Our Father

On fathers with intellectual disabilities

Iren Åhlund

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Abstract

Our Father - a study of fathers with learning disabilities
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Most studies on parenthood and learning disabilities focus on mother and child. Very little is known about fathers with learning disabilities. Moreover, people with learning disabilities are rarely asked to tell their own stories. The aim of the current study is to identify the role of the father in families where one or both of the parents have learning disabilities. The laws and regulations dealing with the rights of people with learning disabilities in Sweden are reviewed and the social support systems for all parents in Sweden are described.

The empirical study is a qualitative phenomenological interview study, inspired by narrative traditions. The study describes how fathers with learning disabilities view the support systems. The primary data consists of the two life stories of fathers with learning disabilities and one observation in a family. The findings suggest that, although Sweden has a highly regarded disability policy and social support systems, and even though fathers with learning difficulties are assured equal rights as members of the society and as parents, by the Human Rights Act, they are not treated equally. Rather they face structural inequalities. Their strengths and needs are not recognized, gender-based support is not used and last but not least, there is a lack of adequate competence in the support system. As long as the fathers are not included in the discussions about strength and weakness in families where at least one parent has a learning disability, then these families will not be given a fair chances of fulfilling their role as parents.

Keywords: fathers with learning disabilities, narratives, parenting, fatherhood

Foreword

I did not realize how many areas touch on fatherhood in general and specifically on fatherhood where the father has an intellectual disability.

I thought that my own family with four fathers (my husband and my three sons) and my wise, strong daughter and her partner, and my loving daughters-in-law, contained most elements of fatherhood and the roll of fathers, in relation to children and partners. But the fathers I've met during the course of my study have taught me that life is more multifaceted than that. Society's view on parenthood, on fatherhood and on disability must be analyzed in order to understand fathers with intellectual disabilities in their role as fathers. This is what I have attempted to do in Our Father, and I have also realized that this is just the beginning.

Introduction
Research on parenting and intellectual disability has up until now, focused mainly on mothers' and children's experiences. The National Board of Health and Welfare has reviewed Swedish and international research concerning parents with intellectual disabilities and their children. (Socialstyrelsen, 2005). Of the 167 pieces presented in the research review, eighteen were Swedish. Of the eighteen studies, nine focused on the child's perspective, three are specifically focused on mothers and four deal with families. In only one of these Swedish studies, is there a father represented. An additional twelve Swedish studies were included in the inventory, but these dealt more indirectly with the subject of parenthood.

In the systematic review analysis of research available, there is no clear gender perspective. The surveys that are presented and the conclusions that are drawn about contents of the research pieces, refer to *parent*hood/*parent*ing, despite the fact that fathers are not present in the research and the focus lies on the mother and child.

The research review calls for a gender perspective in research on parenting and points out the lack of research on fathers and fathers' parenting.

In my study, a societal perspective provides the background for the life stories that the fathers tell. A societal perspective means that I put the fathers with intellectual disabilities in a societal context. Swedish disability policy, directives and regulations regarding society's support for parents and children are presented. Special attention is given to evaluations and surveys dealing with whether the people charged with providing support have succeeded or not.

Further, I have examined the reports in which the social service has been reviewed from a gender perspective, as well as the reports evaluating maternity clinics and childcare centres, as to how well they reach the fathers.

I have also read the National Public Health's investigation of parenting from a public health perspective and a special investigation in which fathers' situation was highlighted.

In none of these documents have I found anything written about fathers with intellectual disabilities. Knowledge about fathers with intellectual disabilities is limited, especially in Swedish and Nordic research. (Socialstyrelsen, 2005) The Icelandic researcher, Hanna Sigurjónsdóttir, (2005) has highlighted families and fathers with intellectual disabilities in her thesis and other studies. I have chosen to bringher research in my work since other researchers are working outside of the Nordic region. Even if research from other countries such as Canada, Australia and England can provide much knowledge, the social context that the fathers are living in is different.

The countries' laws, rights and living situations for people with intellectual disability is different from that in Sweden. Iceland differs from Sweden as well, but the similarities are greater in comparison with the other non-Nordic countries. Iceland has legislation on rights that corresponds to Swedish legislation. And Swedish people with intellectual disabilities have a similar living situation to people with intellectual disability in the Icelandic society.

In addition, Sigurjónsdóttirs research is based on the fathers' own stories and experiences, which is unusual. The aim of my work is to increase awareness of fathers with intellectual disabilities and the support that society offers them in their role as fathers. I will also examine what factors have a positive influence on fathers with intellectual disabilities in their roll as fathers and enhance their parenting skills.

Five fathers were asked to participate in the study, and of them, two participated until the end of the study and they are included in the material. One observation was carried out in a family.

Prior knowledge

My interest in, and commitment to, parenthood and disability goes way back.
During my student days in the early 1970s, I took a short course at university titled
"deviant behaviour" which was illustrated by a happy girl with Down
syndrome who played the tambourine. It was my first encounter with people with
intellectual disabilities, and it affected the rest of my life.
My interest stemmed from a desire and a belief that with my intellect I could
find ways to allow people with intellectual disabilities to understand what I
wanted to express and convey. It was a few years later, that it first dawned on me that it was of
even greater in value that *I* would learn to understand what *they* want to express and convey.

In the 1970s, legislation was passed that closed the large institutions located in the area around
Stockholm. The first individuals to move out into the community were children who had been
institutionalised and therefore student homes were opened in the newly built residential areas.
Student homes consisted of apartments with space for four children. The staff worked in shifts and
was responsible for both educational and practical work, as in a "regular home".
I was appointed director for one of these student boarding homes. The four children who
moved in there were about the same age and they came into puberty after a few years.
This created great uncertainty among us on the staff. Issues of sexuality were not in any way
touched on in our training, and we were at a loss in terms of knowing how to deal with the ethical and
moral issues related to disability and sexuality.
With the help of a psychologist, who had no knowledge of intellectual disabilities, we began
the work of several years, leading these young people into an adult life, where sexuality and
family life would be a natural element. The pros and cons of sterilization, unwanted pregnancies,
contraception and various forms of cohabitation were all subjects that were aired in our
discussions.
In the early 1980s, Gunnar Kylén got his doctorate and his dissertation dealt with how people with
intellectual disabilities think and comprehend, and how they perceive reality. The findings that Kylén
presented led to a shift in the field from being a profession that provides care, to a pedagogical
profession. For a period of a few years one could study 20 credits on the subject of intellectual
disability at the Department of Psychology at Stockholm University. Gunnar Kylén was the teacher,
and after every lecture I attended, I could go back to work and solve one or more problems for the
adolescents in the student home. Colored tape to facilitate turning on the right burner on the stove, ,
new, concrete ways of doing mathand much, much more. Kylén's theories explain how thought
develops from the more concrete to the abstract. But most important of all - which many
forget when they talk about the Kylén's theories - is that he stresses the importance of experience in
terms of the positive impact on the ability to use one's way of thinking.
This is the key to the fact that a person with an intellectual disability, who uses a
six year-old's way of thinking, is still much wiser than a six-year-old and can take responsibility for
his/her life.
I think this particular piece of knowledge is so important, for it is still today being written into the
journals and records of some individuals that they are *like a six year old*. How can we then have
confidence in their ability to take responsibility for their life? And even more, ability to take
responsibility for a child?
When I began working many years later with adult education for people with intellectual disabilities,
the debate on sexuality, relationships and parenting was still going on. This was during the 1980s, and
the exodus of the adults from institutions had been going on for a few years. The great fear at the time
was that these women who had moved out into the community would be abused and become pregnant.

That the majority of women had already been sterilized during their institutionalisation, was still not widely known.

Evy Kollberg's thesis on mothers with intellectual disability raised questions about what support could be provided for these mothers so that they could manage their role as mother to a child. This taught me that that there is no one single solution or approach, but that instead each person is unique and has individual abilities and individual challenges.

In adult education we addressed the debate and the need, by offering discussion groups for people with intellectual disabilities that dealt with sexuality and relationships. We also started a group for mothers where they learned about how to care for a child and child development. These groups met once a week for one or more years. In the beginning, the groups' discussions were rather vague. The mothers talked about friendship, love and feelings on a platonic level.

As the competency of we circle leaders increased, so did the demands from participants for relevant knowledge increase and discussions began to deal with more difficult issues such as relationships, marriage and what parenthood could involve.

A theory that was current at the time proposed that people with intellectual disabilities wanted to have children in order to become "normal". Therefore one should explain and speak to them about their disabilities and its consequences, making them "disability aware."

This is a peculiar analysis of people's dreams, for why would people with intellectual disabilities differ from other people, in their thoughts and dreams of children? And by what right do we deprive others of their dreams?

A few years later, I started working for the Swedish National Association for Persons with Intellectual Disability (FUB). Here was a national network of parents with intellectual disabilities who met for a weekend each year. On some occasions I attended these weekends and the contact with these parents,who were a heterogeneous group in terms of many social factors, taught me to view with respect their desire to be good parents.

I have followed a research and development project that FUB played a roll in - the FIB-project in Uppsala, which was carried out between 2005-2008. The aim of the project has been to develop knowledge about, and support for, families where one or both parents have an intellectual disability.

As a result of this project, I have learned about community support efforts, about how the support around families can be formed, and about the difficulties and obstacles that need to be addressed so that the support measures can be as effective as possible for the families. The project has highlighted how important it is that the staff that provides support for the family has knowledge about intellectual disabilities and their impact. The need to meet the families with respect is also emphasized.

I have seen that the fathers' role and experience is missing, and that one talks about "parents" and families, but this usually refers to just the mother and the child. The parents' own involvement in how support is designed for their families must be further developed in order to strengthen the parents' self-esteem and self-image.

In the contacts I've had with people with intellectual disabilities through the years, I have met people who have become parents. For some of them it has worked out well. They have received the support they need in a way that has strengthened their ability to care for their child. For others, it has been difficult coping with the daily responsibility of parenthood, and they have received support and help in putting their child into foster care without their right as the child's parents being violated. And then there are the people who did not receive the help and support they needed, and who have had to give up their children, leaving them with the feeling that they no longer have any rights as the parents of the child.

Everyone has the right to have a family life and to have children. It is society's responsibility to provide all citizens with the support and resources to cope with their parenting. (. (Bill 1999/2000: 79) If the father is left out, his parenthood has not been give the opportunity to develop to its full potential. Parents with intellectual disabilities are not a group. Rather they are individuals, mothers and fathers who are all different. They have different capabilities and shortcomings, and they have the right to be met as individuals, on their own merits.

It is with these experiences and opinions that I commence my work on Our Father.

Several elements are influenced by my experiences and my opinions. The choice of topic, the organization of the study, reflections on past research, interaction with the fathers, and not in the least, the conclusions I reach in the analysis.

I have chosen to use phenomenology as a scientific approach. It is used to describe human experience and it is useful for researchers within different areas who want to understand how others think. (Denscombe, 2009)

I feel my previous experiences of parenting and intellectual disabilities have been helpful when I have focused on how life can be for a father with intellectual disabilities and also when I have studied social services and how they can work for a person with intellectual disabilities.

With my prior understanding of the disability and its consequences, I have chosen to see and understand in the way that the fathers in the study can see and understand.

I have therefore focused on factors beyond the father's intellectual disabilities when I have analysed my data. I have chosen to see primarily how social support works for him as a citizen, with the rights and obligations that all citizens have, and only thereafter take disability into account. Without my prior understanding and without my past experience, I would probably have been more inclined in my work to focus on the disability and probably given it more weight in the fatherhood role.

I have aimed to highlight fatherhood from three perspectives: society's support for parents, fatherhood and policies dealing with fatherhood and thereafter, fatherhood when the father has an intellectual disability.

Background

Introduction
In the following sections I describe the Swedish National Action Plan for the disability policy that I consider to be the social context that applies to fathers with intellectual disabilities. I then describe the support given to expectant parents, new parents and parents up to the child's 18th birthday. Support is provided through pre-natal healthcare centres, children's healthcare centres and family centres. Since parents with intellectual disabilities do not constitute an exception - they are included within the scope of the laws and regulations applicable to all citizens - I have chosen to examine social support to all parents, and thereafter examine the special assistance I could find for parents with intellectual disabilities and finally support for fathers with intellectual disabilities. It is at the crossroad of these efforts and the staffs attached to them, that fathers with intellectual disabilities are given support and assessed in terms of their fatherhood. It is therefore of interest to assess the level of knowledge and competence and the prevailing attitudes towards fathers in general, and fathers with intellectual disabilities in particular.
I discuss the concepts and definitions used when describing people with intellectual disabilities. Since uniform concepts, both national and international do not exist, it is necessary to understand the concepts used by different researchers and by doing so, understand the results they produce.

