to the diagnosis have been found in different countries. Dutch studies of parents of children with cerebral palsy have indicated a much higher level of resolution (> 80%), with the level being related to both severity of the disability and, to some extent, time since diagnosis (Rentinck et al., 2010; Schuengel et al., 2009). Some of the discrepancies in results between studies may be explained by differences in the consequences of the diagnosis for American families (Marwin and Pianta, 1996) and Dutch families. The link between the family’s economic resources and access to health care and high quality education differ between countries (Schuengel et al., 2009). Oppenheim et al. (Oppenheim et al., 2007; Oppenheim, Koren-Karie, Dolev, & Yirmiya, 2009) investigated parent resolution in Israeli parents of children with ASD or pervasive developmental disorder (PDD) using the RDI. In their study, only 33-37% of mothers and 52% of fathers were considered to be resolved. In accordance with Marvin and Pianta (1996), Oppenheim et al. (2007) found no relation between severity of diagnosis or time since diagnosis and parent resolution, and were unable to find an explanation for the relatively small number of parents in their sample being resolved.

Results from studies of reaction to diagnosis described above indicate that some parents manage well, while others find it more difficult to adapt to the situation. The original dichotomous coding system of the RDI has been challenged by Wachtel and Carter (2008), who developed a continuous scale to reflect resolution as a dynamic process. When factor analysis of the scale was conducted, the two factors’ emotional resolution and acceptance resolution were found. Parent’s emotional resolution appeared to be an important factor for parent-child interaction, as it was related to parents' cognitive and supportive engagement with their children with ASD (Wachtel & Carter, 2008).

Parental Representations and Attachment of Children with ID

A relationship between maternal representations of a child with ID, parent sensitivity and child attachment has been established (Oppenheim et al., 2007). The ID of a child appears to affect the link between parenting behaviour and child attachment. Oppenheim et al. (2007) found that there was an association between resolution and maternal sensitivity towards the child, and that low-functioning children were particularly sensitive to low involvement by parents resulting in their lower responsiveness. An association between certain negative affects (worry, pain and sense of burden) and insensitive and unsupportive behaviour by the mother towards her child has been found (Button et al., 2001), although this may not necessarily constitute a causal relationship. Disorganised attachment is more common among children with autism, Down's syndrome and CP than in TD children (van Ijzendoorn, Schuengel, & Bakermans-Kranenburg, 1999). In order to better understand the relationship between parental sensitivity and attachment among children with disabilities, van Ijzendoorn et al. (2007) compared children with ASD, mental retardation, language delays, and TD children and their parents. In all groups, except for the children with ASD, the level of parental sensitivity was related to child attachment security and organisation, as well as child responsiveness. The authors speculated that children with ASD may require different parental behaviour than other groups of children, as normal parenting behaviours may be experienced as threatening for the child due to neurological impairment (van Ijzendoorn et al., 2007). In a later study by Oppenheim et al., mothers' insightfulness into the experience of their child with ASD in combination with resolution to diagnosis were related to secure attachment of the child (Oppenheim, Koren-Karie, Dolev, & Yirmiya, 2009).

Parents' reactions to the diagnosis have been explored from the standpoint of attachment theory. Implicit in the concepts of resolution/lack of resolution is the view that parents experience the diagnosis as a loss, and that the loss is followed by a grieving process that may end with parents succeeding or failing to reorganise their internal working models of the child. Parental reaction to the diagnosis has turned out to be of great significance not just for the parents themselves, but also for the mental health of their children. Although these findings are of great importance, the field of research on parents' reactions to the diagnosis is not yet comprehensive, and basic assumptions such as treating the discovery of the disability as a loss that is followed by certain stages of grieving have been challenged (Blacher, 1984).

Finding out that one's child has ID may cause parents to grieve the loss of an expected typically developing child, however, the experience is most likely mixed with some positive feelings related to a new member having entered the family. Parenting a child with ID is an ongoing process, and throughout life new challenges will occur (Seltzer & Heller, 1997), which means that theoretical models of grieving may not accurately describe the process that these parents are going through.

Fathers of Children with ID

The majority of studies to date have focused on mothers' experiences of parenthood and reactions to the child's ID, and fathers have sometimes been described as invisible or marginalised (MacDonald & Hastings, 2010b), as they did not become subjects of research until the 1980s (Blacher & Baker, 2002). However, as fathers appear to increase their involvement in the care of these children, fathers have become a new point of interest (MacDonald & Hastings, 2010b). This increase in father involvement may be due to, for instance, the de-institutionalisation of individuals with disabilities (MacDonald & Hastings, 2010b) and changes in the social construct of the father's role in Western society (Tseng & Verklan, 2008). Although fathers' involvement may vary widely on an individual level and is affected by the cultural context, it has been found that on a group level there is an increase in the interaction between fathers and children compared to past generations (Pleck, 1997). Consequently, we would expect children to affect their fathers to a greater extent – both in terms of rewards and new challenges. Likewise, we would expect fathers to be of increasing importance to their child with ID. Study IV explores the experiences of Swedish fathers parenting a child with ID in a longitudinal perspective.

One may ask why fathers as a group would differ in any essential way from mothers, and why fathers of children with ID and their special circumstances are of particular interest. Male parents have been found to be important, if not essential, in their role as parents (Pleck, 2010). It may not be the fact that they are men *per se* that is important (as same sex couples are equally competent parents (McCann & Delmonte, 2005)), or that they differ from mothers in terms of masculinity (Pleck, 2010). What appears to be significant is that their presence and engagement in childcare constitute important contributions to the child and the partner. Men's parenting behaviour differs from women's, but differences are relatively small and the overlap is considerable between mothers and fathers (Lamb, 2010). Although gender differences influence some of the specificities of parenting behaviour, individual and environmental factors such as personality, timing of first child, child characteristics, and social and economic status of the family also affect parenting behaviour (Lamb, 2010). However, the culturally constructed role of the father in a family setting and in society appears to carry significant meaning in terms of self-image and identity, and is likely to be related to parenting behaviour and relationships within families. Most studies on fathers of children with ID have been carried out in English-speaking and some Nordic countries, which is likely to be reflected in the results. The cultural and social circumstances affecting Swedish parents will be considered in the next section.

The primary focus in current studies about fathers of children with ID/DD has been on how fathers are affected by and manage the unique situation of parenting a child with a disability, as well as their level of involvement in child care. While mothers tend to experience increased levels of stress and depression (Singer, 2006), results from studies of fathers show mixed results. Fathers appear to be less affected by the child's diagnosis in terms of well-being than mothers (Gerstein, Crnic, Blacher, & Baker, 2009; Saloviita, Itälinna, & Leinonen, 2003). Results from studies comparing fathers of children with ID/DD to fathers of TD children point in different directions. Houser and Seligman (1991) found no effects of parent gender or the diagnosis of the child on American parents' levels of stress, while Olsson and Hwang (2001) found that the subgroup of fathers of children with autism experienced higher levels of depression than fathers of TD children in Sweden. In contrast with the modest effects described above, Oelofsen and Richardson (2006) found British fathers of children with DD to be highly affected by the disability of the child in terms of parenting stress, but again less affected than mothers.

When exploring what factors affect Canadian mothers' and fathers' stress over time, from the child's first to tenth year, Hauser-Cram et al. (2001) found child behavioural problems to increase both child-related stress and stress related to the parenting role. Child-related stress in fathers was also related to child gender and level of mother-child interaction, as it increased more steeply over the years for fathers of girls and for fathers in families with low mother-child interaction. Another interesting finding was that fathers' child-related stress increased steeply over the first three years of the child's life, and continued to increase at a slower pace over the seven following years. This pattern differed from mothers whose increase in child-related stress was even over the 10 years (Hauser-Cram et al., 2001). Several explanations have been suggested for why fathers react differently from mothers in parenting a child with ID. For instance, fathers of children with DD are unlikely to increase their level of involvement in childcare to the same extent as mothers do (Dyer, McBride, Santos, & Jeans, 2009), and tend to continue their involvement in paid work to a higher degree than mothers (Olsson & Hwang, 2006). Although Hauser-Cram found generally high levels of father stress, such explanations could be supported by results from the longitudinal study (Hauser-Cram et al., 2001), indicating that fathers in families with low mother-child interaction experience higher levels of stress, perhaps due to an increased responsibility for fathers in terms of childcare. Carpenter and Towers (2008) found that British fathers wish to become more involved in childcare and request service providers and employers to be more accommodating and flexible to facilitate their involvement.

When looking at what father involvement implies, fathers' emphases appear to be on playing, nurturing, discipline, and deciding on services, while they appear to be less involved in activities concerning hygiene, dressing, feeding, teaching, and therapy, or taking children to service providers – tasks that tend to be the mother's main responsibilities (Simmerman, Blacher, & Baker, 2001). A traditional distribution of responsibilities within the family has been found to be accentuated by the presence of the child's disability (Breslau, Salkever, & Staruch, 1982; Gray, 2003), and fathers focus more on issues concerning the world outside the family while mothers pay closer attention to day-to-day tasks and the expectations they feel on themselves (Pelchat, Levert, & Bourgeois-Guérin, 2009). Factors that have been identified to affect fathers are, for instance, if the child is diagnosed with autism (Olsson & Hwang, 2001) or has a relatively mild DD (Trute, 1995), which appear to make fathers more vulnerable to depression. Fathers of children displaying difficulties in terms of language development, affect regulation and behavioural problems tend to be less involved and express negative attitudes towards involvement in childcare (Bristol, Gallagher, & Schopler, 1988).

Several similarities and some gender differences have been found in Finnish parents' adaptation to and coping strategies when dealing with the challenges of the child's disability (Saloviita et al., 2003). For both mothers and fathers, the parent's definition of the situation appears to be a strong predictor of parental stress, and factors such as severity of the disability or other child characteristics appear to affect parents' level of stress indirectly via the definition of the situation, with mothers being more affected by child characteristics and fathers being more concerned with issues around social acceptance of the child (Saloviita et al., 2003).

Mothers tend to use coping strategies more frequently than fathers do which may be a consequence of mothers' situation being more challenging, as they tend to take more responsibility for the child (Saloviita et al., 2003). In the UK, fathers appear to be less likely than mothers to seek social or emotional support (Sullivan, 2002). In comparison with fathers of TD children, fathers of children with ID in the US use more distancing, escape-avoidance and positive reappraisal to cope with difficulties (Houser & Seligman, 1991). It has been suggested that the use of distancing and escape-avoidance may be adaptive strategies for fathers in terms of mental health, as their role often requires less interaction with young children than mothers. It may not, however, be effective in the long run, as the child will continue to be a part of the father's life (Glidden, Billings, & Jobe, 2006). Using these types of coping strategies could counteract the father's involvement in childcare, as fathers who are more present-centred (or mindful) also display higher involvement in childcare (MacDonald & Hastings, 2010a). Fathers' and mothers' reactions may also change with time. When interviewing American parents of children with autism 10 years apart, Gray (2002, 2006) found that most of them felt their situation had improved and became more manageable since their children had become adults.

In an analysis of fathers' published autobiographical accounts of parenting a child with a severe disability, strong ambivalent emotions were found and fathers described feelings of despair alongside experiences of personal development (Hornby, 1992). Although Hornby's sample may not be representative of the population of fathers of children with ID (in terms of SES and education and so on), the study may still constitute an important historical documentation of fathers' very personal accounts highlighting the emotional turbulence experienced by some fathers throughout the child's upbringing. Apart from Hornby's study there appears to be limited knowledge concerning fathers' experiences and inner representations of their children with ID. The limitation is not unique to the field of fathers of children with ID, but appears to apply to father research in general. However, emotional reactions to the child and parenthood are highly important, as they influence the level of motivation for providing sensitive and engaged caregiving (Bell & Richard, 2000), and children with ID may require even higher levels of sensitive parenting than do TD children (Biringen et al., 2005; de Falco, Venuti, Esposito, & Bornstein, 2009).

Parenting a Child with ID in Sweden

Since the 1980s, a pervasive reform of the care for individuals with ID has been carried out in Sweden (The National Board for Health and Welfare, 2009). Just like in many other Western countries children and adults were moved from living in institutions to growing up in families (biological or foster families) and living integrated in the community with support. Being a parent of a child with ID tends to be more demanding than being a parent of TD children, as children with ID require more support and care in general (Hollins, Woodward, & Hollins, 2010). From a global point of view many children with ID and their families are disadvantaged in terms of SES (Emerson et al., 2009; World Health Organisation, 2008). In this context, Swedish families of children with ID may serve as an interesting example for researchers, as the Swedish social welfare system attempts to compensate for the economic hardship. Sweden has relatively generous regulations and support available for all parents in terms of parental leave and parents' allowance, and families of children with ID are often entitled to additional support. Most individuals with ID in Sweden receive some support in accordance with the special civil rights law – the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS). Today, about 36,000 persons with intellectual disabilities (about 0.4% of the population) receive support through the LSS, and more than 17,000 of these are children and youth (The National Board for Health and Welfare, 2009). Families of children with ID can apply for economic compensation for the increased economic burden such as loss of income and the extra expenses due to the requirements of the child with disabilities (RFV, 2002).

Children with ID may attend preschool through the ordinary childcare services. When they reach school age most children with ID attend special school for children with learning disabilities – an integrated part of the ordinary school system. In order to allow parents of children with severe disabilities time off, there is short-term accommodation for their children and also the possibility to access support in their homes. Children who are diagnosed with ID and their families receive counselling, support and treatment by local habilitation teams in addition to the support provided by the regular national health services (The National Board for Health and Welfare, 2009). Despite the seemingly unique possibilities of Swedish families of children with ID to receive healthcare and social and economic assistance, many parents describe great difficulties in gaining access to appropriate support (Socialstyrelsen, 2005). Parents explain that they struggle to get access to knowledge about their rights to receive support, and some families experienced that only when the family was in a situation of crisis the authorities provided the appropriate information and support. To coordinate and apply for support is highly time-consuming for families, tasks that are added to a situation that is already stressful.

Despite the fact that Swedish parents of children with or without ID do not differ substantially in terms of economic status, the parents of children with ID appear to experience similar reactions to the diagnosis of the child, as international studies show in terms of well-being (Olsson & Hwang, 2001; Singer, 2006). Swedish mothers exhibit higher levels of depression than fathers, and mothers of children with autism experience more distress than parents of children with ID (without autism) and children without ID (Olsson & Hwang, 2001). It is important to note that these elevated levels of depression in the Swedish sample were independent of the socio-economic status of the family – a stressor that is known to be related to parenting stress in other countries (e.g., Emerson, 2003). Olsson, Larsman and Hwang (2008) suggested that the cumulative risk of socio-economic hardship (a modified way to measure experienced shortage of economic and material resources in the family), child behavioural problems and negative impact of the child may together with low sense of coherence (a protective factor) explain heightened levels of depression. Mothers may be especially vulnerable to risk factors, as they tend to take on the major part of the increased responsibility in childcare related to having a child with ID (Olsson & Hwang, 2006). These results support the theory that the combination factors on different levels of the ecological system transact and influence the child and the family (Furstenberg et al., 1999).

In a qualitative study by Riddersporre (2003), parents of children diagnosed with Down's syndrome (all of which had ID) were observed during the child's first year. Parents were described as having conflicting emotions towards the child and the disability, and dealt with this conflict in three different ways: (1) idealising—focusing on positive aspects and emotions; (2) struggling—perceiving the world as unsympathetic and hostile; and (3) everyday—avoiding strong emotions searching for normality. Broberg (2011) explored how parents relate to and are affected by expectations and discourses in the Swedish society towards being a parent of a child with ID. Parents related to expectations that having a child with ID is a tragedy and that people, including themselves, expect them to be super parents in order to manage the situation. However, these images appeared too stereotypical to correspond with the dynamic and versatile experience described by parents. Parents also resisted the "clinical gaze" that they perceived from others, which made them feel objectified and vulnerable (Broberg, 2010). Both of these studies (Broberg, 2010; Riddersporre, 2003) highlight the impact on the parents of the perceptions and discourses in society, which are communicated both through professionals and the general public.

The roles of mothers and fathers are highly affected by expectations and cultural values of the society that families are living in and traditional patterns of dividing responsibilities tend to be strong (Breslau et al., 1982; Gray, 2003). Swedish parents are encouraged by the state to share responsibility for childcare and household duties equally (Socialdepartementet, 2007). However, in studies of Swedish parents of TD children, Elvin-Nowak (Elvin-Novak, 2001; 2005) found the experiences of mothers and fathers to be quite different in some aspects. An experience of guilt in relation to childcare was common among mothers. They described how they were trying to manage the balance between participating in working life and at the same time fulfilling the expectations of being a good enough mother (Elvin-Novak, 2001). On the contrary, many fathers expressed satisfaction with their contribution as parents in general, independent of the variation of their actual involvement in childcare (Elvin-Nowak, 2005). Elvin-Nowak interpreted this anomaly as a result of the transformational state of the father's role in Swedish society. Although fathers are encouraged to increase engagement in childcare, the change is slow and the standards for the new father's role do not appear to be set. The standard for what constitutes good enough fatherhood appears to be flexible and can be determined by individual fathers.

To summarise what signifies the situation of Swedish parents of children with ID, they seem to experience many of the same difficulties as parents in other parts of the world. Despite the relatively generous social and economic support available for those families, some parents experience difficulties getting access to such benefits, which may add further strain. Many Swedish couples appear to have a traditional division of responsibilities, while there is a tendency among others to strive towards equality – a diversity that could also be expected to be found among parents of children with ID.

Viewing the Child through the Eyes of the Parent – Methodological Perspectives

Studies I, II, III, and IV all explore parents' descriptions and experiences of their child with ID. However, they differ in terms of aims and perspectives. Parents' descriptions of characteristics of their child with ID can be collected for different purposes and carry different meaning depending on how questions are formulated and upon the setting in which questions are asked. In studies I and II, mothers and fathers of children with and without ID were asked to individually describe their child's temperament through questionnaires. In studies III and IV, parents' subjective perceptions and experiences of the child and parenthood were collected through semi-structured interviews and subsequently analysed with interpretative phenomenological analysis (Smith, Flowers, & Larkin, 2009). In the following sections, the value and meaning of parents' descriptions collected through different methods will be discussed.

Measuring Child Characteristics through Parents' Descriptions

In the context of research, larger studies investigating child characteristics typically use one parent's ratings of the child – most commonly the mother's (Seifer, Sameroff, Dickstein, Schiller, & Hayden, 2004). When investigating child characteristics researchers aim to collect descriptions of children that are as close to "objective reality" as possible. What is implied by objective reality is not easily defined, but it is of great importance to clarify what informants base their ratings on. Different types of informants such as teachers, parents and children tend to differ in their descriptions of child characteristics (Achenbach et al., 1987). However, agreement between informants who are in a similar relationship to the child such as teacher-teacher or mother-father tend to be higher suggesting situational specificity (Achenbach et al., 1987). The tradition of using mothers' ratings instead of the mean mother-father ratings or ratings by independent raters may have both financial and practical reasons. Seifer, Sameroff, Dickstein, Schiller, and Hayden (2004) investigated the reliability of mothers' temperament ratings of their children. Mothers' ratings of children from other families corresponded surprisingly well with trained raters and were considered reliable. However, when rating their own children, mothers' ratings turned out to be positively biased. What this otherwise nicely designed study does not tell us is whether mothers' ratings are less reliable or valuable than trained raters. The differences found could be an indication that mothers' ratings contain a high degree of subjectivity or, alternatively, that mothers have a better knowledge and understanding of their own child's behaviour than do "objective" raters.

The fact that different types of informants differ in their ratings of child characteristics remains a problem for researchers, as there is no obvious standard or correct version to relate to. Trained raters have commonly been thought to provide the most accurate descriptions of child characteristics, but results from a review by Achenbach et al. (1987) suggest that differences between raters could simply be a reflection of differences in the relationships between raters and the subject that is being rated. What turns out to be important is to have an awareness of the relational content when interpreting results from studies of child characteristics.

One approach that has been used to further understand the dynamics of parents' ratings of their children is by looking at interparental agreement. Martin and Halverson (1991) found certain child characteristics, particularly behavioural problems and "difficult temperament", to be related to parental agreement, while parental characteristics did not predict parental agreement on child temperament. Mothers tend to be more discriminating, rating "normal" healthy children as more positive and easily managed (compared to fathers ratings), and children with behavioural problems less positively in terms of management. Inter-rater correlations were higher for parents of children displaying difficult behaviour within the non-clinical range than for parents of TD children with less difficult behaviour. For parents of children considered above the clinical cut-off point for behavioural problems parental agreement was low. The main body of research investigating parental agreement has been focused on parents' ratings of child behavioural problems. The results show that parents agree to a higher degree about externalising problems compared with internalising behaviour (Duhig, Renk, Epstein, & Phares, 2000). This may be due to externalising problems being observable and easier to detect. A small, but systematic, difference was also detected between parents with mothers reporting more behavioural problems than fathers (Duhig et al., 2000).

So far, little is known about the differences and similarities in mothers' and fathers' ratings on temperament in children with ID. Stoneman (2007) found that correlations between mothers' and fathers' ratings of children with ID were around 0.54. Children with ID as a group are known to display higher than normal levels of behavioural problems, which could affect the level of agreement between parents. This is an issue that was further investigated in study I.

In studies I and II, the parent's ratings of the child's temperament were explored in relation to experiences of the child's positive and negative impact on the parent. In study I children were grouped according to diagnosis. As the mixed group of children with ID and specific diagnostic groups are known to be heterogeneous in terms of behaviour, in study II children were clustered according to temperamental profile. The aim was to clarify the specific impact of child temperament on parents.

Interpreting Parents' Subjective Experiences

Results from studies of parental representations indicate a high level of subjectivity and affective content in parents' descriptions of their children. Despite this, parents are commonly used as informants of child characteristics and clinicians rely heavily on parents' reports about child symptoms when diagnosing emotional and behavioural problems (Achenbach et al., 1987). As mentioned before, parents' internal representations of the child and parent-child relationship influence the parent's behaviour towards the child, and in turn child behaviour (MacKenzie & McDonough, 2009). For instance, when looking at mothers' representations of their infants and the relationship between infant's crying and experienced burden, MacKenzie and McDonough found that maternal representations moderated the impact of infant crying on parental perceptions. Mothers who had distorted or disengaged internal representations of their child were particularly negatively affected by their infant's crying, while most mothers considered to have balanced representations of their child were unaffected by the crying. These results indicate that it is not only the actual behaviour of the child that affects the parent’s experience. Psychological processes within the parent such as internal working models may be equally important in shaping parenting behaviour. A further important result found by MacKenzie and McDonough (2009) was that negative perceptions of infants (unrelated to infant behaviour) were related to increased crying and difficult behaviour at 33 months of age.

Parental representations can be explored by asking parents about their perceptions, attributions and interpretations of the child’s characteristics and behaviour. In studies III and IV, parents’ narratives about their everyday lives with a child with ID were explored to further understand how the child with ID may be experienced by fathers and mothers. Interviews were analysed using interpretative phenomenological analysis (IPA). The aims of IPA are twofold: “1) an attempt to understand the participants’ world: to produce a coherent, third-person, psychologically informed description, with the aim of getting as close to the participants’ view as possible; 2) interpretative analysis: to position descriptions in a relationship to a wider social, cultural or theoretical context, to provide a critical and conceptual commentary on the participants’ sense-making activities” (Larkin, Watts, & Clifton, 2006, p. 104).

As the IPA is an approach to research rather than a systematic method (as opposed to methods like grounded theory), applying IPA methodology requires the researcher to be familiar with and let the analytic process be guided by philosophical standpoints. According to Smith, Flowers and Larkin (2009) key elements of IPA are that it is idiographic, phenomenological and hermeneutic. Schleiermacher was one of the early philosophers that influenced the IPA method (Smith, Flowers, & Larkin, 2009), stating that all human expression can be interpreted within the hermeneutic tradition through reconstruction of the premises framing the expression (Palmer, 1969). The interpreter should aim to relive what the participant has experienced and ultimately “understand someone better than he understands himself”. In IPA the means for reaching these aims are a combination of careful methodology in which the researcher on the one hand conveys the participant’s own experience and on the other hand applies a theoretical framework for analytical interpretation of these personal experiences.

Schleiermacher also pointed out the importance of balancing an understanding of the individual expression with identification of the general. Although Schleiermacher is primarily seen as a representative of hermeneutics, these basic statements communicate much of the key elements of IPA. Heidegger developed some important aspects of a phenomenological-hermeneutic tradition when he described how we approach and experience the surrounding world (Palmer, 1969). Most things we see are already interpreted and we take a lot of things for granted. For instance, when walking into a carpenter's workshop we have ideas about what most tools are meant for without reflecting on it. Identifying those things taken for granted is a central objective of the phenomenological approach. We also have a notion of the extent of our own existence – that life will end at some point, etc. – which influences our way of relating to phenomena. Gadamer pointed out the significance of time and people's ideas around the past and the future (Palmer, 1969). Everything that we see and experience is seen through a person's relationship to history and ideas about what is about to happen in the future. These ideas need to be examined as contextual factors. For instance, the child's diagnosis of ID may affect some of the basic assumptions that many parents have about what future family life will be like, and sometimes require a redefinition of expectations and things taken for granted. By applying a phenomenological approach this process may be articulated by participants and placed in a theoretical context by the researcher.

A methodological contribution from Heidegger was the *hermeneutic circle*, which describes how the process of interpretation and understanding is ongoing, alternating between new understandings of the parts and the whole. Another tool from hermeneutics of the IPA was picked up from Ricoeur (1993), illustrating the different modes of the interpretation process – the hermeneutics of empathy and of suspicion. These approaches represent different ways of reading transcripts or listening to interviews in which the researcher either focuses on reliving the participant's experience, or analyses it from an outside theoretically informed perspective. The IPA process includes both of these modes, and the research report should clearly communicate both levels of interpretation.