Swedish disability policy, legislation and regulations

The formulation of disability policy, legislation and regulations concerning people with disabilities in Sweden and the design of the Swedish welfare system and society's support to parents, constitutes the framework in which fathers with intellectual disabilities live.

Disability
In 2000, the Swedish parliament passed a national action plan for disability policy, called
"From patient to citizen" (Prop. 1999/2000: 79).
It starts from the *United Nations 22 Standard Rules, Agenda 22, to ensure people with disabilities participation and equality.* (1993) Sweden has undertaken to comply with these rules and the national action plan established the main goals of the Swedish disability policy. The plan states that society should be designed so that people with disabilities of all ages can fully participate in society and that there should equal opportunities for women and men. Policies should also be formed so that the obstacles to full participation are identified and eliminated and so that discrimination will be prevented and combated. Policy should also be designed so that children, adolescents and adults with disabilities are given the prerequisites for independence and autonomy. The National Action Plan involves government authorities, municipalities, organizations and many other actors. But it also is the concern of all citizens. It is our shared responsibility to guarantee that people with disabilities receive the same rights and opportunities as other citizens. (Prop. 1999/2000: 79) Naturally, the laws and regulations that exist in society include persons with intellectual disabilities. In addition to these laws, there is a special law, which shall guarantee persons with certain disabilities, a *good* life situation - which differs from the wording of the Social Services Act which is a *reasonable standard of living*.

Act concerning Support and Service for Persons with Certain Functional Impairments (LSS)
Lag (1993:387) is a law of individual rights, which shall guarantee a good life situation for persons with extensive and permanent disability; that they get the help they need in their daily life and that they can influence what kind of support and services they receive. The goal is to allow the individual the opportunity to live like others.
Section § 9 of the act specifies the kind of special support and service can be provided. In this legal text there is no mention the right to support in parenting. The special grounds for the law, however, says that social services are obliged to provide help in the same way that help would be provided to parents who for some other reason are unable to care for their children. The right to support in

parenting - for all citizens - is formulated in the *National Strategy for comprehensive parental support – Everyone wins,* based on the suggestions made by the inquiry *Parent support – Everyone wins* (SOU 2008:131). This strategy is presented in detail in my study, in the section on society's support for families.

UN Declaration of Human Rights
UN Declaration of Human Rights, § 16, paragraph 1, gives all people the right to marry and have children.

UN Convention on the Rights of Persons with Disabilities
The convention does not create any new rights. The Convention seeks to eliminate barriers for people with disabilities in attaining their human rights. The convention, which focuses on non-discrimination, lists the necessary measures so that people with disabilities are able to achieve their civil and political, economic, social and cultural rights.
(Ds 2008:23)

UN Standard Rules
In December, 1993 the UN General Assembly adopted *Standard Rules on the Equalization of Opportunities for Persons with Disabilities.* Sweden has adopted the rules as a basis for their disability policy and is working actively to translate the rules into practice. One of the standard rules (Rule 9) deals with Family life and Personal integrity. States are called upon to promote opportunities for people with disabilities to live a family life. States' obligation to ensure that necessary counselling exists is highlighted as well as the right for people with disabilities to receive the same help as others in the area of family planning. Measures to combat negative attitudes towards people with disabilities getting married and becoming parents, should be encouraged and the media should be encouraged to to combat such negative attitudes. Sweden has ratified both the UN Declaration on Human Rights by the UN Standard Rules.

UN Convention on the Rights of the Child (UNCRC)
UN Convention on the Rights of the Child from 1989, establishes the rights of children and several sections deal with the right of children to be cared for by their parents and also children's rights to be protected from harm.
The government's child law policy is expressed in the *Children's policy - a policy for children's rights* (Skr2007/08: 11) and names the four areas of priority during the coming years. The first area is to develop and improve the process of following the UNCRC. The second area focuses on parental support, by taking develop a national strategy for such support. The third area is to combat all forms of violence against children, and the fourth area is to work for a strengthening of children's mental health. The government plans to follow up children's living situations in 2010 to see in which areas their rights need to be strengthened. (www.regeringen.se / sb / d) .

Parental Code
The Parental Code is the law governing paternal and maternal rights, child support, incapacity and the rights of children. It also gives the child the right to care, security and a good upbringing. (Law 1983:47).
The child's best interests are to be the basis for all decisions on custody, residence and visitation rights. When determining what is best for the child, special focus should be put on the risk that the child or another family member would suffer abuse or that the child be wrongfully removed or retained or otherwise ill-treated, as well as on the child's need for a close and positive contact with both parents.
The basic rule concerning the custody of children is in Chapter 6, paragraph 3, of the Parental Code. It states that from birth, a child is under in the care of both parents if they are married to each other, and under in the care of the mother alone, in all other cases. If the parents subsequently marry each other, then from that time on the child is under the care of both parents. Unmarried parents may obtain joint custody of their children by court decree, by notifying the Social Welfare Board at the time paternity is established, or - if the court has not previously decided custody - by notifying the tax authorities. Since people with intellectual disabilities are less likely than the general population to be married (Eriksson, H & M Tideman, 2010), this question is crucial for fathers with intellectual disabilities and their

relationship to their children. If the mother should lose custody of the child, the father loses custody as well, unless he has actively sought joint custody at an earlier stage.

Conflicts of interest between different laws

A dilemma that may arise when the interests of vulnerable groups conflict with each other is that the laws do not provide guidance on what should be the primary consideration. Children's rights and the welfare of the children should however always prevail over those of the adults. Parents with intellectual disabilities feel that their capacity is questioned by the professionals and have difficulty in understanding why. Professionals can feel that it is difficult to protect and safeguard the welfare of both parties. (Hindberg, 2003)

Another dilemma is that the parents have difficulty in asserting their rights and if they do so, can be perceived as being non-cooperative in their parenting by social workers and support staff. This in turn can be used against them when it comes to their right to have custody of their child. (Sigurjónsdóttir, 2005)

Kollberg (1989) makes clear that an intellectual disability in itself may not be grounds for losing custody. Rather, the parents' potential to function as parents should be the decisive factor.

An additional problem is that the professionals who are to provide support for parents are the same individuals who could decide whether they are fit parents or not. This situation can prevent the parents from exposing their need for help, for fear that they will be judged as inadequate in their parenting skills. (Sigurjónsdóttir, 2005)

I have not been able to go into more detail - within the framework of this work - about the studies on Swedish laws and regulations and how they work in the interests of parents with intellectual disabilities.

Since the rights to service for persons with intellectual disabilities are usually regulated by the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) (Act 1993:387), and LSS does not contain anything about the right to parental support, it is administratively difficult to find a basis for such investigations.

Some international studies have shown that parents with intellectual disabilities lose custody of their children more often and for reasons that would not apply if the parents did not have a disability. This is dealt with further on, in the chapter on the National Board of Health and Welfare's information review, in which the care and custody of children is discussed.

Concepts and definitions

In this section I describe the different concepts and definitions used when describing intellectual disabilities. In my work, I use *people with intellectual disabilities* since this is the term established by the terminology council of the National Board of Health and Welfare. If other terms are used in my text, they are related to the people or the text I'm referring to.

The advocate organization for people with developmental disabilities (The Swedish National Association for Persons with Intellectual Disability - FUB) uses the term "mental retardation" on the grounds that the legal text in the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) (Act 1993:387) uses this term. Several organizations that are forums for people with intellectual disabilities, such as the national organization Grunden and Organization 10 in Halmstad, are protesting against the term "mental retardation", saying that it is both misleading and offensive.

Awareness about concepts and definitions reveal views about humanity and the attitudes behind the terms. (Vogel, 2010)

National and international research on parenting, in which one or both parents have an intellectual disability, lack a common definition of the disability. It is therefore crucial to take note of each researcher's definition, in order to come to an understanding of the results of research. (Sigurjónsdóttir, 2005)

Concepts
The terminology council of the National Board of Health and Welfare was appointed in 2005 at the request of the government. The aim was to standardize the use of national terms and concepts and to develop a coherent information structure in the healthcare sector. In 2007, the terminology council made a decision on the revision of the terms disability and handicap. They established that the correct terms are now disability and impairment and that the term handicap should be avoided.

Disability is defined as a reduced physical, mental or intellectual capacity and impairment is defined as the limitations imposed by a disability on the person, in relation to their surroundings.

Examples of limitations are for example, various problems in coping with the demands of daily life and reduced participation in employment, social relationships, leisure and cultural activities, education and democratic processes. It is mostly a question of poor accessibility and poor adaptation of the person's surroundings. (Www.socialstyrelsen.se / fragorochsvar /funktionsnedsattningochfunktionshinder)

In 1980, the World Health Organization (WHO) adopted an international classification of injury, illness, disability and handicap. This was later replaced by a new classification, called ICF (WHO, 2001). ICF (International Classification of Functioning, Disability and Health) emphasises functional capacity and is thus a complement to International Classification of Diseases (ICD-10), which focuses on diseases and health problems.

The concept of *mental retardation* can be defined in many different ways.

The lack of a uniform definition depends on what purpose the definition has and why the diagnosis was made, says Granlund (2009). The various definitions are consistent in that they refer to a reduced intellectual capacity combined with a lack of ability to cope with everyday life.

Differences in definitions depend on how intelligence is being defined, how this is translated into measurable skills in terms of interaction with the surrounding environment and how much weight is put on adaptive skills and social skills.

A classical IQ assessment can be useful for medical or administrative purposes. The emphasis on adaptive behaviour and social skills is used more for action-related diagnoses. The latest definition is: "A disability characterized by a concomitant reduction in intelligence and adaptive skills in at least two of the three following areas: academic skills, social skills and practical skills" (AAMR, 2002, quoted by Granlund, 2009).

In an article from 2010, Vogel has analyzed controversial words from a critical perspective.

There is a general perception that the group of people currently described as having a disability, have more difficulties in daily life because of the demands they face. The challenge is to find words that are

neutral and non-discriminatory to describe a condition that most people associate with difficulties. Different analyses of terminology show the development from describing the functional impairment as "mentally retarded" to " a person with mental retardation".

A common criticism is that the expressions are long and are awkward to use, and they lack a universality which is required for terms that include major and subordinate concepts. It is worth noting however, that the currently recommended term, *person with disabilities*, once again places the reason for the disability with the person him/herself. The use of this term is therefore not in line with the advocacy organisations' desire to show that the causes lie with the environment. (Vogel, 2010)

How intelligence and intellect are defined, varies with the reason why one wants to measure this function and how the results will be used. The concepts we use when we study developmental disabilities need to be defined in relation to each other. Examples of three concepts that are used are intellect, intelligence and cognition. Intellect and intelligence can be included in the umbrella concept of cognition. There are different views on the concept of intelligence and depending on how we view intelligence, an intellectual disability can have different meanings and implications. (Granlund, 2009)

A theory on intellect

In Sweden, Kylén's model of intellect and intellectual disability has been used (Kylén, 1974). It is based on epistemological theories and emphasizes the link between ways of thinking, ways of structuring information and intellect.

It is rather strongly associated with adaptive capacity and is therefore suitable when assessing supportive measures and is less suitable when classifying persons for administrative purposes.

I choose to describe Kylén's theory on intellect (Kylén, 1974) in more detail, since my purpose in explaining or viewing the disability is not administrative, but rather I shall illustrate how the surrounding environment should adapt support for fathers with intellectual disability in order to increase the men's ability to adapt to their role as fathers.

Kylén also highlights the importance of experience in terms of a person's ability to utilize their way of thinking.

This is crucial because still today, tests are used where a person's cognitive ability is measured. If the test shows that a person reasons or *thinks like* a five year-old, it is easy to conclude that the person's parenting skills are marginal. But a person with an intellectual disability, can, with all the experiences he/she has amassed during a lifetime, function on a completely different level than a five year-old, given the five year-old's limited life experiences.

Evaluations still use age-related assessments of persons with intellectual disabilities, which, according to Kylén's theory, is totally misleading when trying to determine the functional level of the person concerned.

Kylén describes three levels of disability in his model: severe, moderate or mild intellectual disability. Within each level, five different categories are used to interpret and understand reality. The five categories are quality (what?), quantity (how many, much?), place (where?), time (when, for how long) and reason (why, if I do this).