Studies III and IV both have an idiographic approach in that they follow parents' individual paths from discovery of the disability and relating experiences to individual contexts, and defining themes both within and across participants' accounts. A phenomenological approach guided analysis of data in the search for an inside perspective of parents' self-defined meaning and experiences of parenting a child with ID/DD. Parents' ways of managing and thinking about parenting a child with ID/DD was further interpreted from a psychological perspective with a combination of inductive and deductive strategies, initially allowing data to shape themes and then applying concepts from the theory of parental representations (Zeanah & Benoit, 1995) on the themes.

Summary of Studies

General and Specific Aims

General aim

Research looking at parents’ experiences of having a child with ID has tended to focus on negative effects of problematic child behaviour rather than the full range of experiences and behaviour (Hastings & Taunt, 2002). Parents of children with ID, and mothers in particular, experience somewhat higher levels of parenting stress and depression (Singer, 2006), although the experience of parenting a child with ID has been found to vary greatly both within and between parents (e.g., Green, 2007; Marvin & Pianta, 1996). To explore the diversity of parents’ experiences, the four studies aimed to investigate parents’ descriptions and experiences of their child with ID during their first few years from two different perspectives. In studies I and II, parents’ descriptions of child temperament were analysed and explored in relation to positive and negative impact of the child. In studies III and IV, interviews with parents exploring their subjective experiences of the child and the parent-child relationship were analysed.

Study I

Behavioural problems in children with ID are known to, at least in part, explain increased levels of parenting stress (Baker et al., 2005; Hassall et al., 2005; Hastings, 2002; Herring et al., 2006). Study I focused on parents’ descriptions and experiences of general behaviour (temperament) in children aged 0-6 years with and without ID. The three aims of the study were:

1. To examine differences and similarities in parents’ descriptions of child temperament, and what positive and negative impact young children with or without ID have on their parents;
2. To compare parents’ descriptions of child temperament, as well as positive and negative impact of diagnostic subgroups; and
3. To investigate differences between mothers’ and fathers’ ratings, as well as mother–father agreement on temperament in children with and without ID.

Study II

Despite previous efforts to understand temperament in children with intellectual disability (ID), and how child temperament may affect parents, the approach has often been limited to exploring child temperament in relation to the diagnosis, with the inherent risk of overlooking individual variation of children's temperament profiles within diagnostic groups. By approaching temperament in children with ID with cluster analysis, we were hoping to clarify to what extent individual variation in temperament is related to parents' experiences of their children. The four aims of this study were:

1. To identify meaningful temperament profiles among children with ID. The exact shapes of profiles are difficult to predict, as the method of cluster analysis is exploratory. However, according to previous findings, we expected children with ASD to belong to a profile marked by high negative emotionality (Konstantareas & Stewart, 2006) and shyness, and low sociability (Bailey et al., 2000), while, for instance, children with DS (Down syndrome) would be expected to be rated as low in emotionality (Gartstein et al., 2006; Nygaard et al., 2002) and high on sociability (Fidler, Hepburn et al., 2006);
2. To validate temperamental profiles found in children with ID by exploring the relationship between temperament profiles and measures of other child behaviour;
3. To explore whether temperament profiles are related to, and may predict, positive and negative impacts on parents, and consequently may constitute a risk of increased parenting stress; and
4. To compare temperamental profiles of children with ID, in terms of differences and similarities, to temperament profiles of age-matched TD children.

Study III

The aim of study III was to explore variation in parents' descriptions and experiences of their child, aged between 0 and 5 years, that was recently identified as having an ID. Two steps of analyses were made looking at (1) content and meaning, and (2) format and narrative style. More specifically the three aims were:

1. To find out how parents' describe their child with ID;
2. To explore how parents' describe the child's ID; and

3. To investigate and interpret how parents describe their experience of being a parent in this context.

Study IV

Fathers' interaction with and presence in the lives of children with ID has increased over the past few decades as a consequence of deinstitutionalisation of children and changes in the father's role (MacDonald & Hastings, 2010b). The main aim of the present study was to explore fathers' experiences of parenthood in relation to a child with ID/DD in a longitudinal framework from the initial discovery of the disability and during the five following years. Three specific aims of the study were:

1. To follow eight fathers' individual paths from discovery of the disability and five years on, relating experiences to individual contexts, and defining themes both within and across participants' accounts;
2. To search for an inside perspective of fathers' self-defined meaning and experiences of parenting a child with ID/DD; and
3. To interpret fathers' ways of managing and thinking about parenting a child with ID/DD from a psychological perspective with a combination of inductive and deductive strategies, initially allowing data to shape themes and then applying concepts from theory of parental representations (Zeanah & Benoit, 1995) on the themes.

Methods

Study I

Participants in study I were parents of 55 children with ID/DD recruited at their initial contact with clinics providing services for children with disabilities. The aim in recruiting was to sample a heterogeneous group representing the variety in the population of parents of children with ID/DD with the common experience of having found out that their child has an ID/DD within the past six months. In the group of parents of children with ID/DD, 55 mothers and 44 fathers of 55 children returned complete questionnaires. Children with ID/DD were either diagnosed, or were in the process of being diagnosed, with ID and/or autism. They were aged between 5 months and 79 months (mean age 37 months) and 62% were boys. Primary diagnoses of the children were: intellectual disability nos (N=14); autism/ASD (N=12); Down syndrome (N=9); Cerebral Palsy/motor impairment (with ID) (N=5); other diagnoses, including chromosomal abnormalities (N=15).

A control group consisting of parents of TD children was recruited through the SPAR register (a national register of all individuals in Sweden). In the control group, 178 mothers and 149 fathers of 183 children returned complete questionnaires. The mean age of children in the control group was 41 months, and 55% were boys. The ID and control groups were matched on child gender, age and residential area. Parents' characteristics such as age, level of education or annual professional income did not differ significantly between groups.

The Swedish version of EASI Temperament Survey, containing the five subscales: Emotionality, Activity, Shyness, Sociability, and Impulsivity (Buss & Plomin, 1984; Hagekull & Bohlin, 1990), was used to measure temperament in children. Parents were sent one questionnaire each via mail and were instructed to complete the questionnaires individually. Two subscales from the Family Impact Questionnaire (FIQ; Donenberg & Baker, 1993) were used to measure the child's positive and negative impact on the parent.

Analysis of variance (ANOVA) and post hoc t-tests were performed to explore differences between children with and without ID/DD, between diagnostic groups, and between mothers' and fathers' ratings. Level of agreement between mothers' and fathers' ratings was investigated using analysis of absolute and global agreement and Pearson's correlations.

Study II

The samples of study II overlapped with samples of study I in terms of recruitment procedures and criteria for inclusion. However, data in study II were selected from data collections made over the years 2005-2009 from the same sample with the aim of assembling a more homogenous group in terms of child age. Participants in study II were 49 mothers and 33 fathers of 49 children with ID or DD (if the child had not received a diagnosis of ID due to recent discovery of delay), and some of them had an additional primary diagnosis. The children were aged between 48 months and 82 months (mean age 61 months) and 63% were boys. The children's primary diagnosis in addition to an ID/DD as reported by parents were: Down syndrome (DS) (N = 8); ID/DD nos (ID) (N = 11); autism spectrum disorder (ASD) (N = 20); Cerebral palsy/motor impairment (CP/MI) (N = 6); and 'uncommon diagnoses', including uncommon chromosomal abnormalities or syndromes (N = 4). There were no significant differences between the diagnostic groups in terms of child age. A contrast group consisting of parents of TD children was recruited according to the same procedure as in study I. A total of 80 mothers and 58 fathers of 82 children (mean age 59 months) out of which 59% were boys participated. The ID and contrast groups were matched on child gender, age and living area. Parents' characteristics such as age, level of education and annual professional income did not differ significantly between groups.

Just like in study I, the Swedish versions of the EASI Temperament Survey (Buss & Plomin, 1984; Hagekull & Bohlin, 1990) and the positive and negative subscales of the Family Impact Questionnaires (Donenberg & Baker, 1993) were used. Additionally, the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) and selected parts of the Nisonger Child Behaviour Rating Form (NCBRF; Aman, Tassé, Rojahn, & Hammer, 1996) measuring self-injury and stereotypic behaviour were used. Child's level of functioning was also rated. All questionnaires were completed individually by parents.

After removing outliers, 42 children with ID/DD and 78 children in the contrast group were cluster analysed separately using the mean mother-father rating of the child's temperament. Initially, hierarchical cluster analysis (Ward's method) was performed, followed by K-means clustering resulting in a final 3-cluster solution. Child behavioural problems, self-injury/stereotypic behaviour and level of functioning were used to confirm that clusters were meaningful. Analyses of group differences between clusters were carried out using Analysis of variance (ANOVA), repeated measures ANOVA, and post hoc t-test with Tukey's HSD correction. Hierarchical regression analyses were performed to investigate whether cluster membership made a unique contribution to positive and negative impacts on parents in addition to behavioural problems.

Study III

The sample consisted of 17 Swedish parents (8 mothers and 9 fathers) of 9 children aged between 5 months and 5 years. All parents were biological parents of the target child who was diagnosed with intellectual disability and/or autism, or was in the process of being diagnosed. The aim in recruiting was to sample a group providing examples of the variance in the population of parents of children with ID, but with the common experience of having found out that their child has an ID within the past six months. The sample was a subsample of the larger samples of studies I and II.

Mothers and fathers were interviewed individually with a semi-structured interview. The aim of the interview was to elicit descriptions of parents' perceptions and subjective experiences of everyday life with their child. The interview questions dealt with the following topics: positive and negative aspects of their present life situation, changes in perceptions of self and of the life situation related to the child, previous expectations compared to present life situation, and expectations about the future.

The aims of IPA are twofold: 1) an attempt to understand the participants' world: to produce a coherent, third-person, psychologically informed description, with the aim of getting as close to the participants' view as possible; and 2) interpretative analysis: to position descriptions in relation to a wider social, cultural or theoretical context, to provide a critical and conceptual commentary on the participants' sense-making activities (Larkin et al., 2006). Two steps of analyses were made: 1) analysis of content and meaning of *what* was being said (Kvale, 1997); and 2) analysis of format and narrative style of *how* parents spoke of the child, parenting and the disability (Gergen & Gergen, 1984; Grice, 1975; Hesse, 1999). An inductive approach was applied to allow for the most prominent themes in parents interviews to guide the formation of themes.

Study IV

The study applied a qualitative longitudinal design. Interviews with eight fathers (from the sample of study III) were carried out at three time points between the years 2005 and 2010. Each father's experience of parenting a child with ID/DD was explored from the time of the child's diagnosis throughout the following five following years. Fathers were first interviewed within six months following the discovery of the disability (I1). They were subsequently interviewed one year (I2) and five years (I3) following the first interview. Every father was interviewed by the authors using the same interview guide as in study III, with the additional regarding experiences of the child and the father-child relationship at the third interview.

As in study III, an interpretative phenomenological analysis (IPA) (Smith et al., 2009) was used to analyse relevant data. The study has an idiographic approach with the aim to follow eight fathers' individual paths from discovery of the disability and five years on, relating experiences to individual contexts and defining themes both within and across participants' accounts. A phenomenological approach guided analysis of data in the search for an inside perspective of fathers' self-defined meaning and experiences of parenting a child with ID/DD. Fathers' ways of managing and thinking about parenting a child with ID/DD was further interpreted from a psychological perspective with a combination of inductive and deductive strategies, initially allowing data to shape themes and subsequently applying concepts from the theory of parental representations (Zeanah & Benoit, 1995) on the themes.

Main Findings

Study I

Children with ID were described as having higher levels of shyness and impulsivity, and lower levels of activity and sociability compared to TD children. The two groups did not differ significantly in terms of emotionality. Differences between diagnostic subgroups were found on all the EASI scales except activity: children with Down syndrome had lower levels of emotionality than children with ID/DD nos., ASD, and other diagnoses. Children with CP/motor impairment were rated significantly lower on emotionality than children with ASD. The ASD group was rated significantly higher on shyness when compared with children with DS and lower than all other groups on the sociability scale. Children with ID/DD nos. had the highest level of impulsivity out of all diagnostic subgroups, and differed significantly from children with DS and other diagnoses.

Children with ID/DD were rated higher on negative impact on parents and lower on positive impact when compared to TD children. When comparing diagnostic subgroups in terms of impact on parents, children with DS or CP/ MI were found to have less negative impact than children with ASD and children with ID/DD nos. The level of parents' positive emotions did not differ significantly between diagnostic subgroups.

No mean differences were found between mothers' and fathers' ratings in either of the two groups, and mother-father agreement was equally high among couples in the ID/DD and control groups. Parents of children with and without ID were considered reliable informants of child temperament, particularly when using the mean of mothers' and fathers' ratings.

Results of the present study indicate both diversity and certain common temperamental characteristics when comparing diagnostic groups. Children with ASD were rated as having the most extreme temperament. Despite differences in temperament among subgroups with ID/DD in terms of temperament and negative impact on parents, positive impact on parents was on a similar level for all diagnostic subgroups indicating that positive impact may be a separate construct from negative impact – not just the opposite end of the same scale.