Comprehension of these qualities is examined by evaluationg whether the person understands how different things used or by sorting objects according to common characteristics.

Quantity comprehension deals with how the person can understand numbers, quantities and sizes. Time comprehension is examined by evaluating whether the person can tell time by using a watch, by evaluating comprehension of the time required for different events and by determining if the person can plan a certain number of days ahead or can look back. Causal comprehension is examined by investigating how many steps the person is able to comprehend in a given chain of events, and if the person can compare the effects of different ways of carrying out a task. Sense of space is assessed by examining whether the person can find his/her way in different environments, whether the person can read maps and understand directions. (Granlund, 2009)

This approach to intellectual disabilities provides information on *how* a person with the disability is thinking. This information is crucial when support measures for the person are to be designed. If the support is not tailored to the individual's way of thinking and understanding, then the positive effects that were intended will not be achieved. The person's experience plays an important role in how they can use the various categories. The more experience a person with an intellectual disability has, the

better the person can interpret and understand life events. (Kylén, 1974)
This fact may have influenced the results of previous research, in which parents with intellectual disabilities who were studied in the research, had grown up in institutions and not been part of daily life in the way that the parents with intellectual disabilities had been who had grown up as citizens in society.

Definitions of intellectual disability
In most currently accepted definitions of intellectual disability, it is emphasized that the diagnosis requires a limitation in both the functions of intelligence and adaptive behaviour. (Granlund, 2009). Those who carry out the evaluations should have the training and experience required and decisions based on the evaluation should be made by persons with appropriate experience and training in the field of intellectual disabilities. In addition, the evaluators should have comprehensive knowledge about how the environment's design affects how an individual functions on an everyday basis. (Granlund, 2009) It is only when the individual support is totally adapted to the individual's way of thinking and understanding his/her surroundings, that a realistic assessment of an individual's ability can be made. In Sweden, support and service to persons with intellectual disability is regulated by a separate law, the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS), (Act 1993:387). This means that a group of citizens with intellectual disabilities can be defined administratively.
Government statistics dealing with the population of persons with intellectual disability is based on the people who have received support under this act. The persons who have been judged to be entitled to this support often have significant impairments in intelligence and adaptive skills.
However, the definitions and concepts concerning intellectual disability need to be adapted as the life situations of people with intellectual disabilities change and these people are given the opportunity to live life like anyone else, together with everyone else,

Persons identified for administrative purposes as having an intellectual disability make up 0.4 per cent of the population in Sweden. Since the 1930s, the level that defined an intellectual disability varied between IQ 50 and IQ 85 in the Nordic countries. Calculations based on the lower IQ produce a group that makes up less than 0.5 percent of the population. However calculations using the higher IQ produce a group of people defined as having an intellectual disability that make up more than 15 percent of the population. (Tössebro & Kittelsaa, 2004, p 24)
This shows that the instruments that used to measure intellectual disability, as well as the definitions that are used, are social constructions.

Society's support to all parents

Introduction

In this section I focus on the societal perspective of parenthood by describing the support that society provides all parents and the government bodies that are charged with providing support measures. I have read studies and evaluations of these efforts using a gender perspective in order to illuminate the amount of support fathers receive and I found that fathers are named specifically as an important group to reach. And within these government bodies, there is an awareness that special efforts are required in order to reach fathers. I have also searched for fathers with intellectual disabilities in the wording that deals with society's support for fathers in general, but I have not found any text that focuses on these fathers as a group in need of special assistance. I will present how the support for parents with intellectual disabilities works by assessing an evaluation of a Swedish support group and I will also present Swedish and international research on support for parents with intellectual disabilities. I did not find anything written specifically about fathers, rather the researchers use the term *parents*, which usually means the mother. In some studies fathers are included, but then only as background figures. An Icelandic thesis is the only research that I have found on the support to fathers with intellectual disabilities and their own perception of this support. (Sigurjónsdóttir, 2005) This thesis is presented in the section of my study entitled *Research on fathers with intellectual disabilities.*

Everyone wins?

The report *Parental support – everyone wins*, *national strategy for society's support and assistance to parents in their parenting roll* (SOU 2008:131), suggests a long-term national strategy for comprehensive parenting support .The inquiry's mandate was to develop strategies for a comprehensive support for parents and basically it simply stated that there are large groups that are not reached within the scope of general support to parents. The inquiry's own preface emphasized that parents of children with more specific needs and parents who themselves have more specific needs, require different and more specialized measures than those described in the report. The comments from disability organizations and the government's ombudsman for children express the opinion that the need for more direct, practical support so that the family's everyday life can function is more important than the general support to all. Several expressed a desire for a new committee in order to take stock of these more specific needs and describe how more specialised parenting support could be designed and implemented. (Ministry of Health dnr S2009/554/FH).

The report (SOU 2008:131) takes up proposals for the support to be offered to all parents until the child turns 18. All parents are offered the same opportunities for support and assistance so the strategy describes itself as a universal preventive measure. No single group of parents are selected for any specific reason. The authors of the report do not believe that parents with intellectual disabilities or their children are in need of special assistance.

Parental support is defined as an activity that gives parents knowledge about children's health, their emotional, cognitive and social development and / or strengthens the parents' social networks. The support is characterized by cooperation, and the strategy highlights three forms of collaboration - exchange of information, which is the most cursory form, joint action that involves the planning and implementation of joint activities, and finally co-production which includes services with joint funding and organization.

The report proposes that the nature of the services should decide which form of cooperation is appropriate. Collaboration requires time, respect and consensus among the different stakeholders, support from management and politicians, as well as structure and evaluation.

The overall aim of the strategy is that all parents should be offered parenting support during the child's entire childhood. Three sub-strategies are also defined: increased collaboration on parenting support, an increased number of meeting venues for parents and an increased number of trained family facilitators and universal, evidence-based support programs. Information on parental support should reach all parents. It should be comprehensive and easily accessible, for example on the municipality's website. There should be a parenting site on the municipal website. Internet is given focus as a meeting place for parents and in the strategy report it is noted that there are a large number of websites for parents and that it is difficult to determine their quality. (SOU 2008:131)

Parental support - design and content
The support programs that are used to improve parenting skills are often developed in other countries and it can be difficult to transfer them directly to Swedish conditions. This fact may influence the effect they have. (SOU 2008:131)
A number of research results concerning support for parents with intellectual disabilities show the necessity of adapted support and that it is only when support is given based on the parent's specific circumstances that one can see positive effects on their parenting skills. It is of crucial importance for parents with intellectual disabilities that the support program is designed in line with their ability to understand and use it. If this is not done, and their parenting skills do not improve, the parents will be seen as the reason for the shortcomings, when in fact it was the support program that were lacking. (Feldman, 1994, Llewelyn, McDonnell, Russo, Mayes & Honey, 2002, Olsson & Springer, 2006).
At Örebro University, there is a on-going project that evaluates the support programs that are used in Sweden for parental support and a statement will be ready in 2013. It is not clear from the information I have had access to, whether a part of the project's aim is to take into account parents with intellectual disabilities.

Parental Support for parents with intellectual disabilities under review
The government has given the National Board of Health and Welfare the assignment of analyzing how general family/parenting support interventions can be complemented and how existing interventions aimed at parents with disabilities can be made more effective in creating the conditions for family life so that parents and children can develop both as individuals and as a family entity. The assignment also includes an analysis of how existing interventions directed at the target group, help to increase the accessibility to activities in the community that are offered to all children and parents. The National Board of Health and Welfare is to present its proposals by September 1, 2010.

Prenatal care and its mission
In April, 2004, the government appointed a commission to review the Swedish parental insurance plan to see if it functions in the best interest of the child and if it contributes to gender equality. *Reformed parental insurance - Love, Care, Security (SOU 2005:73)*. As part of the review, a study of maternal healthcare centres and children's healthcare centres was conducted to see how they view their mission to educate the country's parents. (SOU, 2005:73 car 4).
In the report (SOU 2005:73, car 4) it is established that the maternal health centres are mandated to provide for monitoring pregnancy, breastfeeding support, postpartum support and preparatory parenting courses for *both* fathers as mothers. Dating from a parliamentary resolution in 1979, parental education has been seen as the main task for both maternal healthcare centres and children's healthcare centres. All parents should be offered educational group activities before and after the birth of their child. The maternal healthcare centre is responsible for parent education courses prior to birth and the children's healthcare centres are responsible for parent education courses after the birth of the child. Parents should be given the opportunity to prepare themselves for parenting, to come in contact with other parents and to gain greater insight into parents' situation in today's society. The courses should strengthen the mother's and father's confidence in themselves as parents, by providing knowledge about parenting skills and general community information. Most first-time fathers participate in childbirth preparation training. However, it is common that fathers do not participate in the training at the children's healthcare centres. But the review notes that many communities make active efforts to get fathers to participate by forming special father groups.
According to the report (SOU 2005: 73, appendix 4), the mission of the maternal healthcare centres encompasses the entire family, that is to say - the midwife should work using a psychosocial

approach. However most midwives are focused on the medical care of the mother. The focus on maternal health gives the father the role of the secondary parent, even before the baby is born. The father's responsibility for the child is via the mother - he should support and assist the mother. In addition to this focus on the mother, it is stated that the father is equally important. But he should do things that the mother cannot do. Gender equality and shared parenting is formulated based on the mother's biological role during pregnancy and breastfeeding, and when this is the basis for division of responsibility, the father becomes a helper and a supporter. Midwives and nurses are well aware of the fact that this division has a negative impact on the future sharing of responsibilities within the family. Parent groups and in some cases "father" groups are often seen as a solution. However, these are usually held during the workday which makes fathers' participation difficult. But even when attempts have been made to hold the courses in the evening, fathers are still absent from the courses that are held after the birth of the child. (SOU 2005:73, car 4)

The common perception is that men talk to men, and the father groups are led by men who are fathers themselves. (SOU 2005:73, car 4) The fact that fathers are excluded from speaking with trained child healthcare staff has been criticized. The level of knowledge about parenting - from a gender point of view - is relatively low among professionals working in maternal healthcare and children's healthcare, as well as among the active volunteer fathers who are group leaders. More training is needed, as the interviewees pointed out.

It is up to individual midwives and nurses to articulate what is meant by shared parenting and responsibility. A clear focus on the non-negotiable and shared obligations of parenting, as well as clear instructions on how these can be communicated, would increase professionalism and help those who will have the trainer's roll. Prior to the birth of the child, there is no clear focus on the upcoming parenthood. The woman's ability to carry and give birth to a child does not make her a qualitatively different kind of parent than the man.

The staff of the maternal healthcare centres should convey research-based knowledge about parenting and gender. One should consider how parent groups could be organized to include men. Professional guidance should be given to the groups and the structure using "father" groups can be developed to apply even to the mothers. An experienced mother and an experienced father can lead discussions about parenting. (SOU 2005:73, appendix 4)

Child health care and its mission

Elwin - Novak also reviews the children's healthcare centre and its mission in the report. (SOU, 2005:73, car 4). The mission of the children's healthcare centres is regulated by the county council, health and medical services board, primary healthcare board or by the municipal and social welfare board. The mission has its origins in the laws, regulations, and various policy documents that have been adopted. (Health Act, (HSL) SFS 1982:763)

The work within the children's healthcare system can be said to be based on the overall objectives to promote health, prevent the onset of injury and illness and respond to parents' needs with tailored service support and care. The work has two foci, one psychosocial and one based on health policy. In turn this means that the work to be performed, requires efforts directed towards both the individual / family as well as at other related activities and decision-makers at different levels. (SOU 2005:73, car 4)

On behalf of the National Public Health Institute, the children's healthcare authority in Uppsala has carried out a Parental Support Project. The project had three main objectives: a review of what services parents of children of different ages require, a detailed analysis of the existing parent-support activities provided by children's healthcare centres and the maternal healthcare centres and the implementation of an evidence-based parenting programs in a number of preschools in Uppsala. The project was a few months in duration during 2008 and the results were used in the document *Parental support - everybody wins. A national strategy for community support and assistance to parents in their parenting roll (SOU 2008:131)*. A number of smaller projects were carried out within the scope of the Parental Support Project, some of which focused on the fathers' contacts with the children's healthcare centres. The fathers did not feel that they were particularly welcome at the centres. So despite the fact that nurses at the centres express how important it is to involve fathers, they didn't succeed in reaching the fathers. Fängström and Smeds (Parental Support Project, 2008, Chapter 4) say that this shows that gender perspective must be a conscious part of the work carried out at the children's healthcare centres

and that it's not enough with good intentions. Concrete tools as well as discussions on attitudes within the profession and within the centres own staffs are needed. Even the physical environment sends out signals about how the centres work. In a study of the waiting rooms at the children's healthcare centres, most waiting rooms are mother-child oriented. The magazines in the waiting room, the furniture and the messages on the bulletin board were aimed primarily at mothers.

Parent groups at the children's healthcare centres have difficulty recruiting fathers. Here the researchers concluded that the time of day that the meetings are held needs to be reviewed, that efforts should be made to recruit male leaders to the groups and that the meetings should have themes that include fathers. Even the open pre-school programs focus on mothers and children, which makes the fathers feel unwelcome or ill as ease. Here the researchers suggest separate "dad" days, a different selection of toys and a conscious effort to support fathers in building up social networks. (Parental Support Project, 2008: Chapter 4).

In the activities that were examined and in the measures and proposals listed in the parental support project's report, there is no mention of parents with disabilities anywhere. Consequently, fathers with intellectual disabilities are not mentioned anywhere and are not the subject of reflection.

Social Services

As is the case for all other citizens, parents with intellectual disabilities are entitled to support from the Social Services Act. (Social Services Act, SFS 2001:453). According to the Social Services Act, the municipality has a special responsibility for certain groups, of which people with disabilities are one. Free will and self-determination is the basis of all services provided under the Social Services Act. The services should also be designed to take advantage of a person's competencies and willingness to change his/her social situation. The social welfare board is also responsible for children who have been abused, or who are at risk in some way.

Anyone who becomes aware of something that could necessitate intervention by the social welfare board in order to protect a child, is obligated to notify the board. The Board can designate a specific contact person or a contact family who has the task of helping the individual in their private affairs, if the individual requests or consents to this.

When the Social Services Act (SFS 2001:453) cannot sufficiently guarantee a good life situation for persons with intellectual disabilities, these persons may request support measures under the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS). However LSS contains no specific text on the right to assistance in parenting, which can be interpreted by the LSS administrator as meaning that this kind of support should not be approved. This means that fathers must seek help from the social welfare board. It is therefore of interest in my work to illuminate social welfare services specifically from a gender perspective.

The social welfare services from a gender perspective

The National Board of Health and Welfare has reviewed the social services from a gender perspective in a document of the type - *monitoring and evaluation*. (The National Board of Health and Welfare, 2005-103-6)

The task of The National Board of Health and Welfare was to monitor, analyze and report gender differences in the services provided by the social service and, if necessary, make proposals for action. The gender perspective based on a needs perspective has been applied by the investigators doing the review. The social service's views on gender affect the assessment of a people's needs and how the social service carries out their tasks. This means that men and women should have the same opportunities, but not always given the same the same kind of support, in order to have their needs met in a way that is knowledge-based and cost-effective.

The investigators feel that The Social Welfare Act's emphasis on the needs of the individual, makes the gender perspective invisible.(Welfare, 2005-103-6). Gender equality as a concept is missing in the laws governing the tasks of the social service. Investigators say that gender awareness needs to permeate the entire process, from judging the need for actions, to outcomes and impacts, at the social services, county administrative boards and the National Board of Health and Welfare.

The gender distribution at different levels within social services, both at staff level and with in political sphere, may be significant in terms of the social welfare boards' assessment of the support measures needed by men and women. The bulk of social services staff are women.

From a gender perspective, the family is central. The social service's perception of what a family is, and what roles women and men play in it, affects all aspects of family law. The traditional nuclear family has changed and many different forms of cohabitation and relationships now exist. The investigators further conclude that how the staffs of the social services view these new forms has crucial meaning in terms of how they respond to and evaluate men and women in their roll as parents. Of 193 municipalities, only 15% responded that they had decided on a policy, guideline or directive on gender equality. More than half had never made any analysis of the impact that various decisions have for women and men. Many municipalities have called attention to the gender distribution of social services personnel. Seventy percent of the municipalities felt that staff's gender affects what measures and support are provided to male and female clients respectively.

Investigators have examined the social services provided for children and young people, and they found that the services reflect traditional perceptions of gender and family. The fathers are absent in the inquiries and evaluations done by the child welfare authorities. It is the shortcomings of the mother that determines whether or not the child should be placed outside the home.

There is a great lack of knowledge about gender equality within disability care. (Welfare, 2005-131-6). General speaking, there is a lack of information about how many people there are with different types of disabilities and how many are in need of intervention from social services.

The inquiry further notes that there is a clear trend that more men than women receive assistance under the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) and that women with disabilities have greater financial difficulties than men. Finally, the investigators studied the gender perspective within the organizations involved in voluntary social work, such as disability organisations, and found that women are overrepresented. There is a danger that fathers and questions related to fatherhood are left unaddressed since women are running these organisations, although men dominate the boards of the organisations.

The investigators noted that all areas of the social services need to be the subject of research from a gender perspective. The National Board of Health and Welfare issued an information brochure, *A first step towards gender equality in social services,* (2004-1-4) to inspire a change in all areas of social service. (The National Board of Health and Welfare, 2005-131-6)

Family Centers - a form of collaboration

Family centres are a form of collaboration that the strategy promotes. Vilken strategi? There are 131 family centres in Sweden and the most common form is shared premise for maternity care, children's healthcare and the local social service office. The work done at the family centres is 90% preventative. In a few locations around the country the Children and Youth administration is located in the family centre instead of the social service office, since the latter is often perceived as an authority and therefore linked to problem situations.

The National Board of Health and Welfare has done an inventory of the work done by the family centres as well as by the municipal operations with a similar design. The assignment also included the compilation of existing evaluations and reports and called for utilizing international experience. (National Board of Health and Welfare, 2008-131-16)

Family centres and similar centres in Sweden can be divided into two categories with different approaches: a *service-oriented approach* and a *targeting approach*.

The service-oriented family centres base their work on a public health perspective and work primarily with general prevention work, so-called universal prevention. Approximately 90 percent of family centres and similar centres are service oriented. The work of the family centres can vary significantly, depending on which partners are included.

The family centres that use a targeting approach also base their work on universal prevention, but here it is more common with targeted measures for the children and families who have been identified as having problems, so-called selective and indicating measures. The social services are included, such as benefits assessment (by the social service authority) and the measures granted by the social services. Ten percent of family centres and similar centres include a social service authority. Visitors to the centres are predominately parents who come from socio-economically strong groups. This means that fathers, persons born abroad and to socio-economically disadvantaged families are underrepresented. Approximately 30% of family centres/similar centres have outreach programs directed towards men in

the form of father groups.

The investigators state that the criticism directed towards the family centres who use a targeting approach, concerns inadequate treatment of anonymity and that the presence of social service office could be perceived as problematic.

According to The National Board of Health and Welfare's survey (National Board of Health and Welfare, 2008-131-16) 20 % of family centres/similar centres use programs that are based on a specific program or are manual-based, such as Aggression Replacement Training (ART), Community Parent Education Program (COPE), Communication method (Comet), and Marte Meo, an interaction method. These programs are not adapted for parents with intellectual disabilities, but these are the programs that these parents are offered, since a specially designed program doesn't exist.

In the spring of 2008, the National Board of Health and Welfare national did an inventory of the methods local governments used to prevent serious mental health problems in children.

The inventory (National Board of Health and Welfare, 2009-126-176) shows that the social services reported that 90 different methods and structured approaches are used in the open care services. Of these methods, twelve were reported for children in risk environments (abuse, mental illness or domestic violence) and twenty of the methods relate to parent education. The inventory shows that the social services have taken an interest in and use a systematic and structured approach. This is evident in the form of a large number of reported manual-based interventions for children in risk environments, parents, young offenders, and those in need of structured family therapy. However, clear descriptions of methods and content are often lacking, as well as evaluations of the more individually tailored approaches such as family education intervention in the home. These services are often provided for extended periods and can be more intrusive in the lives of children and families; they are usually provided in the home and lack transparency. They are seldom evaluated by the municipalities themselves. There is a need for a national evaluation of approaches and practices - in particular, an evaluation of the less structured approaches to family education interventions in the home and individual counselling. (National Board of Health and Welfare, 2009 - 126 - 176)

There are no Nordic research studies on the effect of family centres work on the social, emotional or cognitive development on children and families' and the non-Nordic evaluations are of uncertain value because of contextual differences.

(National Board of Health and Welfare, 2008-131-16)

Society's support for families where parents have intellectual disabilities

Swedish studies

There are only a few older Swedish studies that describe support for families where one or both parents have intellectual disabilities. Common to these studies is that they demonstrate that social support is insufficient in insuring a good life situation for the parents and children. This insufficiency is due to both economic factors and the fact that those who are to decide services and provide services, lack adequate expertise about the disability and its consequences

In one study, Gillberg (1983) describes support in terms of financial assistance and respite support for the parents. Rönnström (1983) says that maternal education should be adapted, if social wellfareworkers support families and contacts.

Olson and Springer (2004), describe the need for and the complexity of the support for these parents. Several research and development offices in municipalities around the country have developed guidelines for families with intellectual disabilities and how they can be supported in their parenting. In these guidelines, the need for coordination among different professional group is pointed out as in the need for knowledge about the disability and its consequences.

An evaluation of the implemented support activities

During 2006-2008, the municipalities of Uppsala county established collaborative groups for families with intellectual disabilities. Representatives from the maternal care centres, nursery schools,

primary schools, special education schools, children's healthcare centres, habilitation, LSS, social services, and psychiatric care are all included. Two methods projects have been implemented within the framework of the FIB-project. The purpose of the first project was to develop the existing support provided to families in the home. The purpose of the second was to create a new service, within the existing services at a family centre, namely joint activities for parents and children. The project was evaluated at its conclusion. (Jöreskog, 2009).

The purpose of the evaluation was to describe the activities that had been developed and take advantage of the experiences that had been acquired during the project. This experience should be related to relevant knowledge and focus should be put on the knowledge that contributes to possible approaches and addresses the difficulties involved.

In the case of support in the home, the children appreciated assistance regarding meal situations and homework the most. (Jöreskog, 2009) Parents have appreciated support in creating structure and order and support in how to help maintain functioning relationships within the family. The therapists working in the home have been a link for communication between children and parents, as well as a link between parents and schools and government agencies. This support must be characterized by a long relationship so that the parents will feel secure. The therapists working in the home should also convey that a positive development is possible and demonstrate the positive changes that are taking place. The cognitive tools that the therapists provided have been beneficial. When support in the home works, it also creates dependence on the part of the parents, even if their self-esteem has been strengthened. The parents worry that the support might cease and that they might not get support when they need it.

Therapists working in the home point out that several aspects of their work differ from when they work with families where parents do not have an intellectual disability. For example, at the outset, the parents' experiences of alienation and criticism create distrust and fear when it comes to support in the home. Therapists working in the home must have a thorough knowledge of intellectual disabilities and their consequences and they must have access to appropriate guidance. They also need to be flexible in terms of their work which may include setting up meetings with healthcare providers, social services, schools and day-care centres.

Joint activities for parents and children, with refreshments and games are perceived positively by the children. (Jöreskog, 2009) The children were given information about different disabilities, so they could better understand their parents. Whether increased understanding has been achieved is difficult to measure, but the children indicate that they now have strategies for action by using words such as "accept help from someone else", "dare to tell," or "say no". The parents describe themselves as a group that has difficulty in getting the help they need and the biggest problem is that they are at home and unemployed. They also have very limited financial resources.

Parents also say that they always find themselves rejected by the authorities who tell them that they have turned to the wrong person with the wrong problem. Group activities have given parents a sense of community with other parents, new knowledge of how agencies function and an increased desire to do new things. Team leaders see their parents' increased social networks as important. However they express doubts as to whether the newly acquired knowledge can be put to use by the parents at home and they also see that children have a great need for support and help. (Jöreskog, 2009)

In other parts of Sweden similar activities have been launched, using various forms of collaboration in providing support for parents with intellectual limitations. Stockholm, Kristianstad, Hässleholm and Ostersund are some examples. However I have not been able to find any evaluations of these activities.

International research on support for families

In an Australian study Llewelyn, (1995), has examined parents' views on support measures. Results indicate that the first preference of parents with intellectual disabilities is to seek support from their partner and secondly from someone in the extended family - before they sought professional help. Llewelyn & McConnell, (2002), also clarify that family members play a central role in supporting the process. Throughout life, family members were the primary source of both practical and emotional support.