Study II

Three clusters were found among children with ID: *active/outgoing*, *disruptive* and *passive/withdrawn*. The active and outgoing cluster within the ID group was marked by low negative emotionality, shyness and impulsivity, as well as high activity and sociability. The disruptive cluster was characterised by the highest level of negative emotionality, shyness and impulsivity. Within the disruptive cluster, variances in emotionality, activity and shyness were relatively high, which could be due to the merging of two clusters from the 4-cluster solution and may imply partly different profiles. In the passive and withdrawn cluster, children were consistently rated as low or average in temperament variables, giving the impression of a less extreme and considerably more passive and withdrawn temperament profile. They were rated as particularly low in activity and sociability. The disruptive and passive/withdrawn clusters turned out to be unique profiles of children with ID, as they differed substantially in shape from clusters among TD children. Children within the active/outgoing cluster did not appear to differ from the clusters found among the TD children in terms of shape of profile or level of temperament variables. The validity of cluster solutions among children with ID gained support in relation to other child behavioural variables. Children in the disruptive cluster had higher negative and lower positive impact on the mother, and, in addition to child behavioural problems, membership in the disruptive cluster contributed uniquely to the prediction of negative and positive impact on mothers in particular. The initial hypotheses with regard to shapes of profiles that would include children with DS and ASD were partly confirmed.

Study III

Three factors were found in all interviews, indicating the parents' level of processing: 1) *emotional expressions regarding the child*; 2) *experience of the disability*; and 3) *time orientation*. Emotional experience with regard to the child summarised the organisation of positive and negative descriptions of the child in each narrative. Most parents described their child in both positive (affectionate/loving) and negative terms, indicating a more or less balanced experience of their child. In contrast, a few parents' narratives were more limited, describing their child in predominantly positive or negative terms offering a less nuanced picture. Experience of the disability included narrative material characterised by various degrees of acceptance of or preoccupation with the disability. Acceptance was characterised by describing the disability as a minimal or integrated part of the child, reflecting on emotional change, a sense of meaning, or personal development. The parents that appeared preoccupied with the disability were focusing on different themes such as a search for the right diagnosis, the child with ID in relation to the surrounding world. Time orientation was obtained by extracting the narrative tense in each interview. The narratives varied in terms of tense and flexibility. Some narratives were only set in the past or present, while others were mainly set in the past or present but with some attempts to think about the future as well. Yet another group was considered as “moving freely” between the past, present and future, showing a higher degree of flexibility. The three factors together may construct an image of the parent’s individual process of adjusting to the diagnosis of the child. Although parents of children with ID describe negative emotions in relation to the child and the disability, most of these parents also describe positive emotions that seem to balance the negative experiences.

Study IV

The fathers explicitly described how receiving the diagnosis of the child had affected them as persons in the theme an *interrupted path - no longer taking things for granted.* When looking at themselves as fathers of the specific child with a disability, each father perceived himself as *being a good father* most of the time with self-confidence declining only temporarily at times of great strain. The diagnosis of the child was an unexpected influence for these fathers no matter at what age the disability was discovered. The fathers’ ways of integrating, managing and living with this insight was a process over the five years of the study and was described in the theme *dealing with the unexpected* containing the subthemes *vulnerable openness, contained openness,* and *avoiding the unexpected.* After the initial shock of discovering the diagnosis, five of the fathers described a pronounced change in perception of parenthood and the father-child relationship over time. Through different paths they moved from attempts to avoid impact of the disability through different strategies, towards a contained openness in relation to the disability and the child. Two fathers described no such attempts to avoid effects of the disability, and were instead initially highly vulnerable to the ups and downs experienced by the child, subsequently arriving at a more contained openness towards the reality of the child and the disability. One father’s descriptions showed little change over time, as he maintained an avoiding strategy throughout the five years, which appeared to be an obstacle to developing a close father-child relationship as this had not been established previous to the diagnosis.

General Discussion

Children with ID as a group are known to be experienced as more challenging than TD children, as behavioural problems and difficult temperament appear to be common among these children. However, parents' positive experiences of child characteristics are also important factors affecting the experience of parenthood (Hastings & Taunt, 2002). The experience of parenting a child with ID is by no means uniform as child behavioural factors interact with other risk and protective factors. In the four studies described in this dissertation, an open perspective was taken focusing on parents' subjective descriptions of parenthood, the parent-child relationship, the child as a person, as well as more specific dimensions of child behaviour (temperament). Parents' narratives and ratings of the child were explored in relation to the diversity of parental perceptions of and emotions towards their child with ID.

To understand and evaluate the results of the four present studies it is important to consider the sample in terms of demographic variables and the common experiences that made them suitable participants of the studies. Families of children with ID all over the world tend to be disadvantaged in terms of economy, access to education (Emerson et al., 2007), and medical and psychosocial support (Nehring & Betz, 2007). In research on parents' emotional experiences of parenting their child with ID, isolating the psychological effects of the diagnosis and child characteristics from the effects of other risk factors such as poverty and lack of resources and support is not an easy task. Swedish families are not completely spared from these difficult circumstances, but the social welfare system and national health services in Sweden provide relatively good support for families of children with ID, at least diminishing these stressors (Olsson & Hwang, 2003), which makes Swedish parents of children with ID an interesting group to study.

The participants in studies I-IV originated from the same population and overlapped to a certain extent, as described in the summary of the studies above. In studies I and II, results from families of children with and without ID were compared. The lack of differences in terms of socio-economic status and parents' level of education between families of children with and without ID is somewhat unusual from an international perspective. The children with ID in the samples vary in type of diagnosis and age, but the parents all shared the common experience of having recently learned that their child has an ID at the first point of data collection. Many of these parents were waiting for a more specific diagnosis, which most of them also eventually received. Others would receive an uncommon diagnosis, with little knowledge existing about the cause and prognosis of the disability. Consequently, many parents went through a period of uncertainty, searching for knowledge about how the disability would affect the development of the child and the family – a state that is known to be stressful for many parents (Graungaard & Skov, 2007). Others anticipated a slightly more predictable path ahead, as their child had a syndrome that was relatively well explored and common with the possibility of meeting other families with similar experiences.

Parents' Experiences of the Child with ID

When interviewing parents about their daily lives with the child with ID (in studies III and IV), parents' narratives revealed information about their relationships at various levels of the ecological system and how these relationships affected the parent. In study III, mothers and fathers spoke about their experiences of the relationship to the child and their relationships to individuals and institutions of the exo- and macrosystems indirectly via the diagnosis of the child. Parents' time orientation and flexibility could be an indicator of the parent's psychological reactions and attempts to deal with the present situation. Parents' narratives were considered to vary between balanced and limited descriptions of the child. Narratives containing both positive and sometimes a relatively high prevalence of negative descriptions of the child were considered balanced descriptions, taking the special circumstances of the recent diagnosis into account. The interviews that were considered balanced all contained descriptions of joy and affection in relation to the child. These positive experiences of parenthood could counterweight some of the difficulties experienced by parents, and possibly promote well-being in both parents and children as proposed by Beresford (1996). The descriptions of the child that were considered limited lacked the nuance and variation of the more balanced descriptions, and indicated a lack of reward in the parent-child relationship that was present in the balanced descriptions.

Rosenblum, Dayton and McDonough (2006) analysed the affective tone of parents' descriptions of their TD children and assigned them to three categories: disengaged, balanced and distorted, according to the Working Model of the Child (WMCI) classification system (Zeanah & Benoit, 1995). Interviews classified as balanced according to the WMCI contain high levels of joy, medium levels of anxiety, and lower levels of anger, sadness and indifference (Rosenblum et al., 2006), which differs partly from the content considered balanced in study III. However, when listening to the parent's perspective, receiving a diagnosis is known to affect parental perceptions of the child negatively, and the presence of descriptions of difficulties and shortcomings of the child are perhaps unavoidable as indicated by results from studies of expressed emotion (Beck, Daley et al., 2004; Hastings et al., 2006;

Hastings & Lloyd, 2007). The long-term effects of these negative perceptions on the child need to be further explored, as they could be expected to affect parenting behaviour and, indirectly, also child behaviour just like in families of TD children (Rosenblum et al., 2006).

The simple notion that parents go through a process of grieving ending with a state of acceptance has been criticised, as parents of children with ID may encounter new challenges as the child grows older (Blacher, 1984). Some studies of reaction to diagnoses have claimed that there is little or no change in parents' resolution related to time since diagnosis (Marvin & Pianta, 1996; Oppenheim, 2007), while other studies have found a tendency for parents to move towards resolution over time (Rentinck et al., 2010; Schuengel et al., 2009).

In study IV, eight fathers' accounts over a five-year period were explored. The fathers' ways of speaking about their child and their own personal development in relation to the experience of parenting a child with ID indicated a process of development in most fathers. Initially, several fathers used strategies to avoid negative emotional reactions to the diagnosis, as was also found by Houser and Seligman (1991) with fathers using more escape-avoidance and distancing strategies to cope with the situation. Consistent with results from Hauser-Cram et al. (2001), several of the fathers in study IV appeared to experience an increase in stress from the first point of data collection, peaking at the second point (one and a half years following diagnosis). However, five years after they learned about the disability, most fathers in study IV appeared to have reached a state of composed openness, as they described a more stable emotional state in which they were less vulnerable to the challenges of the disability. These results are consistent with findings by Gray (2002; 2006), indicating that parents of children with autism experience a situation that improves and stabilises over time. On the contrary, Hauser-Cram et al. (2001) described a continuous increase in child-related stress, although the increase was smaller as the child grew older.

Differences in results could be due to several reasons. There is an inherent risk in studying a small sample such as in study IV, as it may not be representative of the population. However, there are also cultural aspects that could help explaining the differences in results between studies. Swedish fathers are encouraged to engage in childcare by the state (Socialdepartementet, 2007). A substantial portion of Swedish couples share parental leave during the child's first few years to some extent (Statistics Sweden, 2010), and following divorce about one-third of children alternate between parents' residences on a weekly basis as parents share responsibility for childcare (Lundström, 2009). These aspects are both represented in the present sample with fathers' involvement in childcare showing a wide variation. In study IV, fathers clearly confirm the rewarding aspects of having a close relationship with the child, a reward that may counterweight some of the difficulties related to the diagnosis and perhaps reduce stressful experiences.

Mothers and fathers who were considered preoccupied with the disability (in study III) revealed how they may be affected by relationships to others and to society in the exo- and macrosystems in relation to the disability. Parents were searching for certainty, or trying to understand or change the diagnosis of the child. They appeared to ascribe power to the diagnosis and the health system possessing the right to diagnose. Some parents were preoccupied with how other people perceived their child and worried about the child's right to have a place in society, which provides examples of how cultural values may have great impact on the individual. Although Swedish parents know that their child has the legal right to receive social and economic support, many parents also have the experience of having to struggle to get access to support (The National Board for Health and Welfare, 2005), which causes great worry about the child's future. As can be concluded from the voices of Swedish parents of children with ID (The National Board for Health and Welfare, 2005), having the legal right to support does not necessarily mean that it is easily accessed and may require parents to be competent advocates of the child's rights.

Some parents appeared to have arrived at an acceptance of the disability only a few months following the diagnosis. A state of acceptance seemed to involve little activity or struggle in relation to the diagnosis as it was seen as an integrated part of the child. The parents reflected on the emotional change that they had experienced since they first found out about the diagnosis and about the variation in their emotions related to the disability. In a study by Lloyd and Hastings (2008) looking at psychological variables in relation to parental well-being, general acceptance of the situation without trying to avoid challenges related to the diagnosis was found to be negatively associated with maternal stress. Scorgie and Sobsey (2000) suggested that having a child with a disability can be viewed as a transformative experience that may have long-term positive psychological effects on the individual. According to Palus (1993), transformations in parents involve an initial state of disequilibrium, which is later followed by reorganisation. A person's normal ways of "doing things" no longer work in the new situation and alternative ways eventually have to replace the old habits. The concept of acceptance may be adjacent to the reorganisation described by Palus (1993) in that parents are able to describe the process of personal transformations. In study IV, several fathers initially appeared to resist or avoid the impact of the disability. Later, they retrospectively described a process of disequilibrium followed by reorganisation, as fathers found new ways of approaching the future with more open expectations in the theme A broken path—no longer taking things for granted.

Parents' Descriptions of Child Temperament

Temperament in children is considered to be shaped by a combination of a biological base, developmental aspects and environmental factors (Nigg, 2006). The biological base of temperament in children with ID appears to be affected by the specific disability to various extents for different types of diagnosis as found in studies I and II. An attempt to map out some of the variation in how child behaviour and characteristics may affect parents was made in studies I and II, taking two different approaches to analysing child temperament – one dividing children into diagnostic groups and one dividing groups according to temperament profile.

Previously, a relationship between child behavioural problems and parenting stress has been established (Hassall, Rose, & McDonald, 2005; Hastings, 2002; Herring et al., 2006). Studies I and II explored child temperament as a measure of a broader range of behaviour instead of just focusing on what is considered as difficult behaviour in children. Despite being part of a highly heterogeneous group in terms of temperament, children with ID in study I differed from TD children, as they were described as shyer, more impulsive, less sociable, and less active by their parents. In terms of negative emotionality there was no difference between children with or without ID, but diversity was found within the ID group. Children with DS or CP/MI were described as having low negative emotionality, while children with ID, ASD or other diagnoses were rated high on this scale. Parents experienced their child with ID to have less positive and more negative impact when compared to TD children. When investigating whether there were any specific temperamental traits that were experienced as having positive or negative impact, negative emotionality appeared to be related to high negative impact. Impulsivity was related to both low positive and high negative impact in children with ID.

These results provide some indication that temperament may be related to diagnosis, and that certain common traits are more frequently found among children with ID when compared to TD children. What it doesn't explain is whether there are certain combinations of temperamental traits that are experienced as more or less positive or negative by parents. In study II, the same sample was explored through a person-oriented approach, attempting to identify temperament profiles (by using cluster analysis). This approach turned out to generate more fruitful results, as two unique clusters were found among children with

ID that did not resemble any of the clusters among the TD children. The extreme scores on the temperament subscales found among children in these two clusters indicate that their behaviour differs substantially from that of TD children. A third cluster, however, was also found that on the contrary resembled clusters in the comparison group, indicating behaviour within the typical range for the age group.

Results from study II confirm that temperament profile to some extent relates to diagnosis, although there are also individual differences within diagnostic groups. The disruptive temperament profile in particular, together with behavioural problems, appears to be strong predictors of less positive and more negative impact on mothers. Children with disruptive temperament were described as having high negative emotionality, impulsivity and shyness. These high ratings indicate that the child tends to show distress and easily becomes upset, has little inhibitory control, short decision time, and limited persistence in ongoing tasks, as well as feeling inhibited and awkward in new social situations (Strelau, 1998). The disruptive temperament profile appears to be experienced as challenging, and these children were also rated as having the highest levels of behavioural problems. The relationship between extreme or difficult temperament and behavioural problems has been debated and is not clear (DePauw, 2009; Nigg, 2006). Although there is likely some overlap between the concepts, temperament and behavioural problems also refer to independent characteristics, as the predictive power of behavioural problems on mother's positive and negative impact was distinctly improved when combined with temperament profile in study II.

The family is one of the most important environmental factors of young children, and parents' perceptions of and behaviour towards their children have been found to affect the temperament of TD children (Pesonen et al., 2008). Yet, there is little knowledge about the effects of parental perceptions and behaviour on temperament in children with ID. In studies I and II, parents' ratings of child temperament indicate that a majority of children with ID/DD differ from TD children in terms of temperament. Consequently, one would expect the temperamental profiles found to be partly affected by parents' level of stress and related parenting behaviour, as well as by aspects of subjectivity in parents' ratings. These two factors are obviously present in ratings of both children with and without ID, although the component of parenting stress is known to be higher among parents of children with ID. Parents' perceptions of their children could also be affected by the discovery of the diagnosis. The information about how the disability will affect the development of the child provided by clinicians and other sources may interfere with parents' ability to see the child as they are, and may indirectly affect child behaviour.

The well-being of mothers seems to be more negatively affected than the well-being of fathers by having a child with ID (Singer, 2006), and mothers in general tend to rate children with behavioural problems as more difficult than fathers do (Duhig et al., 2000; Martin & Halverson, 1991). As expected, fathers did not seem to be as negatively affected by the child having a disruptive temperament as mothers were in study II, although fathers showed a similar tendency. There was no difference in how mothers and fathers described the child's temperament, indicating that their perceptions of the child were similar even though their emotional reactions differed. In their longitudinal study of parents of children with ID, Hauser-Cram et al. (2001) found fathers to be less affected than mothers in terms of stress related to the role as parent. This could explain some of the differences in depression previously found related to gender with mothers being more susceptible to depression (Singer, 2006). A father who perceives the child's behaviour as difficult may remain relatively unaffected by this experience in terms of well-being, as it does not affect his way of perceiving himself as a father. Mothers, on the other hand, appear to be more highly affected in their role as mothers (high parent-related stress), perhaps attributing responsibility for the child's challenging behaviour to and blaming herself for the difficulties (Hauser-Cram et al., 2001)

Methodological Considerations

Representativeness of samples

Participants in the four studies were recruited via health services for children with disabilities according to ethical guidelines to preserve anonymity of families who declined to participate. Out of the 150 families who were mailed questionnaires, about 45% returned questionnaires at the first point of data collection. As a result of the data collection procedure, no information about families who did not wish to participate was available. Hence, the representativeness of the sample could not be evaluated in relation to missing data. Many of the parents could be expected to experience emotional turmoil as a result of the diagnosis and some of them had recently become parents – situations in which parents may not prioritise participating in research. The present sample may consequently be somewhat atypical, perhaps not completely representing families experiencing great difficulties. Despite this, the response rate could be considered relatively high for this type of sample, and the variation in parents' responses was wide.

The samples in studies I to IV were all selected from the same project, with parents who had recently found out that their young child had or was in the process of being diagnosed with an ID. This resulted in a relatively heterogeneous sample with a wide variety of specific diagnoses in the ID group. It also meant that a few children, as they grew older, were diagnosed with DD or another diagnosis rather than ID, which will always be the downside of including families early in the child's life to capture the initial experiences. The choice of collecting data from such a heterogeneous group of parents was based on the assumption that the parents had in common the experience of learning that their child had a condition that would continue to affect the child and the parents throughout life, despite the fact that the specific diagnoses varied. It would have been desirable to have a larger sample in order to make more solid subgroup analyses based on specific diagnosis. However, considering that Sweden is a small and sparsely populated country, and that some diagnoses are unusual, this was not possible in the present studies.

In studies III and IV, the sample size was deliberately limited to make in-depth analysis possible. The disadvantage of investigating a small sample is the risk of finding sample-specific characteristics that may not apply to other samples, although the risk could be considered limited as only themes that were present among all participants were presented. The samples of studies III and IV varied in terms of several factors such as child diagnosis and age, as well as educational level and socio-economic status of the parents.

Validity of measures

The choice of using the EASI temperament inventory also needs to be discussed, as there are several alternative measures of temperament. The IBQ/CBQ (Rothbart, 1981; Rothbart, Ahadi, Hersey, & Fisher, 2001) have been used in several studies of children with ID. The IBQ/CBQ are adapted to different age groups and contain a larger number of items than the EASI. Due to a combination of good psychometric properties and a short format that is easy to administer, and the fact that each child's age was unknown when questionnaires were initially sent out, the EASI was preferred. Parents' subjective positions when describing their child's temperament also needs to be considered because these ratings are known to be influenced by the parent-child relationship. It would have been preferable to collect child data through independent observations of the children in addition to data from parents. However, these methods would have required more resources. Instead, the longitudinal aim of the project was prioritised within the means available.

The two subscales measuring positive and negative impact of the FIQ (Donenberg & Baker, 1993) were used in studies I and II. These scales are commonly used as integrated parts together with other scales in the general positive and negative family impact scales. However, in the analysis of the impact of child temperament on the parents, the two subscales were considered more appropriate measures of the specific impact that the child had on the parent in both negative and positive direction independently. The psychometric properties of these subscales need to be further investigated.

The interview guide used in studies III and IV focused on the everyday life of parents of children with ID. This approach was expected to elicit descriptions of the experiences that were most prominent and important to parents at the time of the interview. The interview style was less direct than other interview guides employed for collecting data of parental representations (e.g., reaction to diagnosis interview, Pianta et al., 1996, and WMCI by Zeanah & Benoit, 1995). The aim of exploring parents' internal representations of the child developed during the course of the project as parents' narratives turned out to contain rich data about the child and the parent-child relationship. A potential disadvantage of using an open interview style that does not request parents to directly describe the child and the parent-child relationship is that information from some parents remains unexplored. Some parents might have provided more comprehensive information about representations of the child if they had been asked more direct questions. This was not considered a major problem in the present studies as almost all parents presented rich and varied material about their child and about the disability. However, to ensure that important aspects had not been missed, direct questions concerning the child and the parent-child relationship were added at the end of the interview guide of the final data collection.

Analysis and value of results

As mentioned above, parents' ratings of temperament contain subjective aspects with relational factors that might affect results. When describing a child's behaviour in terms of frequency or level of emotionality, activity, sociability, shyness and impulsivity each parent's frame of reference remains unknown. The rating could vary depending on if the parent compares the child to other children with or without ID, and on the relative "goodness of fit" with the parent's own temperament. Analysis of mother-father agreement is sometimes used to explore the reliability of parents' ratings. Despite the fact that behavioural problems in general, and internalising problems in particular, tend to reduce the level of parental agreement (Duhig et al., 2000; Martin & Halverson, 1991), results from study I indicated little differences in level of agreement between parents of children with or without ID. A plausible explanation for the lack of differences between groups could be that additional factors affect the level of mother-father agreement and compensate for the effect of internalising problem behaviour. For instance, regular meetings with health professionals in which the child's behaviour is discussed, and more pronounced behavioural traits in children with ID, could promote increased parental awareness of child characteristics and consequently higher parental agreement. The high level of agreement between mothers and fathers could be an indication that parents of children with ID are equally reliable sources of information about child behaviour as parents of TD children.

In studies III and IV, interpretative phenomenological analyses were carried out. The aims of both studies were explorative, initially applying an inductive approach to analysis. Nevertheless, it is important to be aware of the researcher's preconceptions and perspectives as IPA puts an emphasis on interpretation – an activity during which the researcher is required to use experience and knowledge in an attempt to understand the participants' world, and to position descriptions in relation to a wider social, cultural or theoretical context (Larkin et al., 2006, p. 104). In studies III and IV, parents' narratives were analysed from two parallel perspectives: the parent's experiences as an individual, and the parent in relation to a child with special needs and the possible consequences in terms of quality of parenting. Making psychological interpretations of parents' representations means sometimes describing connections that the parent may not be aware of or agree with. The researchers are aware that there are other ways to interpret the same data and that other perspectives could be applied. The results of studies III and IV find substantial support in the literature but need to be further explored as valid constructs. If the study was to be replicated in a different sample, it is likely that researchers would find the same factors and possibly some new constructs that were not detected in the present studies. The factors could be quantified and investigated through questionnaires on larger samples.

The present studies (I-IV) all explored the parent's descriptions and experiences of the child with ID. It would be desirable that future research would relate these findings to measures of the child's well-being and observations of child temperament, parenting style and parent-child interaction to further understand the transactions between parents and their child with ID.

Clinical Implications

Although studies I-IV were not carried out in a clinical setting, some useful clinical implications may be drawn from the results:

- Early interventions stimulating parent-child communication could promote the parent-child relationship as well as child development.
- Interventions to promote parent-child interaction may focus on the different parts of the transactional relationships between parent and child – parents' internal representations, child behaviour and parenting behaviour.
- When meeting with families of children with ID clinicians need to be aware that temperament in children with ID varies extensively and that children with atypical temperament may be a group at risk.

When looking specifically at fathers' individual processes following the discovery of the disability in study IV, reactions to the child's diagnosis seem to be somewhat delayed as most fathers initially appear to avoid dealing with the impact of the disability on everyday life. By avoiding the impact of the disability, a certain distance to the child seemed to follow. Later, those fathers' narratives indicated a more accepting approach to the disability and a closer relationship to the child. It is possible that both fathers and children would benefit from interventions promoting the process of developing a close father-child relationship at an early stage. Graungaard and Skov (2007) reported that both mothers and fathers wish to do something for their child even before they receive a definitive diagnosis. This motivation and decisiveness in parents could be directed at developing the parent-child relationship, which does not require a more specific diagnosis. Parents could, at an early stage, be given tasks that promote interaction with the child. With support from professionals, parents could learn to interpret the child's signals and promote the child's socio-emotional development and communication skills.

Sameroff and Fiese (2001) suggest that interventions could be directed at redefining the parents' beliefs and expectations about the child, which would affect parenting behaviour. Low-functioning children in particular have been found to be negatively affected by insensitive parent behaviour (Oppenheim et al., 2007; van Ijzendoorn et al., 2007). Results from studies III and IV indicate that parental perceptions and emotions towards the child with ID are diverse and may be contradictory. Parents who are negatively affected by the diagnosis may benefit from counselling, individually or in groups, to manage emotional reactions to the diagnosis. Professionals should encourage parents to explore the contradictory emotions triggered by the diagnosis, and promote general acceptance of life as it is, without trying to avoid the sometimes challenging experiences (Lloyd & Hastings, 2008). As perceptions change, the parent's reactions and parenting behaviour may also change, which could have positive effects on child behaviour and reduce behavioural problems.

Fathers tend to report being less affected than mothers in terms of well-being in relation to the child with ID (e.g., Olsson & Hwang, 2001, Singer, 2006), and they are commonly less engaged in childcare activities while focusing on problem-solving outside the family system (Frey, Fewell, & Vadasy, 1989). Fathers in general are less likely to use psychological support and participate in interventions related to childcare that are available through the health services (Phares, Rojas, Thurston, & Hankinson, 2010). This could be due to fathers not feeling the need for support, or that they expect not to benefit from the support available. However, many fathers are motivated to participate in the care of children if for instance health services are willing to make appointments outside of office hours (Carpenter & Towers, 2008). Other fathers may need to be properly informed about how important they are for their child and their partner.