Booth & Booth (1998) speak of a perspective on parents' skills, which they call a "shared competence". The concept is that parenting is composed of a relationship of mutual dependency that is the basis for carrying out parental duties. Parenthood is a shared concern for the whole family network, which strengthens and supports parents in their role. Booth & Booth say that in light of this, (1998), parenting should be regarded in its social context, rather than set of parents made up of two individuals. Nonetheless, until recently, research has largely focused on parents as individuals, regardless of the social context. (Traustadóttir & Sigurjónsdóttir, 2004, Chapter 3)

Society's support for fathers
In a review of government reports, the findings of the National Board of Health and Welfare and the Ministry of Health's mapping, it is clear that the topic of fatherhood and how to get fathers involved with their children, has been an issue for over two decades. The aim has been to gain greater knowledge and understanding of fatherhood, so that efforts could be evaluated and tailored to the fathers' needs. The Ministry of Health was commissioned by the government to identify, describe and analyze activities aimed at parent education and parent support. The contract specified that the mapping should provide examples of the importance of the father's roll and describe examples of activities relating to family education for families with special needs. (SOU 1997:161)
The commission's view is that children need and are entitled to both parents throughout their childhood, whether or not the parents live together. Parents have a fundamental right to be parents to their child throughout childhood.
Support in parenting is expressed as the knowledge and support that society can give to parents to develop their competence and confidence in parenting from pregnancy and throughout childhood. (SOU 1997:162, p. 34) Proposals to encourage fathers to make use of their parental leave include such measures as special father coaches, joint efforts to reach out to fathers, and increased competency concerning the male role and the father's role during the compulsary military service and at youth clinics. Military service should include time for discussion about such issues as parenting, relationships, child development and the needs of children. However, none of these efforts reach fathers with intellectual disabilities to any great extent since they rarely do military service and compulsory military service has also changed greatly in recent years and no longer includes the majority of young men. (Fathers with disabilities are not mentioned in the reports at all.) Further proposals that have been presented include changing the name of maternity clinics to parent centres and giving special attention to parents with physical disabilities at the centres, which must therefore be made handicap accessible. It is clear that "accessibility" is directed towards parents with just physical disabilities. Methods to develop support for parents whose children are placed in foster care is another proposal (SOU 1997:161)This proposal is of importance for fathers with intellectual disabilities.

Society's support for fathers with intellectual disabilities
Although the various government authorities dealing with parent support are all aware that special efforts need to be made to reach fathers in general, fathers with intellectual disabilities are not mentioned anywhere in the reports I have read.

Fatherhood and Swedish policies concerning fatherhood

Introduction
In this section I describe the view of fatherhood in Sweden and how policies dealing with fatherhood are formulated. The view of fatherhood is relevant to my work in at least two aspects. The first is that society's view of fatherhood influences fathers and how fathers are regarded by the authorities who design or provide support for parents, including fathers with intellectual disabilities. The second aspect is that the standards that society sets for "good" fatherhood, are the standards used when assessing if fathers with intellectual disabilities are capable fathers and whether they should be allowed to take on fatherhood.

The view of fatherhood and fatherhood roles
Parents are crucial to children's health and welfare. The mother has hitherto been perceived as the most significant parent for the child. This has had implications for the support that is offered to parents today – i.e. it is primarily mothers who are offered interventions. This kind of parental support is an obstacle for equal parenting.
It is vital to emphasize the father's importance to a child's health, development and well-being and to design support for parents so that both women and men will benefit. (Bremberg, 2009)
Fathers play many different and varied roles, their importance is often indirect and the social construction of fatherhood varies over time, and within different societies. (Hwang, 2005) It is not enough to simply look at the relationship between child and father, in order to understand the father's importance to their children. A family is made up of a group of people, all of whom affect each other. Insecure parents, where both the mother and father are not sure what to do when alone with the child, can create a more secure situation for the child when both of them are together with the child. They support each other, they consult each other and perhaps encourage each other when things go well. As a result, the child also does better, cries less and the parents feel affirmed and become confident in their role. The father also devotes time to the child, giving the mother an opportunity to do other things.
Studies show that the relationship between the parents both indirectly and directly affects the child's bonding. If the parents' relationship is good, it is more likely that the child will bond well with both the mother as well as the father. Conflicts between the mother and father can be more detrimental to the child than the absence of the father or a separation between parents and children. (Hwang, 2005)

Five different roles of fatherhood
Hwang (2005) highlights some key areas where social support should be designed for fathers in order to increase their involvement in the family and the child. One area is the social networks that fathers have. Fathers' networks are slightly smaller than the mothers' social networks and Hwang discusses how this affects the father's relationships within the family. Most of the fathers' networks consist of persons related to the family. The networks of fathers from working-class backgrounds focused more on relatives. Hwang describes five different father roles that require different social networks. There is the *traditionalist,* where the father works full-time mother and works part time. He has his hobbies, which take some time, but spends Saturday and Sunday doing something active with his children. This kind of father role requires a small, homogenous and family-centred network that can stand up to changes. Typical male pastimes encourage traditional thinking and the network that centred around family relatives acts as a brake if the woman wants to change her husband's behaviour.

The *innovator role* is when the father and mother have shared the parental leave, they both work full-time and both carry out the domestic chores. His social network is often of a different nature - it is larger and anchored in several different and separate environments. This network is dominated by friends and contact between the various members of the network is not as frequent. *The trapped father* is the father where theory and practice are out of sync. The father says that of course fathers should be home with the children and take responsibility for domestic chores, but it is just not possible in his type of job. The social network in this case can be the workplace where career and the company are the main focus. Hwang reasons that men are often at an important phase in their career when they become fathers. The *single father* is a new role that describes the father who takes sole responsibility for his home and children. Here, the social network is particularly important, especially the relationship with the child's mother. A single father can get much more assistance and support from his social network than a single mother. The fifth fatherhood role that Hwang identifies is the *Sunday father*. This refers to the father who has the child every other weekend. The vast majority of single-parent families consist of a mother and a number of children. The Sunday Father has traditionalist overtones and has a social network that can help with childcare and housework during this period, which he often sees as a waiting period, in anticipation of forming a new two-parent family. Other Sunday fathers can have more of the innovator role. They may experience frustration at not having custody of their child, be bitter about societal norms, government agencies and women-biased courts. Their social networks often consist of other fathers in the same situation. The relationship with the child's mother is often poor, and since the former social network no longer functions, the new social network will be very important. (Hwang, 2005)

The fatherhood roles of fathers with intellectual disabilities
It can be difficult to see how fathers with intellectual disabilities fit into these five different roles. The *traditionalist* role requires a full-time job and male hobbies, something that most fathers with intellectual disabilities do not have. The *innovator* role, in which the mother and father share parental leave and then work full-time and share the household chores, does not fit either. Parental leave can be difficult to take for a father with intellectual disabilities, who goes to a daily activity centre or has employment subsidized by an activity stipend. The situation where both parents would also work full-time is not common at all. On the other hand, one could see fathers with intellectual disabilities as genuine innovators, so innovative that the people around them don't understand their role in the family and their importance to the child.

The *trapped* father, who is squeezed between a career and children, probably doesn't exist. There are few fathers with intellectual disabilities who are in the midst of careers. However fathers with intellectual disabilities can feel trapped if they are taking part in activities provided by the law on Support and Service for Persons with Certain Functional Impairments (LSS), but would like to take parental leave or care for his children at home. I have not found any information dealing with *single* fathers with an intellectual disability. In research on fathers with intellectual disabilities, I have only found one father who had received custody of his children. He had begun a new relationship with a woman who did not have an intellectual disability, and was awarded custody of his children, instead of the children's biological mother, who was single and had an intellectual disability. (Sigurjónsdóttir, 2005).

In the end, the *Sunday father* may be the father role that in fact exists. It is difficult for fathers with intellectual disabilities to maintain routines and contacts so they can spend time with their children who are placed in foster homes, or are in the custody of mother.

Swedish policies concerning fathers

Bergman and Hobson (2002) describe the Swedish policies that deal with fathers and the role of the father in a historical perspective. They analyse policies dealing with fathers and fatherhood using a gender-related approach, just as many researchers have previously done in the case of motherhood and parenting policies. Using a historical perspective and a discussion about fatherhood and what it has meant in many different countries as a point of departure, they conclude that men in the role of citizen are defined as soldiers and taxpayers, not as fathers. However, women are primarily seen as mothers. In the Swedish language, "fatherhood" has a more biological/administrative definition. The word "fatherhood" occurs in the context of establishing paternity, DNA tests and disputes about biological paternity. "Motherhood" however, which is often replaced with "parenthood", is usually associated with the caring and loving nurturing of children.

This can clearly be seen in the Swedish debate about fathers who have been deprived of their biological fatherhood, according to Bergman and Hobson. Fatherhood, in this context, is not treated as something important for the child – as a relationship between father and child - but rather more as a financial obligation. Fatherhood is a sterile, biological, and not linked to the child.(Bergman & Hobson, 2002).

Bergman and Hobson also show that if the nurturing side of fatherhood is emphasized in Swedish discussions, it is often in the context of policies concerning the months designated for fathers in the parental leave policy. The idea of the male breadwinner is disseminated and accepted, and society took measure against the fathers who did not fulfil their obligations. However with a growing variety of family forms that have become increasingly common in today's society, the situation has changed. Despite this, the view of the biological father has not changed. He is still considered as the key person who will contribute financially to his child's costs, regardless of the mother's income. A biological father will always have the right to joint custody of his child, even if he had not had contact with the mother after she became pregnant. (Bergman & Hobson, 2002) This is established by court regulation, by notifying the Social Welfare Board in connection with the establishment of paternity, or - if the court has not made a previous decision on custody - by notifying the tax authorities.

In recent decades, policies dealing with fatherhood have increasingly focused on nurturing measures, according to Bergman and Hobson (2002). The authors believe that the nurturing father is still a controversial concept, especially if the discussion concerns what is considered masculine. The Swedish expression "velour papa", is only found in Sweden. The father as breadwinner is the image of a real man, propagated in advertising, in literature and movies. A stay-at-home dad runs the risk of being feminized and the family loses its masculine member. When parental leave for fathers was introduced in Sweden in the 1970s, it was launched with the picture of a very masculine father. The Swedish weightlifter, Hoa-Hoa Dahlgren, with an infant in his arms, was used to attract Swedish fathers to stay at home with their infants. The message was that stay-at-home dads did not have to be "velour papas". The campaign wanted to communicate that *real* men actually cared about their children and working class fathers were the primary target group of the campaign. During the eighties, the authorities had changed their strategy and a brand new campaign was launched to attract yuppie fathers to take their leave. Despite these campaigns and the generous allocation of parental leave for fathers, few fathers in fact use their allocated months, according to the authors.

Finally, the authors note that it is not enough that Swedish men increasingly define themselves in terms of their family and as fathers. They also note that it is still problematic for men to stay at home and take responsibility for home and children.

Economic reasons are not sufficient. Nor that fathers with low incomes stay at home to any great extent. (Bergman & Hobson, 2002)

Fathers with intellectual disabilities in policies dealing with fathers

I have not been able to find any information about how society treats fathers with intellectual disabilities when paternity is being established. Since few of these fathers are married, (Eriksson & Tideman, 2010), this should be a concern for the fathers who do not want the mother to be granted sole custody of the child. But do these fathers receive information about how to have their paternity registered? Does the fact that they are economically disadvantaged fathers make it less important to determine the father's financial obligations to the child?

If fathers with intellectual disabilities and their commitment to family and children are going to be judged in terms of how much parental leave they take, then they will not rank well. Can people with intellectual disabilities take out parental leave if they are taking part in activities provided by the law on Support and Service for Persons with Certain Functional Impairments (LSS)?

The argument that families lose their masculine member when stay- at-home dads are feminized, as Bergman and Hobson (2002) refers to, would be useful to examine from the perspective of fathers with intellectual disability. How do they define their masculinity? Some explanations can be found in the research I refer to in the section on research on fathers with intellectual disabilities.

Swedish society has embraced Nirje´s principles of normalization. (Nirje 1969a, 1969b; Nirje 1994, p. 175) Nirje highlights eight consequences that must to be analysed in order to create a daily life situation for people with intellectual disabilities that mirrors as closely as possible normal life in society.