Results from studies I and II indicate that many children with ID differ substantially from TD children in terms of temperament, and that children with disruptive temperament may be experienced as particularly challenging by mothers. Children rated as having a passive/withdrawn temperament profile also differ from the profiles of TD children and may be considered extreme, as these children show little activity and are described as less sociable than all other children. A disruptive child may pose great challenges to parents, while there is a risk that children with passive/withdrawn temperament may not receive the stimulation that they need because they demand less interaction from parents. Sameroff and Fiese (2001) suggested that in addition to working on parents' beliefs and perceptions of their child, families of children with behavioural problems could also be offered interventions directed at treating child behaviour. These interventions may involve medical or behaviour interventions, or work indirectly via parents participating in parent training to improve their strategies to manage behavioural difficulties.

Concluding Remarks

So far the diagnosis of ID has been based on assessing intellectual functioning and adaptive behaviour of the individual. To challenge the view that disability is situated only within the individual, the World Health Organization (2011) has emphasised that the degree or severity of the disability depends on the type and extent of impairment together with factors in the environment. These factors interact to facilitate or limit activity and participation in daily life. This conceptual model to assess the degree of the disability could also translate to the experiences of parents. Mothers and fathers explain that they are affected, not just by the impairments in different cognitive or physical domains of the child, but also by the support and constrains of the environment.

Mothers' and fathers' experiences are similar in many aspects, but some differences have also been found. Mothers seem to be generally more affected by child characteristics than fathers are. It may not be the severity of the diagnosis in terms of intellectual functioning and adaptive behaviour that determines how parents are affected in terms of parenting stress. Instead, extensive caretaking demands and behavioural difficulties appear to increase parenting stress, while the child's pro-social behaviour may have positive effects. The fact that fathers appear to be slightly less affected by child behaviour and caretaking needs could be due to the tendency of fathers to participate less in and take less responsibility for the daily care of children. Mothers consequently interact more with health care and educational institutions and may be more affected by the quality of these interactions than fathers are. Fathers' use of coping strategies, particularly escape-avoidance and distancing, may partly work as protective factors against parenting stress. Fathers spend more time interacting with external aspects of the exosystem through active participation in working life, which appears to affect their perspective on the child's disability as they tend to be more concerned with the child's future life and interaction with the environment outside the family. Differences in mothers' and fathers' roles and experiences should not, however, be overemphasised as all parents seem to be affected by, and in turn affect, a number of factors within the ecological model. Personal resources influence how parents experience and interpret input from the environment. Together, all these factors shape transactions between parents and other individuals in their surrounding world, including the child with ID.

References

Achenbach, T. M., McConaughy, S. H., & Howell, C. T. (1987). Child/adolescent behavioral and emotional problems: Implications of cross-informant correlations for situational specificity. *Psychological Bulletin, 101*(2), 213-232.

Aman, M. G., Tassé, M. J., Rojahn, J., & Hammer, D. (1996). The Nisonger CBRF: A child behavior rating form for children with developmental disabilities. *Research in Developmental Disabilities, 17*(1), 41-57.

American Association on Intellectual and Developmental Disabilities. (2012). *Definition of Intellectual Disability*. Retrieved 2012-06-04, from http://www.aaidd.org/content_100.cfm?navID=21

Bailey, D. B., Jr., Hatton, D. D., Mesibov, G., Ament, N., & Skinner, M. (2000). Early development, temperament, and functional impairment in autism and fragile X syndrome. *Journal of Autism and Developmental Disorders, 30*(1), 49-59.

Baird, G., Cass, H., & Slonims, V. (2003). Diagnosis of autism. *BMJ, 327*, 488-493.

Baker, B. L., Blacher, J., & Olsson, M. B. (2005). Preschool children with and without developmental delay: Behaviour problems, parents' optimism and well-being. *Journal of Intellectual Disability Research, 49*(8), 575-590.

Beck, A., Daley, D., Hastings, R. P., & Stevenson, J. (2004). Mothers' expressed emotion towards children with and without intellectual disabilities. *Journal of Intellectual Disability Research, 48*(7), 628-638.

Beck, A., Hastings, R. P., Daley, D., & Stevenson, J. (2004). Pro-social behaviour and behaviour problems independently predict maternal stress. *Journal of Intellectual & Developmental Disability, 29*(4), 339-349.

Beckman, P. J. (1991). Comparison of mothers' and fathers' perceptions of the effect of young children with and without disabilities. *American Journal on Mental Retardation, 95*(5), 585-595.

Bell, D. C., & Richard, A. J. (2000). The search for a caregiving motivation. *Psychological Inquiry, 11*(2), 124-128.

Bennett-Gates, D., & Zigler, E. (1998). Resolving the developmental-difference debate: an evaluation of the triarchic systems theory models. In J. A. Burack, R. M. Hodapp & E. Zigler (Eds.), *Handbook of Mental Retardation and Development*. New York, NY: Cambridge University Press.

Beresford, B. (1996). Coping with the care of a severely disabled child. *Health and social care in the community, 4*(1), 30-40.

Biringen, Z. (2000). Emotional availability: Conceptualization and research findings. *American Journal of Orthopsychiatry, 70*(1), 104-114.

Biringen, Z., Fidler, D. J., Barrett, K. C., & Kubicek, L. (2005). Applying the Emotional Availability Scales to children with disabilities. *Infant Mental Health Journal, 26*(4), 369-391.

Blacher, J. (1984). Sequential stages of parental adjustment to the birth of a child with handicaps: Fact or artifact? *Mental Retardation, 22*(2), 55-68.

Blacher, J., & Baker, B. L. (Eds.). (2002). *The best of AAMR: Families and mental retardation: A collection of notable AAMR journal articles across the 20th century*. Washington, DC: American Association on Mental Retardation.

Blacher, J., & Hatton, C. (2007). Families in context: Influences on coping and adaptation. In S. L. Odom, R. H. Horner, M. E. Snell & J. Blacher (Eds.), *Handbook of Developmental Disabilies*. New York: The Guilford Press.

Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research, 50*(3), 184-198.

Blacher, J., Neece, C. L., & Paczkowski, E. (2005). Families and intellectual disability. *Current Opinion in Psychiatry, 18*(5), 507-513.

Boström, P., Broberg, M., & Hwang, C. P. (2010). Different, difficult or distinct? Mothers' and fathers' perceptions of temperament in children with and without intellectual disabilities. *Journal of Intellectual Disability Research, 54*(9), 806-819.

Boström, P. K., Broberg, M., & Bodin, L. (2011). Child's positive and negative impacts on parents - A person-oriented approach to understanding temperament in preschool children with intellectual disabilities. *Research in Developmental Disabilities, 32*(5), 1860-1871.

Bowlby, J. (1980). *Attachment and loss*. New York, NY: Basic Books.

Breslau, N., Salkever, D., & Staruch, K. S. (1982). Women's labor force activity and responsibilities for disabled dependents: A study of families with disabled children. *Journal of Health and Social Behavior, 23*(2), 169-183.

Bridges, F. A., & Cicchetti, D. (1982). Mothers' ratings of the temperament characteristics of Down Syndrome infants. *Developmental Psychology, 18*(2), 238-244.

Bristol, M. M., Gallagher, J. J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: Adaptation and spousal support. *Developmental Psychology, 24*(3), 441-451.

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

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist, 32*(7), 513-531.

Burack, J. A., Hodapp, R. M., & Zigler, E. (Eds.). (1998). *Handbook of mental retardation and development*. New York, NY: Cambridge University Press.

Buss, A. H., & Plomin, R. (1984). *Temperament: Early developing personality traits*. Hillsdal: NJ:Erlbaum.

Button, S., Pianta, R. C., & Marvin, R. S. (2001). Mothers' representations of relationships with their children: Relations with parenting behavior, mother characteristics, and child disability status. *Social Development, 10*(4), 455-472.

Carpenter, B., & Towers, C. (2008). Recognising fathers: The needs of fathers of children with disabilities. *Support for Learning, 23*(3), 118-125.

Daniels, D., & Plomin, R. (1985). Origins of individual differences in infant shyness. *Developmental Psychology, 21*(1), 118-121.

de Falco, S., Venuti, P., Esposito, G., & Bornstein, M. H. (2009). Mother-child and father-child emotional availability in families of children with Down syndrome. *Parenting: Science and Practice, 9*(3-4), 198-215.

de Ruiter, K. P., Dekker, M. C., Verhulst, F. C., & Koot, H. M. (2007). Developmental course of psychopathology in youths with and without intellectual disabilities. *Journal of Child Psychology and Psychiatry, 48*(5), 498-507.

Delmore-Ko, P., Pancer, S. M., Hunsberger, B., & Pratt, M. (2000). Becoming a parent: The relation between prenatal expectations and postnatal experience. *Journal of Family Psychology, 14*(4), 625-640.

Donenberg, G., & Baker, B. L. (1993). The impact of young children with externalizing behaviors on their families. *Journal of Abnormal Child Psychology: An official publication of the International Society for Research in Child and Adolescent Psychopathology, 21*(2), 179-198.

Duhig, A. M., Renk, K., Epstein, M. K., & Phares, V. (2000). Interparental agreement on internalizing, externalizing, and total behavior problems: A meta-analysis. *Clinical Psychology: Science and Practice, 7*(4), 435-453.

Dyer, W. J., McBride, B. A., Santos, R. M., & Jeans, L. M. (2009). A longitudinal examination of father involvement with children with developmental delays: Does timing of diagnosis matter? *Journal of Early Intervention, 31*(3), 265-281.

Dykens, E. M. (2000). Psychopathology in children with intellectual disability. *Journal of Child Psychology and Psychiatry, 41*(4), 407-417.

Easterbrooks, M. A., & Biringen, Z. (2005). The Emotional Availability Scales: Methodological Refinements of the Construct and Clinical Implications Related to Gender and At-Risk Interactions. *Infant Mental Health Journal, 26*(4), 291-294.

Eisenhower, A. S., Baker, B. L., & Blacher, J. J. (2005). Preschool children with intellectual disability: syndrome specificity, behaviour problems, and maternal well-being. *Journal of Intellectual Disability Research*, *49*(9), 657-671.

Elvin-Novak, Y. (2001). *I sällskap med skulden*. Stockholm: Albert Bonniers förlag.

Elvin-Nowak, Y. (2005). *Världens bästa pappa?: Om mäns relatoner och strävan efter att göra rätt*. Stockholm: Bonnier.

Emerson, E. (2003). Mothers of children and adolescents with intellectual disability: Social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disability Research, 47*(4-5), 385-399.

Emerson, E., & Einfeld, S. (2010). Emotional and behavioural difficulties in young children with and without developmental delay: A bi-national perspective. *Journal of Child Psychology and Psychiatry, 51*(5), 583-593.

Emerson, E., Fujiura, G. T., & Hatton, C. (2007). Internatonal Perspectives. In S. L. Odom, R. H. Horner, M. E. Snell & J. Blacher (Eds.), *Handbook of Developmental Disabilies*. New York: The Guilford Press.

Emerson, E., Graham, H., McCulloch, A., Blacher, J., Hatton, C., & Llewellyn, G. (2009). The social context of parenting 3-year-old children with developmental delay in the UK. *Child: Care, Health and Development, 35*(1), 63-70.

Fidler, D. J., Most, D. E., Booth-LaForce, C., & Kelly, J. F. (2006). Temperament and behaviour problems in young children with Down syndrome at 12, 30, and 45 months. *Down Syndrome: Research & Practice, 10*(1), 23-29.

Frey, K. S., Fewell, R. R., & Vadasy, P. F. (1989). Parental adjustment and changes in child outcome among families of young handicapped children. *Topics in Early Childhood Special Education, 8*(4), 38-57.

Furstenberg, F. F., Cook, T. D., Eccles, J., Elder, G. H., & Sameroff, A. (1999). *Managing to Make It: Urban Families and Adolescent Success*. Chicago: University of Chicago Press.

Gartstein, M. A., Marmion, J., & Swanson, H. L. (2006). Infant temperament: An evaluation of children with Down Syndrome. *Journal of Reproductive and Infant Psychology, 24*(1), 31-41.

Gergen, K. J., & Gergen, M. M. (Eds.). (1984). *Historical social psychology*. Hillsdale, NJ: Lawrence Erlbaum Associates Publishers.

Gerstein, E. D., Crnic, K. A., Blacher, J., & Baker, B. L. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disability Research, 53*(12), 981-997.

Glidden, L. M., Billings, F. J., & Jobe, B. M. (2006). Personality, coping style and well-being of parents rearing children with developmental disabilities. *Journal of Intellectual Disability Research, 50*(12), 949-962.

Goodman, R. (1997). The Strengths and Difficulties Questionnaire: A research note. *Journal of Child Psychology and Psychiatry, 38*(5), 581-586.

Graungaard, A. H., & Skov, L. (2007). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. *Child: Care, Health and Development, 33*(3), 296-307.

Gray, D. E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual and Developmental Disability, 27*(3), 215-222.

Gray, D. E. (2003). Gender and coping: the parents of children with high functioning autism. *Social Science & Medicine, 56*(3), 631-642.

Gray, D. E. (2006). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research, 50*(12), 970-976.

Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science & Medicine, 64*(1), 150-163.

Greenbaum, C. W., & Auerbach, J. G. (Eds.). (1998). *The environment of the child with mental retardation: Risk, vulnerability, and resilience*. New York, NY: Cambridge University Press.

Grice, H. P. (1975). Logic and conversation. In P. Cole & J. l. Moran (Eds.), *Syntax and semantics* (Vol. 3, pp. 41-58). New York: Academic Press.

Hagekull, B., & Bohlin, G. (1990). *The Swedish Translation of the EASI Temperamental Survey*. Uppsala University.

Harwood, K., McLean, N., & Durkin, K. (2007). First-time mothers' expectations of parenthood: What happens when optimistic expectations are not matched by later experiences? *Developmental Psychology, 43*(1), 1-12.

Hassall, R., Rose, J., & McDonald, J. (2005). Parenting stress in mothers of children with an intellectual disability: The effects of parental cognitions in relation to child characteristics and family support. *Journal of Intellectual Disability Research, 49*(6), 405-418.

Hastings, R. P. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual & Developmental Disability, 27*(3), 149-160.

Hastings, R. P., Daley, D., Burns, C., & Beck, A. (2006). Maternal distress and expressed emotion: Cross-sectional and longitudinal relationships with behavior problems of children with intellectual disabilities. *American Journal on Mental Retardation, 111*(1), 48-61.

Hastings, R. P., & Lloyd, T. (2007). Expressed emotion in families of children and adults with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(4), 339-345.

Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with developmental disabilities. *American Journal on Mental Retardation, 107*(2), 116-127.

Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., & Krauss, M. W. (2001). Children with disabilities: A longitudinal study of child development and parent well-being. *Monographs of the Society for Research in Child Development, 66*(3), 1-131.

Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research, 50*(12), 874-882.

Hesse, E. (1999). The adult attachment interview: Historical and current perspectives. In J. Cassidy & P. R. Shaver (Eds.), *Handbook of attachment: Theory, research, and clinical applications* (pp. 395-433). New York, NY: Guilford Press.

Hodapp, R. M., Burack, J. A., & Zigler, E. (1998). Developmental approaches to mental retardation: a short introduction. In J. A. Burack, R. M. Hodapp & E. Zigler (Eds.), *Handbook of mental retardation and development.* New York, NY: Cambridge University Press.

Hollins, S., Woodward, S., & Hollins, K. (2010). Parenting an infant with a disability. In S. Tyano, M. Keren, H. Herrman & J. Cox (Eds.), *Parenthood and Mental Health*. Padstow: Wiley & Sons, Ltd.

Hornby, G. (1992). A review of fathers' accounts of their experiences of parenting children with disabilities. *Disability & Society, 7*(4), 363-374.

Horowitz, F. D., & Haritos, C. (1998). The organism and the environment: Implications for understanding mental retardation. In J. A. Burack, R. M. Hodapp & E. Zigler (Eds.), *Handbook of Mental Retardation and Development*. New York, NY: Cambridge University Press.

Houser, R., & Seligman, M. (1991). A comparison of stress and coping by fathers of adolescents with mental retardation and fathers of adolescents without mental retardation. *Research in Developmental Disabilities, 12*(3), 251-260.

Jansen, P. W., Raat, H., Mackenbach, J. P., Hofman, A., Jaddoe, V. W. V., Bakermans-Kranenburg, M. J., et al. (2012). Early determinants of maternal and paternal harsh discipline: The generation R study. *Family Relations: An Interdisciplinary Journal of Applied Family Studies, 61*(2), 253-270.

Janson, H., & Mathiesen, K. S. (2008). Temperament profiles from infancy to middle childhood: Development and associations with behavior problems. *Developmental Psychology, 44*(5), 1314-1328.

Kanner, L. (1953). Parents' feelings about retarted children. *American Journal of Mental Deficiency, 57*, 375-383.

Kasari, C., & Bauminger, N. (Eds.). (1998). *Social and emotional development in children with mental retardation*. New York, NY: Cambridge University Press.

Kasari, C., & Sigman, M. (1997). Linking parental perceptions to interactions in young children with autism. *Journal of Autism and Developmental Disorders, 27*(1), 39-57.

Kau, A. S. M., Reider, E. E., Payne, L., Meyer, W. A., & Freund, L. (2000). Early behavior signs of psychiatric phenotypes in fragile X syndrome. *American Journal on Mental Retardation, 105*(4), 286-299.

Klein-Tasman, B. P., & Mervis, C. B. (2003). Distinctive personality characteristics of 8-, 9-, and 10-year-olds with Williams syndrome. *Developmental Neuropsychology, 23*(1-2), 269-290.

Klingner, J. K., Blachett, W. J., & Harry, B. (2007). Race, culture, and developmental disabilities. In S. L. Odom, R. H. Horner, M. E. Snell & J. Blacher (Eds.), *Handbook of Developmental Disabilities*. New York: The Guilford Press.

Komsi, N., Räikkönen, K., Pesonen, A.-K., Heinonen, K., Keskivaara, P., Järvenpää, A.-L., et al. (2006). Continuity of temperament from infancy to middle childhood. *Infant Behavior & Development, 29*(4), 494-508.

Konstantareas, M. M., & Stewart, K. (2006). Affect regulation and temperament in children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 36*(2), 143-154.

Koskentausta, T., Iivanainen, M., & Almqvist, F. (2007). Risk factors for psychiatric disturbance in children with intellectual disability. *Journal of Intellectual Disability Research, 51*(1), 43-53.

Kuhn, J. C., & Carter, A. S. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry, 76*(4), 564-575.

Kvale, S. (1997). *Den kvalitativa forskningsintervjun*. Lund: Studentlitteratur.

Lamb, M. E. (Ed.). (2010). *The role of the father in child development* (5th ed.). Hoboken, NJ: John Wiley & Sons Inc.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology. 3* (2), 102-120.

Larson, E. (1998). Reframing the meaning of disability to families: The embrace of paradox. *Social Science & Medicine, 47*(7), 865-875.

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research, 50*(3), 172-183.

Leve, L. D., Kim, H. K., & Pears, K. C. (2005). Childhood temperament and family environment as predictors of internalizing and externalizing trajectories from ages 5 to 17. *Journal of Abnormal Child Psychology, 33*(5), 505-520.

Lloyd, T., & Hastings, R. P. (2008). Psychological variables as correlates of adjustment in mothers of children with intellectual disabilities: Cross-sectional and longitudinal relationships. *Journal of Intellectual Disability Research, 52*(1), 37-48.

Luescher, J. L., Dede, D. E., Gitten, J. C., Fennell, E., & Maria, B. L. (1999). Parental burden, coping, and family functioning in primary caregivers of children with joubert syndrome. *Journal of Child Neurology, 14*(10), 642-648.

Lundström, K. (2009). Växelvis boende ökar bland skilsmässobarn. *Välfärd, 4*, 3-5.

MacDonald, E. E., & Hastings, R. P. (2010a). Mindful parenting and care involvement of fathers of children with intellectual disabilities. *Journal of Child and Family Studies, 19*(2), 236-240.

MacDonald, E. E., & Hastings, R. P. (2010b). Fathers of children with developmental disabilities. In M. E. Lamb, (Ed.), *The role of the father in child development* (5th ed.). Hoboken, NJ: John Wiley & Sons Inc.

MacKenzie, M. J., & McDonough, S. C. (2009). Transactions between perception and reality: Maternal beliefs and infant regulatory behavior. In A. Sameroff (Ed.), *The Transactional Model of Development: How Children and Contexts Shape Each Other*. Washington, DC: American Psychological Association.

MacMillan, H. L., Boyle, M. H., Wong, M. Y.-Y., Duku, E. K., Fleming, J. E., & Walsh, C. A. (1999). Slapping and spanking in childhood and its association with lifetime prevalence of psychiatric disorders in a general population sample. *Canadian Medical Association Journal, 161*(7), 805-809.

Marcovitch, S., Goldberg, S., Lojkasek, M., & MacGregor, D. L. (1987). The concept of difficult temperament in the developmentally disabled preschool child. *Journal of Applied Developmental Psychology, 8*(2), 151-164.

Martin, R. P., & Halverson, C. F., Jr. (1991). Mother-father agreement in temperament ratings: A preliminary investigation. In J. Strelau & A. Angleitner (Eds.), *Explorations in temperament: International perspectives and measurement.* (pp. 235-248). New York, NY: Plenum Press.

Marvin, R. S., & Pianta, R. C. (1996). Mothers' reactions to their child's diagnosis: Relations with security of attachment. *Journal of Clinical Child Psychology, 25*(4), 436-445.

Mathiesen, K. S., & Sanson, A. (2000). Dimensions of early childhood behavior problems: Stability and predictors of change from 18 to 30 months. *Journal of Abnormal Child Psychology, 28*(1), 15-31.

Mayseless, O. (2006a). Studying Parenting Representations as a Window to Parents' Internal Working Model of Caregiving. In O. Mayseless (Ed.), *Parenting representations: Theory, research, and clinical implications* (pp. 3-40). New York, NY: Cambridge University Press.

Mayseless, O. (Ed.). (2006b). *Parenting representations: Theory, research, and clinical implications*. New York, NY: Cambridge University Press.

McCann, D., & Delmonte, H. (2005). Lesbian and gay parenting: Babes in arms or babes in the woods? *Sexual and Relationship Therapy, 20*(3), 333-347.

McKeever, P., & Miller, K.-L. (2004). Mothering children who have disabilities: A Bourdieusian interpretation of maternal practices. *Social Science & Medicine, 59*(6), 1177-1191.

Michaels, G. Y., & Goldberg, W. A. (Eds.). (1988). *The transition to parenthood: Current theory and research*. New York, NY: Cambridge University Press.

Morrissette, C. (2012). *About.com: Developmental Delay*. Retrieved 2012-06-12 from http://preemies.about.com/od/glossary/g/DevDelay.htm

Nehring, W. M., & Betz, C. L. (2007). General health. In S. L. Odom, R. H. Horner, M. E. Snell & J. Blacher (Eds.), *Handbook of Developmental Disabilies*. New York: The Guilford Press.

Nigg, J. T. (2006). Temperament and developmental psychopathology. *Journal of Child Psychology and Psychiatry, 47*(3-4), 395-422.

Nygaard, E., Smith, L., & Torgersen, A. M. (2002). Temperament in children with Down syndrome and in prematurely born children. *Scandinavian Journal of Psychology, 43*(1), 61-71.

Odom, S. L., Horner, R. H., Snell, M. E., & Blacher, J. (2007). The construct of developmental disabilities. In S. L. Odom, R. H. Horner, M. E. Snell & J. Blacher (Eds.), *Handbook of Developmental Disabilies*. New York: The Guilford Press.

Oelofsen, N., & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual and Developmental Disability, 31*(1), 1-12.

Olsson, M. B. (2008). Understanding Individual Differences in Adaptation in Parents of Children with Intellectual Disabilities: A Risk and Resilience Perspective. In L. M. Glidden (Ed.), *International Review of Research in Mental Retardation 2009 (Vol. 36)*. Burlington: Academic Press.

Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research, 45*(6), 535-543.

Olsson, M. B., & Hwang, C. P. (2002). Sense of coherence in parents of children with different developmental disabilities. *Journal of Intellectual Disability Research, 46*(7), 548-559.

Olsson, M. B., & Hwang, P. C. (2003). Influence of macrostructure of society on the life situation of families with a child with intellectual disability: Sweden as an example. *Journal of Intellectual Disability Research, 47*(4-5), 328-341.

Olsson, M. B., & Hwang, C. P. (2006). Well-being, involvement in paid work and division of child-care in parents of children with intellectual disabilities in Sweden. *Journal of Intellectual Disability Research, 50*(12), 963-969.

Olsson, M. B., Larsman, P., & Hwang, P. C. (2008). Relationships among risk, sense of coherence, and well-being in parents of children with and without intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 5*(4), 227-236.

Oppenheim, D., Dolev, S., Koren-Karie, N., Sher-Censor, E., Yirmiya, N., & Salomon, S. (2007). Parental resolution of the child's diagnosis and the parent-child relationship: Insights from the Reaction to Diagnosis Interview. In D. Oppenheim & D. F. Goldsmith (Eds.), *Attachment theory in clinical work with children bridging the gap between research and practice*. New York, NY: Guilford Press.

Oppenheim, D., Koren-Karie, N., Dolev, S., & Yirmiya, N. (2009). Maternal insightfulness and resolution of the diagnosis are associated with secure attachment in preschoolers with autism spectrum disorders. *Child Development, 80*(2), 519-527.

Palmer, R. (1969). *Hermeneutics. Interpretation theory in Schleiermacher, Dilthey, Heidegger and Gadamer*. Evantone: North Western Univerisity Press.

Palus, C. J. (1993). Transformative experiences of adulthood: A new look at the seasons of life. In J. Demick, K. Bursik & R. DiBiase (Eds.), *Parental Development*. Hillsdale, NJ, England: Lawrence Erlbaum Associates, Inc.