Some of the consequences Nirje highlights: being able to experience normal life phases, being able to live in a two gender world, being able to live under normal economic conditions and with normal residential standards.

But is normalization getting what everyone else in society gets, or is it to getting what these persons need in order to be able to live like everyone else in society? The target group - fathers with intellectual disabilities - is not a strong group in a political context and have difficulty making their voices heard.

Previous research

Introduction

This section presents previous Swedish research on parenting in which one or both parents have an intellectual disability. The society and the view of people with intellectual disabilities that existed when the research was conducted, is described and discussed.

The National Board of Health and Welfare has inventoried research on parenthood and intellectual disabilities. (Socialstyrelsen, 2005) The inventory includes Swedish and international research during the period of the 1990s and up until 2003.

This summary and my own additions to the current Swedish and international research are commented on. I have chosen to divide the section on previous research into three areas that I wish to highlight in my study.

The first area of research is *family and life situations*. External stress factors such as unemployment, low income and housing conditions have a greater impact on parenting than the intellectual disability. It is therefore important to understand the daily life situation of parents with intellectual disabilities in order to determine what kind of support they need in their parenting.

The second area of research is *partner relationships*. The parents' relationship affects the child's health and well-being (Hwang, 2005; National Public Health Institute, 2009) and support staff and social workers' attitudes about families and their internal relationships can create barriers for fathers taking an active father roll. (Sigurjónsdóttir 2005) Sigurjónsdóttir reasons that since there are few people with intellectual disabilities who live in traditional partner relationships, one needs to understand that less traditional forms of relationships can be stable and significant. Sigurjónsdóttir (2005)

The third research area is *when parents lose custody of the child*. The studies I have found show that when one or both parents have an intellectual disability they more often lose custody of their children and that the basis for custody decisions are different when parents have an intellectual disability. Social workers and decision makers lack the competence necessary to judge whether the state should take custody of the child or not. (Booth, 1994; Sigurjónsdóttir, 2005, Gustavsson and Springer, 2008)

Social developments in Sweden raised the research on parenting

During the 1980s, institutions were closed down and people with intellectual disabilities moved into the community into small group homes. They were offered jobs at daily activity centres and at schools, special needs classes shared school premises with other classes. The first generation that had not been sterilized and had *not* had access to sex education was growing up. It was first in 1976 that it was forbidden to sterilize someone against their will in Sweden. Concerns about abuse and exploitation, as well as fears of unwanted pregnancies, leading to the issue of parenting and intellectual disability arose and were discussed. No Swedish research on these topics was available at the time, but in 1981 and for some years following, various studies, reports and research were produced.

However, only four Swedish studies were carried out in the course of a decade. (Hindberg, 2003) A study where ten families were followed for four years, concluded that the children in the families where the parents had an intellectual disability did not development normally despite various support measures and some effort by the community authorities. (Rönström, 1981)

The quality or nature of these measures and of the social support offered to these families, is not provided and when Rönström talks about parents and families it is the mother and the child that are being referred to.

In a separate study, fifteen mothers and children were involved in a long term follow-up. The study concludes that the mothers with intellectual disability and with psycho-social issues were unable to care for and raise their children, and that the children were suffering. (Quoted by Hindberg, 2003: Gillberg, Geijer-Karlsson & Rasmusson, 1983) The study regards intellectual disability as the sole explanation for the inability of mothers to take care of their children. Hindberg makes no distinction between the diagnosis of psycho-social stress and one of intellectual disability. (2003)

Kollberg, who had many years of experience as a psychologist in the state care system, began her work that resulted in the thesis *Controversial mothers* (1989). In Kollberg's thesis, 32 mothers with very mild intellectual disabilities are interviewed and the interviews reveal how often social workers

have assessed the parents using their own feelings and prejudices, instead of using the body of proven knowledge that actually existed.

If one focuses on the parents' shortcomings and failures and forgets to see their strengths, as well as the resources that may exist in their social networks, people will naturally feel aggrieved. This negatively affects the level of cooperation between the parents and the social workers. The study also shows that stable emotional relationships in childhood have significant impact on how the women could handle their parental role. All mothers felt that they were always being questioned and they worried constantly that their children would be taken away from them. Of the mothers who lived with a partner, six women had partners who had problems with alcohol or mental problems. None of the fathers were reported to have an intellectual disability. The men were rarely any support to mothers, rather the opposite, says Kollberg. It is not noted what the mothers' views on this issue were. Subsequent research has shown that fathers are the main source of support to the mothers and hence to the children. (Booth & Booth, 2002, Sigurjónsdóttir, 2005)

A fourth study has been performed and includes 17 families with 21 children. The study interviewed social workers in order to determine what kind of support the families were receiving from the social services.

The report highlights the conflicts between the different interests that social workers feel they must protect: the child's right to safe conditions and the parents' right to privacy and autonomy. Social workers see this as irresolvable and they had different strategies to avoid these cases, such as remaining passive or transferring the case to someone else. (Anderson, 1992)

The right's of the child are weighed against the ability of the parents
During the years that the above reports cover, there was a debate going on in Swedish society concerning which perspective researchers and experts took in their jobs.

Hindberg, with his book *"When care fails - about children's vulnerability and society's responsibility",* issued in 2001, supported children's right to a safe and secure childhood. Eva Kollberg, with her long experience as a psychologist in the state care system, could see the phenomenon from a social perspective in which she calls for the mothers' right to support provided in a way that was tailored to their cognitive ability. The goal of functioning support for the mothers was to create a safe and secure childhood for the child. These perspectives were lifted as an argument for or against the rights of persons with intellectual disabilities to have children and care for them. The Swedish National Association for Persons with Intellectual Disability (FUB) through the efforts of Ann-Charlotte Carlberg, (former head of the national office) worked to give the people who had children the opportunity to practice good parenting. FUB:s efforts were based upon the premise that persons with intellectual disability can not be seen as single group, rather they have the right to be treated as individuals with distinct personalities and abilities and be evaluated accordingly. (Socialstyrelsen, 2002)

The project presentation *"It's important how you are towards your children"* is a compilation of interviews with seven families who met for many years in a network within FUB. (Socialstyrelsen, 2002) All the parents expressed how important this network is for them. They have acquired new skills, new contacts and felt strengthened in their parental role. And they appreciated being seen as parents. In one family, it is the father who is the active participant in the network.

The review of the National Board of Health and Welfare
The National Board of Health and Welfare has conducted a systematic review of research and projects relating to parents with developmental disabilities and their children. (Socialstyrelsen, 2005).

Of the 167 works presented in the research review, eighteen are Swedish. An additional twelve Swedish studies are included, but these only indirectly involve parenting. Of the eighteen Swedish studies, nine focused on the child's perspective, three are specifically targeted at mothers and four dealt with the situation of families. A father is present in only one of these studies.

The research review found that an adequate level of support – one that is tailored to the needs of the parents - increases the chances for parents with intellectual disabilities to raise their children (Booth & Booth, Llewelyn, 1994)

In order for the support to strengthen parents in their parenting role and to assure the child a good living situation, the professionals must have a thorough knowledge of intellectual disabilities and their consequences, they must know what strengths the parents have, what difficulties they have and what the needs of the children are.

Coordination of support measures for the families is beneficial and decreases the stress for parents while increasing their parenting ability. Support must be characterized by ongoing support and long term contacts between the families and the professionals.

The review also highlights the difficulties and problems that occur in families where parents have intellectual disabilities. (Socialstyrelsen, 2005) Some of these studies use the intellectual disability to explain the lack of parental ability. Other studies show that parental ability is not directly related to the parents' disability. The parents' adaptive ability and empathic ability, the social network, family finances and health, are all factors that can affect parenting ability. The concept of "parenting ability" is difficult to define, and no single definition exists. It is based on normative values, is socially constructed and is related to the cultural context, according to author of the review.

A clear gender perspective is lacking in the review's analysis of available research. The review also calls for a gender perspective in research on parenting. A father is present in only one of the studies, yet all the studies speak of parenting, parents and families. The lack of research and knowledge of fathers with intellectual disabilities is confirmed. (Socialstyrelsen, 2005).

Research on family life and daily living situations for families

Swedish studies on living situations

It is noted in the research review that there are no Swedish national studies on the living situations of families where one or both parents have and intellectual disability. (Socialstyrelsen, 2005) Since the family's situation is crucial in terms of how the father can handle his roll as a father, I have sought reports dealing with the living situations of persons with intellectual disabilities.

The separate background report, *Studies on the health of people with intellectual disabilities,* which is part of the Public Health Institute's progress report, *Unnecessary Health, the Health Status of Persons with Disabilities,* (R2008: 13) compiles what the research findings show concerning the health and living situations of people with intellectual disability. In summary, it appears that people with intellectual disabilities in Sweden have an increased susceptibility to many diseases, compared with the general population. Moreover, the research dealing with life situations shows similar results in most areas of daily life.

Adults with developmental disabilities live in the same community where other citizens live. Nevertheless, comparisons with the rest of the population show clear differences in living situations in virtually all areas of life, especially when it comes to work, income and social interaction. People with intellectual disabilities rarely have employment in the open market. Some work at Samhall but many do not support themselves through employment; rather they have their main income from the social security system. (author's note: Samhall is a Swedish company that provides development opportunities through employment, for people with disabilities. Samhall is wholly owned by the Swedish government.) And thus they have little influence over their economic situation. The majority live a limited social life and socialize mostly with relatives and staff. The review also shows that an intellectual disability influences health more than gender does.

Many people with disabilities have no earned income, receiving financial assistance to get by. They also have significant costs for health care, medicine and various handicap tools. As a result, they more often refrain from seeking medical care for purely economic reasons, compared to the general population (R2008: 13)

Half of the people living with significant disabilities have no earned income from employment. One particularly vulnerable group is young people who receive an activity stipend and often never get a chance to enter the workplace. According to the report, it is twice as common for people with disabilities to receive government aid as compared with the general population. (R2008: 13) A study of living standards for people with intellectual disabilities in Halland County shows that there is a significant difference in family relationships for adults with intellectual disabilities as compared to other adults. In the former group, 95% of the population live alone, as compared with 38 % among the

rest of society. In 1991, none of the group with intellectual disabilities had children, but in 1995, 2.4% had children.(Tideman, 2000)

To reach the target group, Tideman uses an administrative definition - that is, people who received support of some kind, due to an intellectual disability.

This gives a somewhat distorted picture of the degree of intellectual disability and its consequences for the participants, since the people who did not receive any social support, were not included.

The years during which the study was carried out, were important years for the reform efforts going on in Sweden to create better living conditions for the target group. The new law on special support and services came into force in 1993. The Act gave persons with intellectual disabilities more rights in order to be able to live as everyone else, as citizens in society.

Another study by Eriksson and Tideman (2010) examines the lives of children, adolescents and adults with intellectual disabilities in the Halmstad municipality. The study was designed so that the results can mainly be compared to similar studies for the same group in 1991 and 1995 respectively. The results show that early disability retirement has increased by over 12 percent and that daily activity centres remain the dominant place of employment. Only 4 percent live in a partner relationship, compared with nearly 64 percent among the general population. (Eriksson & Tideman, 2010)

International surveys on living conditions

Research results from England and Australia presented in the knowledge review (Socialstyrelsen, 2005) show that the disability is not a determining factor in how to succeed in parenting, but rather that factors that cause parents' stress contribute to difficulties in parenting. Such factors are low income, lack of social networks and how support for the family is designed, are presented. (Booth & Booth, 1994).

The lack of an international definition of the term "intellectual disability", as used by researchers in different countries, makes it difficult to transfer the experiences from one country to another country. (Sigurjónsdóttir, 2005) I believe similar difficulties are present when evaluating living situation, which are tied into the legislation, living standards and social services of each country.

Research on partner relationships

Most of the studies presented in the knowledge survey (Socialstyrelsen, 2005) only include mothers. Of the 167 studies, only fourteen mention fathers. None of these fourteen deal with fatherhood specifically, rather only as part of parenthood. A small number of studies have highlighted partner relationships and I have chosen to study them more closely to gain more knowledge about the fathers.

Faureholm, (1994), reports that of the two-parent families, the professionals judged that one third lived in a stable relationship, one third lived in a less stable relationship and one third were considered unstable. A Danish study shows that 45% of the mothers were single. (Skov & Henningsen, 2001)

A German study shows that one third of the parents lived in a partner relationship, however not always with the other biological parent.

The mothers in one-parent families were more often in group homes and they were more often separated from the child as compared to those who lived in two parent families. (Pixa-Kettner, 1998)

By using data from three different surveys, Booth & Booth (2002) mapped the men's situation. The compilation is based on interviews with 44 mothers and 11 children.

They found that most mothers had long-term relationships, five years or more. Thirty-eight had been married, 22 were still married, 10 lived alone and 6 had a new partner. Mothers had an average of three children, and 73% had all their children with the same father. Half of the mothers had lost custody of one or all of their children. And half of the mothers had children who suffered some form of abuse. In two thirds of these cases the mother's partner was the abuser. Six of the mothers had children who are victims of sexual assault and in two of those cases, the mother's partner was the abuser. It was further noted that twelve partners/fathers drank regularly, and that nine of them could be violent towards the women or children when drinking.

Despite these gloomy figures, two-thirds of the women felt that the men were supportive. The men contributed knowledge, they contributed resources so that the family adaptive capacity improved, they helped through their social network and they also gave the woman a higher social status. However, the man contributed very little to the family finances, rather, they used the family's resources for

themselves. (Booth & Booth, 2002) The results also reflect researchers' view of people with disabilities and their ability to take responsibility for their lives. When surveys are based on statements from the professionals, parents with problems are over-represented because they more often have contact with the authorities than those parents who handle parenting better. Difficulty in reaching the target group, also means that researchers turn to agencies or social workers to a great extent in order to obtain material for his/her research. (Booth & Booth, 2002)

The important role of the father in supporting mothers and children is also illustrated by Sigurjónsdóttir (2005). Support for families is usually directed to the mother and child, and fathers are made peripheral, which has consequences for the whole family.

Research on when parents lose custody
The situation for families where parents have an intellectual disability is essentially no different from other marginalized groups. But there are factors that make the situation more complex. Children of parents with intellectual disabilities are considered a risk group. It is particularly important that the children are stimulated, that safety aspects in the home are checked regularly and that the children are given a proper diet and good hygienic care. (Socialstyrelsen, 2005)
How these factors apply more to children of parents with intellectual disabilities than to children of mentally ill parents or children of abusive parents is not evident in the research review. There is no national survey in Sweden showing how many children of parents with intellectual disabilities are born annually. (Socialstyrelsen, 2007)
A Swedish study conducted in 1993 found that up to 1.4 per thousand of the newborns in Skaraborg county had a mother with an intellectual disability. This data indicates that approximately 160 children are born annually in Sweden to mothers with intellectual disabilities. (Bager, 2003)
Studies have shown that the children of parents with intellectual disabilities have an increased risk of being neglected and/or abused, as well as of suffering development delays and behavioural disturbances (Socialstyrelsen, 2005: Feldman, 1994; Feldman & Walton-Allan, 1997, Mørch et al, 1997)
Studies indicate that various forms of education, training and support can improve parents' ability. (Feldman, 1994) However the support measures must be designed in accordance with parents' needs and continue over a long period of time in order to have this beneficial effect. (McGaw & Sturmey, 1994, McGaw, 2000)
There are also studies showing that parents with developmental disabilities do not improve their parenting skills, despite the various measures and the use of various programs. Researchers feel that these parents lack the ability to learn the routines of everyday life and that they have difficulty learning new skills and retaining the knowledge that is imparted to them (Accardo & Whitman, 1990, quoted by the National Board of Health and Welfare, 2005).
It is not clear how these programs and initiatives were designed, but another study of a training program carried out in the parents' home, shows that there are several factors that are important for those who are educating the parents. The program's design, its content, how it is presented and how the program encourages learning are some of the factors mentioned. (Llewelyn et al, 2002)
Much of the research that is presented about the custody investigation process shows that child welfare investigations have serious shortcomings. Among other things, the great deficiency in documentation is criticized. In a child custody investigation it is required that the investigative and decision-making process follows a certain procedure, that there is an objective and comprehensive reporting of investigative material and data sources, that information is recorded and, above all, that the decision or proposed decision are given rational motives. (Quoted by the National Board in 2005; Sundell & Egelund & Löfholm and Kaunitz, 2007)
One area that needs to be taken into particular account when developing methods to strengthen parenting skills, is their usefulness in the assessments and investigations involving families where the parent/parents have an intellectual disability. Otherwise one risks drawing conclusions about parental ability on incorrect or insufficient grounds, for example, by focusing on the intellectual disability as it is defined by intelligence tests (Feldman, 1994; McGaw, 2000, Swain & Cameron, 2003).
There is a need to adapt the investigation and assessment process with regard to the disability and its consequences. Such an adaptation could be circumventing the difficulty in talking about the abstract

issues of parenthood. One needs to develop and use other practical methods, in the form of images, audio-visuals and observation, combined with direct practical guidance about how to progress in the investigation process (quoted by the National Board of Health and Welfare, 2005: Llewelyn, McConnell, Russo & Mayes and Honey, 2002).

A progress report, "Children who have parents with an intellectual disability" (Welfare Board, 2007), contains reports, surveys, and monitoring of laws, activities, etc. It confirms what the knowledge review showed, i.e. having access to a functioning network is essential for the well-being of the family. The report also shows the difficulty people with intellectual disabilities have in finding gainful employment, thus contributing to their exclusion from social life and negatively affecting the family's finances. The professionals who encounter these families need to know more about the disability, the parents' abilities, and the situation of the children. The also need to be skilled in talking and conveying information to these parents. Communication that functions well is the basis for positive cooperation between professionals and parents. (Socialstyrelsen, 2007)

Determining parental ability- a Swedish study
By reviewing a number of child welfare investigations, a study has shown how social secretaries assess parental ability. (Gustavsson & Springer, 2008)

In the child welfare investigations covered by the study, the social secretaries reported the sources from which they downloaded the data that were in the investigations: the hospital maternity ward, the childrens' healthcare centre, nursery school, the family's contact at the unit for financial assistance, housing and family support contacts, the investigative homes as well as through conversations with the children and the father (in cases where parents are not living together).Even earlier documents relating to support measures are reported in the investigation. All social workers reported having had conversations with parents.

Sometimes it was clear exactly which people the social worker had interviewed, other times it was less clear who provided the information. Sometimes the state's "investigative network meeting" was named as a source of information. In one investigation it was revealed that the social worker had met the child, but did not have any conversations with the child since a separate study conducted in the investigative home included a description of the child. Another investigation indicated that home visits with the parents had been made.

Gustavsson and Springer (2008) show that in three cases (of four), there is no information about how structured methods and / or assessment instruments were used in the investigation. In one case, it was reported that a "private conversation was carried out based on an interview form," but there was no clarification as to which form was used or what it contained. In another case, social worker reported that they had "followed the United Nation's Rights of Children Convention, using the guidelines of the Social Services Act."

Gustavsson and Springer note that it is necessary that the investigation be adapted if a parent has an intellectual disability. (Gustavsson & Springer, 2008) Three of the four investigations have noted that the parent has a learning disability, in all the cases the mother's intellectual disability was already known. In two of the investigations, there is some reflection on how the intellectual disability might affect parental ability.

Only one of the investigations brings up the need to gather additional information or knowledge about the disability.

There was no reference in any of the investigations about the manner in which the investigation had taken the intellectual disability into account and adapted the investigation process to the fact that the parent had an intellectual disability.

Gustavsson and Springer note that a summary of the parents' skills were particularly underrepresented in the investigations. (Gustavsson and Springer, 2008) The parents' knowledge and skills are important to include because they provide a picture of what possibilities the parents have to carry out the expected tasks. It was noted for example in one of the investigations, that the child did not get enough food, but there was no information on whether the parents possessed knowledge of what a child needed in the form of a nutritious diet and if the parent had acquired the skills needed to prepare meals.

Gustavsson and Springer propose an approach based on a mapping out of the knowledge and skills the parents possess and then collecting data about how she / he uses these skills. In the next stage, learning

ability and development potential should be tested through education and support measures directed at the areas where there appears to be gaps in knowledge and skills. Then, monitoring and observations of the family should be carried out in order to establish if the support measures are working and if the parents are making use of the information and support measures. (Gustavsson & Springer, 2008)

International research on children taken into the custody of the state
In an article, Booth summarizes the research on parents with intellectual disabilities, childcare issues and the courts.(Booth, 2000) Several studies were mentioned that examined the number of children in the care of the state, however none of these were Swedish.

Feldman (1998) reports that 80% of parents with intellectual disabilities in the United States and Canada lose custody of their children. Faureholm (1996) and Pixa-Keltner (1999) say that the figure in Denmark and Germany is 30%. Cross and Marks (1995) found in a British study that for 16 children born to parents with intellectual disability, custody procedures for seven of the children cases were initiated within one week of birth, and in six of these seven, they began directly at birth. These facts, says Booth, could indicate that there are large gaps in the parental ability of these parents, but this should be questioned, since a number of variables that influenced the custody decision were not reported.

Dowdney and Skuse (1993) show that the number of children in state custody is an unsatisfactory measure of parental skills when parents have intellectual disabilities. Many different variables need to be considered in order to assess parental ability and its impact on the well-being of the child. (Booth & Booth, 1994a)

Booth says Czukor (1983) has further shown that parents with intellectual disabilities are particularly vulnerable to losing custody of their children because of prejudicial attitudes, unfounded assumptions about the poor parenting skills, lack of adequate support and other problems. This result is supported by Sigunjórsdóttirs (2005) study of eight Icelandic families where parents have an intellectual disability.

Families where the parents have intellectual disabilities can be seriously disadvantaged by a lack of competence among social workers and support persons, (Mc Connell & Llewelyn, 1998). There is evidence that parents experience prejudiced and discriminatory treatment in child welfare cases. Field workers and society as a whole need more knowledge about these parents so that stereotypical ideas can change. The professionals who meet the parents have good training, but it does not include knowledge about intellectual disabilities.

Parents deserve to be met with a positive attitude and to become actively involved in the plans regarding themselves and their children. Even the lawyers and representatives of the parents (in court cases regarding custody issues) need expertise in disabilities so that these vulnerable parents will have a fair representative for their cause. (McConnell & Llewelyn, 1998)

The gender perspective in research on disability and fatherhood

Introduction
In this chapter, I discuss social science research on disability and its lack of awareness concerning gender and that the fathers with disabilities have been rendered invisible since the social conceptions of fatherhood and disabilities have not been the subject of analysis. By studying the phenomenon of parenting and intellectual disability solely from the mother's and the child's perspective, fathers are made invisible. Despite the emphasis on gender equality in Swedish society, the emphasis is on women when it comes to care and nurturing. I use the term gender perspective in terms of the importance of *analyzing the meaning and implications of what is defined and understood as masculine or feminine ways of knowing, feeling and acting.* (Alvesson & Due Billing, 1999).

Disability and gender
Social science research on disability can be described as unaware of gender, since it often ignores how the social conceptions of gender affect and are affected by women and men with disabilities and their actions and living situations. The gender perspective in research has become more common, especially in U.S. and British research on disability. Much of this research is conducted by feminist researchers, women who themselves have a disability. Barron (2004) argues that there are several reasons that research on disability is not linked to gender. Barron argues further, that the men have been, and are still, absent from the field of disability research. They are made invisible in the sense that social perceptions of men and masculinity have rarely been the subject of studies and analysis. (Barron, 2004)

Gender and men's studies
The Swedish Government allocated funds in 1997 for a survey of "the Nordic men's studies". One overall result of the survey work, says Folkesson (2000), is that we can not talk about "Nordic men's studies" as a field of research. Such a thing does not exist as a specific field. However, there is extensive research being carried out on men in the Nordic countries, but in a variety of disciplines and with multiple and sometimes conflicting methodological and ideological positioning. There is lively discussion among men, women and gender researchers about how research on men should be conducted. The relationship between men's studies and feminism is the front line in this discussion. Feminism is considered, within the framework of the mapping survey, as a critical and scientific perspective that involves raising problems concerning men and gender-related power. Feminist research is seen as research by men and women about men and women with the application of feminist gender-critical positions. Whether men's studies are feminist or not, depends on the individual researcher's position. *Critical Studies on men* provides a clear positioning in the research field on feminist grounds. Folkesson, (2000), believes that through the work of mapping, it was possible to roughly distinguish three phases and countries in the development of Nordic men's studies: man as a sexual being, man in relation to family policy and man in relation to gender equality policies.
According to Folkesson, the Danes were the earliest and most distinct in their discovery of man as sexual beings in the seventies. Somewhat later, during the eighties and most evident in Sweden, research was produced about men in relation to family and gender policies. During the nineties Norway shows the most vitality in the development of men's studies in the Nordic countries. This was partly due to the documents that were produced then and there, but mainly it was due to active Nordic and international networking that came to have a great significance for the development of this research field throughout the Nordic region. The survey shows that in Finland, parallel with developments in the Scandinavian countries, men and masculinity was also the subject of research and gender-sensitive debate, but this became marginalized in a Nordic context, because of the great differences between the Scandinavian languages and the Finnish language.
Folkesson believes that the Nordic gender-sensitive research on men has been developed in close relationship with women and women researchers. Traditional fields of research within gender and women's studies have also been important in the research that had men as research subjects: family, work, power, politics, gender and economics. The areas that have been more highlighted than others

have primarily been related to the prioritized social policy issues. All the Nordic countries have conducted research on fatherhood. "Daddy research" appears to be the single area that is strongest within Nordic men's studies dating back more than a decade. However Folkesson's report lacks a detailed analysis of men's studies relating to men, fatherhood and disability.