Pelchat, D., Levert, M.-J., & Bourgeois-Guérin, V. (2009). How do mothers and fathers who have a child with a disability describe their adaptation/transformation process? *Journal of Child Health Care, 13*(3), 239-259.

Pesonen, A.-K., Räikkönen, K., Heinonen, K., Komsi, N., Järevenpää, A.-L., & Strandberg, T. (2008). A transactional model of temperamental development: Evidence of a relationship between child temperament and maternal stress over five years. *Social Development, 17*(2), 326-340.

Phares, V., Rojas, A., Thurston, I. B., & Hankinson, J. C. (2010). Including fathers in clinical interventions for children and adolescents. In M. E. Lamb (Ed.), *The role of the father in child development*. Hoboken, NJ: John Wiley & Sons Inc.

Pianta, R. C., Marvin, R. S., Britner, P. A., & Borowitz, K. C. (1996). Mothers' resolution of their children's diagnosis: Organized patterns of caregiving representations. *Infant Mental Health Journal, 17*(3), 239-256.

Pipp-Siegel, S., & Biringen, Z. (1998). Assessing the quality of relationships between parents and children: The emotional availability scales. *Volta Review, 100*(5), 237-249.

Plant, K. M., & Sanders, M. R. (2007). Predictors of care-giver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disability Research, 51*(2), 109-124.

Pleck, J. H. (1997). Paternal involvement: Levels, sources, and consequences. In M. E. Lamb, (Ed.), *The role of the father in child development* (3rd ed.). New York: Wiley.

Pleck, J. H. (2010). Fatherhood and masculinity. In M. E. Lamb, (Ed.), *The role of the father in child development* (5th ed.). Hoboken, NJ: John Wiley & Sons Inc.

Prinzie, P., Onghena, P., & Hellinckx, W. (2006). A cohort-sequential multivariate latent growth curve analysis of normative CBCL aggressive and delinquent problem behavior: Associations with harsh discipline and gender. *International Journal of Behavioral Development, 30*(5), 444-459.

Raghavan, R., & Small, N. (2004). Cultural diversity and intellectual disability. *Current Opinion in Psychiatry, 17*(5), 371-375.

Raphael-Leff, J. (1991). *Psychological processes of childbearing*. London: Chapman & Hall.

Raven, J. C. (1949). *Guide to using the Coloured Progressive Matrices. Sets A,Ab B.* London: H. K. Lewis.

Rentinck, I. C. M., Ketelaar, M., Schuengel, C., Stolk, J., Lindeman, E., Jongmans, M. J., et al. (2010). Short-term changes in parents' resolution regarding their young child's diagnosis of cerebral palsy. *Child: Care, Health and Development, 36*(5), 703-708.

Riddersporre, B. (2003). *Att möta det oväntade; Tidigt föräldraskap till barn med Downs syndrom.* Lund: Lunds Universitet.

RFV (Riksförsäkringsverket), (2002). *Vårdbidrag*. 2002:20, version 4. http://forsakringskassan.se.

Ricoeur, P. (1993). *Från text till handling*. Stockholm: Brutus Östling.

Rosenblum, K. L., Dayton, C. J., & McDonough, S. (2006). Communicating Feelings: Links Between Mothers' Representations of Their Infants, Parenting, and Infant Emotional Development. In O. Mayseless (Ed.), *Parenting representations; Theory, research, and clinical implications*. New York, NY: Cambridge University Press.

Rothbart, M. K. (1981). Measurement of temperament in infancy. *Child Development, 52*(2), 569-578.

Rothbart, M. K. (2007). Temperament, development, and personality. *Current Directions in Psychological Science, 16*(4), 207-212.

Rothbart, M. K., Ahadi, S. A., Hersey, K. L., & Fisher, P. (2001). Investigations of temperament at three to seven years: The Children's Behavior Questionnaire. *Child Development, 72*(5), 1394-1408.

Rutter, M. (1996). Transitions and turning points in developmental psychopathology: As applied to the age span between childhood and mid-adulthood. *International Journal of Behavioral Development, 19*(3), 603-626.

Saloviita, T., Itälinna, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: A double ABCX model. *Journal of Intellectual Disability Research, 47*(4-5), 300-312.

Sameroff, A. (Ed.). (2009). *The transactional model*. Washington, DC: American Psychological Association.

Sameroff, A. J., & Fiese, B. H. (2000). Transactional regulation: The developmental ecology of early intervention. In J. P. M. Shonkoff, Samuel J (Ed.), *Early Childhood Intervention*. New York, NY: Cambridge University Press.

Sanson, A., Pedlow, R., Cann, W., Prior, M., & Oberklaid, F. (1996). Shyness ratings: Stability and correlates in early childhood. *International Journal of Behavioral Development, 19*(4), 705-724.

Schalock, R. L., Luckasson, R. A., Shogren, K. A., Borthwick-Duffy, S., Bradley, V., Buntinx, W. H. E., et al. (2007). The renaming of Mental retardation: Understanding the change to the term Intellectual disability. *Intellectual and Developmental Disabilities, 45*(2), 116-124.

Schmitz, S., Fulker, D. W., Plomin, R., Zahn-Waxler, C., Emde, R. N., & DeFries, J. C. (1999). Temperament and problem behavior during early childhood. *International Journal of Behavioral Development, 23*(2), 333-355.

Schuengel, C., Rentinck, I. C. M., Stolk, J., Voorman, J. M., Loots, G. M. P., Ketelaar, M., et al. (2009). Parents' reactions to the diagnosis of cerebral palsy: Associations between resolution, age and severity of disability. *Child care health and development, 35*(5):673-680.

Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation, 38*(3), 195-206.

Secco, M. L., Askin, D., Yu, C. T., Garinger, J., Mulaire-Cloutier, C., Scharf, L., et al. (2006). Factors Affecting Parenting Stress Among Biologically Vulnerable Toddlers. *Issues in Comprehensive Pediatric Nursing, 29*(3), 131-156.

Seifer, R., Sameroff, A., Dickstein, S., Schiller, M., & Hayden, L. C. (2004). Your own children are special: Clues to the sources of reporting bias in temperament assessments. *Infant Behavior & Development, 27*(3), 323-341.

Seltzer, M. M., & Heller, T. (1997). Introduction: Families and caregiving across the life course: Research advances on the influence of context. *Family Relations, 46*, 321-323.

Shanahan, M., Roberts, J., Hatton, D., Reznick, J., & Goldsmith, H. (2008). Early temperament and negative reactivity in boys with fragile X syndrome. *Journal of Intellectual Disability Research, 52*(10), 842-854.

Simmerman, S., Blacher, J., & Baker, B. L. (2001). Fathers' and mothers' perceptions of father involvement in families with young children with a disability. *Journal of Intellectual and Developmental Disability, 26*(4), 325-338.

Simonoff, E., Bolton, P., & Rutter, M. (1998). Genetic perspectives on mental retardation. In J. A. Burack, R. M. Hodapp & E. Zigler (Eds.), *Handbook of Mental Retardation and Development*. New York, NY: Cambridge University Press.

Singer, G. H. S. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation, 111*(3), 155-169.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis; Theory, method and research*. London: Sage Publications Ltd.

Socialdepartementet. (2007). *Jämställdhetsbonus; Familjepolitisk reform*. Retrieved 2012-04-16 from http://www.regeringen.se/.

Socialstyrelsen. (2005). *Kompetenta föräldrar - beroende av socialtjänstens stöd.* Retrieved 2012-04-16 from http://www.socialstyrelsen.se/. (Publicaton No. 2005-131-33).

Solomon, J., & George, C. (1996). Defining the caregiving system: Toward a theory of caregiving. *Infant Mental Health Journal, 17*(3), 183-197.

Sparrow, S. S., Balla, D. A., & Cicchetti, D.V. (1984). *Vineland Adaptive Behavior Scales.* Circle Pines, MN: American Guidance Service.

Statistics Sweden. (2010). *Women and men in Sweden: Facts and figures 2010*. Örebro: Statistiska Centralbyrån.

Stern, D. N. (1995). *The motherhood constellation: A unified view of parent-infant psychotherapy*. New York, NY: Basic Books.

Stoneman, Z. (2007). Examining the Down syndrome advantage: Mothers and fathers of young children with disabilities. *Journal of Intellectual Disability Research, 51*(12), 1006-1017.

Strelau, J. (1998). *Temperament: A psychological perspective*. New York, NY: Plenum Press.

Sullivan, A. (2002). Gender differences in coping strategies of parents of children with Down syndrome. *Down Syndrome: Research & Practice, 8*(2), 67-73.

Sullivan, P. M., & Knutson, J. F. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect, 24*(10), 1257-1273.

Svensson, B., Bornehag, C.-G., & Janson, S. (2011). Chronic conditions in children increase the risk for physical abuse - but vary with socio-economic circumstances. *Acta Paediatrica, 100*(3), 407-412.

Taggart, L., & McMullan, P. (2007). An exploratory study of teachers' knowledge about the symptoms of depression in young people with and without intellectual disabilities. *Journal of Intellectual Disabilities, 11*(2), 183-195.

Taylor, C. A., Manganello, J. A., Lee, S. J., & Rice, J. C. (2010). Mothers' spanking of 3-year-old children and subsequent risk of children's aggressive behavior. *Pediatrics, 125*(5), e1057-1065.

The National Board for Health and Welfare. (2009). *Swedish disability policy - sevice and care for people with functional impairments*. www.socialstyrelsen.se (Publication No. 2009-126-188).

Thomas, A., & Chess, S. (1977). *Temperament and development*. New York: Brunner/Mazel.

Thomas, A., Chess, S., Birch, H. G., Hertzig, M. E., & Korn, S. (1963). *Behavioral individuality in early childhood.* New York : New York University Press.

Trute, B. (1995). Gender differences in the psychological adjustment of parents of young, developmentally disabled children. *Journal of Child Psychology and Psychiatry, 36*(7), 1225-1242.

Tseng, Y.-S., & Verklan, M. T. (2008). Fathers in situational crisis: A comparison of Asian and Western cultures. *Nursing & Health Sciences, 10*(3), 229-240.

van Ijzendoorn, M. H. (1995). Adult attachment representations, parental responsiveness, and infant attachment: A meta-analysis on the predictive validity of the Adult Attachment Interview. *Psychological Bulletin, 117*(3), 387-403.

van Ijzendoorn, M. H., Rutgers, A. H., Bakermans-Kranenburg, M. J., van Daalen, E., Dietz, C., Buitelaar, J. K., et al. (2007). Parental sensitivity and attachment in children with autism spectrum disorder: Comparison with children with mental retardation, with language delays, and with typical development. *Child Development, 78*(2), 597-608.

van Ijzendoorn, M. H., Schuengel, C., & Bakermans-Kranenburg, M. J. (1999). Disorganized attachment in early childhood: Meta-analysis of precursors, concomitants, and sequelae. *Development and Psychopathology, 11*(2), 225-249.

Wechsler, D. (1991). *Wechsler Intelligence Scale for Children – Third Edition*. San Antonio:The Psychological Corporation,TX.

Wehmeyer, M. L., Buntinx, W. H. E., Lachapelle, Y., Luckasson, R. A., Schalock, R. L., & Verdugo, M. A. (2008). The intellectual disability construct and its relation to human functioning. *Intellectual and Developmental Disabilities, 46*(4), 311-318.

Verri, A., Maraschio, P., Uggetti, C., Pucci, E., Ronchi, G., Nespoli, L., et al. (2004). Late diagnosis in severe and mild intellectual disability in adulthood. *Journal of Intellectual Disability Research, 48*(7), 679-686.

Wachtel, K., & Carter, A. S. (2008). Reaction to diagnosis and parenting styles among mothers of young children with ASDs. *Autism, 12*(5), 575-594.

Warren, S. F., Gilkerson, J., Richards, J. A., Oller, D. K., Xu, D., Yapanel, U., et al. (2010). What automated vocal analysis reveals about the vocal production and language learning environment of young children with autism. *Journal of Autism and Developmental Disorders, 40*(5), 555-569.

Westerinen, H., Kaski, M., Virta, L., Almqvist, F., & Iivanainen, M. (2007). Prevalence of intellectual disability: A comprehensive study based on national registers. *Journal of Intellectual Disability Research, 51*(9), 715-725.

World Health Organisation. (2011). *World Report on Disability*. Malta: WHO Library Cataloguing-in-Publication Data.

World Health Organisation. (2008). *Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health. Final Report of the Commission on the Social Determinants of Health.* Geneva, Switzerland: World Health Organization.

Zeanah, C. H., & Benoit, D. (1995). Clinical applications of a parent perception interview in infant mental health. *Child and Adolescent Psychiatric Clinics of North America, 4*(3), 539-554.

Zigler, E., & Hodapp, R. M. (1986). *Understanding mental retardation*. New York, NY: Cambridge University Press.

Zion, E., & Jenvey, V. B. (2006). Temperament and social behaviour at home and school among typically developing children and children with an intellectually disability. *Journal of Intellectual Disability Research, 50*(6), 445-456.