Gender perspective in research on parenting and intellectual disability
Mayes and Sigurjónsdóttir (2010) highlight three aspects that show why it is necessary to introduce a gender perspective into research on parenting where one or both of the parents have an intellectual disability.
The first is that motherhood and fatherhood are not the same thing. By always describing parents with intellectual disabilities without reference to gender, researchers have ignored the fact that the experiences of the man and the woman can be very different.
The second aspect is that through this genderless description within research, women's experiences are interpreted as parenting and men's experiences have been left completely unaddressed. There is still much work that needs to been done in order to understand the experiences that the men want to convey. It is necessary to understand whether they differ and how they differ from the experiences that women speak about.
The third aspect is that research on families with intellectual disabilities is important for educating everyone from politicians and social workers, to child-care agencies, to support people in the community. Gender perspectives affect the nature and scope of service and support provided to people with disabilities. An attitude that is unaware of the gender perspective may miss possible differences and does not take into account that the needs of mothers with an intellectual disability may be different than the needs of fathers with intellectual disabilities. (Mayes & Sigurjónsdóttir, 2010)

Research on fatherhood

Fathers and family
Plantin (2001) shows that men's experiences of fatherhood vary. The man's perception of fatherhood is influenced by the relationships that characterize family life.
In order for daily life to function, the man's ability to support the family and to combine work and family life, are important prerequisites.
Many of the new fathers had a romanticized image of family life, while the more experienced fathers dared to express that their own needs, interests and the relationship with partner must be prioritized differently during early childhood period. The fathers' motivation was the mutual goal of family life - to provide for the family and the children's best interests, according to Plantin. (2001)

What makes men fathers?
Lupton and Barclay (1997) analyze the social, cultural and symbolic meaning of fatherhood. In order to fully understand fatherhood and masculinity, greater significance must be accorded to knowledge about the importance of relationships with family members, relationships with other key people in the men's social networks, participation in chores at home and the man's commitment as a father. The study revealed several themes in the fathers' discussion about fatherhood. Among them was fatherhood as a natural part of adult masculinity, fatherhood as a strong emotional experience, fatherhood as a commitment that requires effort and time, paternity, one's roll as protector and breadwinner, fatherhood as a source of stress and strain, but also as a source of joy, love and contentment. These themes had varied levels of significance during various stages of fatherhood. Before the baby was born, the men spoke of it as a natural progression to a mature masculinity, and that fatherhood

was a commitment that required effort and time, while the other themes arose only after the birth of the child. For most men in the study, it was essential to bond with their children and create a close relationship from the very beginning. The men also described their feelings toward the child as a desire to protect and love it in a way not previously experienced in relationships with other people.

The study found no evidence that the men felt that nurturing and care of children was linked to the mother. In order for fathers to become good fathers, who can care for and love their children, they need to invest time and energy in learning about the child's needs. The more time they spend with their children, the easier it is for them to interpret signals and meet the needs of the child. The fathers, who, for various reasons were prevented from doing so, clearly expressed dissatisfaction with the situation.

(Lupton & Barclay, 1997)

Fatherhood in relation to the child

Past research on fatherhood has often been carried out by psychologists who are interested in child development. Understanding the impact that developmental psychologists' have on the image of the ideal father is fundamental to understanding society's image of fatherhood, since this impact has been so dominant.

Within psychology, there are many ideas and theories designed to understand and explain how children develop and how this development is related to what the parents do and don't do. In most of these theories, it is usually the relationship between mother and child that is in focus, while the father is usually given lesser significance.

Many of the developmental psychology theories that parents meet, for example, at maternity clinics and child healthcare centres, are based on family types and ways of sharing responsibility that differ from those that the psychological theories assume.

Fatherhood in relation to attachment theory

Attachment theory is the theoretical perspective that currently dominates the psychological research on children's earliest social relationships. This theory also has had a major impact in terms of mothers', and especially fathers' position in relation to the infant. (Hwang, 2000)

The pioneers in attachment theory began using the term attachment in the late 1950s to describe children's relationships with other people. To start talking about children's ties to closely related persons instead of children's dependence on other people, put focus on the infant as an active, participating individual. According to Bowlby (1958), the child has an innate tendency to seek nearness and contact with adults - knowledge which is now fully established in both the scientific disciplines related to children and in parents' general awareness. The early notion of what the concept of attachment involved was that young children must first develop a deep relationship with a person - in most cases the child's mother. The theory was that small children were unable to maintain multiple relationships, and that the child's first love affair with the mother provides a positive model for later relationships in life.

Men were not considered as suitable since they do not possess certain characteristics the child needs in the person that they are to relate to. Therefore, a general attitude within research was a very low acceptance for caregivers other than the mother, in the lives of young children. (Hwang, 2000; Elvin-Novak, 2005a)

Even in other aspects of developmental psychological theories, the idea of the mother's vital role has been prominent since the early 1900s. The underlying idea was that children, in order to lead a good life and achieve optimal development, should live close to and be cared for by their mothers. Successful motherhood, using this interpretive framework, requires a high degree of accessibility and adaptation and gives the woman / mother role as the most important parent. The kind of fatherhood that develops from the mother being the person who is closest to the child, becomes a kind of indirect parenting where the father encourages the child's development by supporting and helping her mother (Hwang, 2000; Elvin-Nowak, 2005a).

Modern critical research within the field of developmental psychology clearly shows that it is neither possible nor meaningful to study the "child" but also include the interpersonal, cultural, historical and political contexts that produce the child (Burman, 1994). Theories about children's needs and the mother's proximity and accessibility were developed during a time when women were confined to the home, with no possibility for economic independence - a time when femininity was manifested through motherhood in an entirely different way than for today's women.

However, research shows that perceptions of the mother as primary parent still have enormous influence on how parents divide the sharing of responsibilities. (Elvin-Nowak, 2001, 2005a; Bekkengen, 2002). Parents think that young children need parents of full-time and that this will happen with limited gender-specific requirements in terms of how parental leave can be used. However, the "translation" from "parent" to "mother" that many parents de facto make, is not consciously based on the feeling that mothers are better parents than fathers (something that is rarely expressed in interviews with parents). It is rather a division of parental leave that is based on a reasoning along the lines of "who would be the best" alternatively "who wants to the most" – a non-reflective way of reasoning that is linked to both the material conditions at the societal level (i.e. the differences in women's and men presence in the labour market and the differences in women's and men's economic situation) and to psychological confirmation processes. (Foundation for Children General House Skriftserie 2004:02, Broberg, Almqvist & Tjus 2003)

Fatherhood and the child's earliest relationships
The knowledge available today on children's earliest social relationships shows that children can have multiple relevant attachments early in life. A majority of children older than seven months have developed emotional ties to both parents, provided that both parents were present in the child's life (Hwang, 2000). Young children can also have relationships at different levels simultaneously. (Schaffer, 1995; Hwang & Wickberg, 2001)

Therefore it can be said that generally speaking, children benefit from an early and close contact with both parents. That the parents early on can establish good contact with the child promotes the positive development of relations between child and parent. Good relationships and good access to both parents promotes harmonious development of the child's identity and promotes the child's maturity and confidence. (Hwang, 1999)

Since the mid 1900s it has been assumed that the mother and the child's initial relationships have a major influence on the subsequent emotional and psychological development of the child. Towards the end of the 1900s, the focus in developmental psychology has shifted from the child's conduct and behaviour to the mother, and from there, on to the father and more equal parenting. The focus of developmental psychologists is still on the infant and its physical, intellectual and moral development and their needs and well-being, but psychologists are now exploring the parent's ability to meet the needs of the child. (Hwang & Wickberg, 2001)

Fatherhood when the father has an intellectual disability
I have chosen to present a thesis about fatherhood and intellectual disabilities in a separate chapter. There is very little knowledge fatherhood in this group and in particular there are few studies in which the fathers themselves are given the opportunity to speak their mind.

Research on fathers with intellectual disabilities

Introduction

There has been very little research done about fathers with intellectual disabilities. Families have been studied, and where fathers are mentioned or involved, they play a minor role in relation to the mother and child. International researchers in England, Canada and Australia have presented interesting results that I refer to in my work. I choose to do an in-depth presentation of Hanna Björg Sigunjórsdóttirs (2005) work because I find it of interest for my work in three different ways. Firstly, her work is one of the few pieces of research that concerns fathers and where the fathers' own stories are the basis of the data in the thesis – something which is lacking in the research carried out by other researchers that I have found. Secondly, the fathers in the thesis live in Iceland, and although there are differences between Icelandic and Swedish society, I consider them to be fewer than the differences between Sweden and other European as well as non-European countries. Thirdly, Sigurjónsdóttir highlights parenthood using a gender perspective and a social perspective, where the individual is seen as a citizen and fellow human being in the social context in which he lives, which is also the view I use in my work.

A study of Icelandic fathers with intellectual disabilities

In her thesis, Sigurjónsdóttir (2005) describes the formal support given to eight families where parents have intellectual disabilities. The thesis highlights parenthood from a gender perspective and devotes a chapter to fathers and their experiences of fatherhood and of formal social support.

The balance of power - or rather the imbalance of power - between the social support system and the individual parent is demonstrated and discussed. Parents are powerless, while the social system is allowed invade their lives, identify their needs and make decisions about their needs. The parents' ability to adapt to the social services' requirements forms the basis of the decision concerning the right of parents to retain custody of their children. The persons who provide support are often the same people who give information to the authority who will decide whether parents possess good parenting skills.

The purpose of this work is to identify the factors that ensure that the support given to the families is perceived as successful by the families. Sigurjónsdóttir (2005) wants primarily to understand the factors in the social service system that increase the competence of the parents and what elements are an obstacle to parents thriving in their parental role.

The results shows that the social relationship between parents and social workers, at both the societal and personal level, is critical in terms of either helping the process of improving parenting skills or impeding the development of good parenting skills. The general perception that people with intellectual disabilities are unable to take care of themselves and make their own decisions plays a critical role in the structural inequalities they face.

This perception affects both the service that is offered and how the individual social worker responds to the parents. Therefore support for the parents focused on what was *wrong with the* parents instead of what was *difficult for* the parents.

When the professionals interpret what problems the families have, they do so based on the view that disability is a characteristic of the individual and not something that arises in the encounter with the surrounding environment. This view leads to the professional focusing on what individuals can't do, instead of focusing on their strengths.

Contact between parents and professionals in many – but not all, official settings, reflected the approach taken to disability as a socially related problem. When the staff had a positive and supportive attitude in relationships with parents, support was well-received. When the social workers acted as a buffer against the outside world's unfair attitudes toward the parents, the self-esteem of the parents grew and they had a more positive self-image. (Sigurjónsdóttir, 2005)

Two reasons are given for why it is important to highlight the fathers' experiences. (Sigunjórsdóttirs, 2005) The first reason is that the fathers are at a disadvantage and disempowered, when the social system's focus is on working with the mother and

child. The second reason is that this discrimination against the role of the father and the social worker's assessment of the father as cooperative or non-cooperative, can affect the services that families receive and the decisions made about the families.

The study included eight families, and in six of the families, both the mother and father participated in the study. The fathers differed from each other in terms of age, number of children, professional employment, housing, living situation and functional ability. The ages ranged between 30 and 55 years. Two of them had lost custody of a child and two were living under the constant threat of losing custody of their child. These four fathers had in common that they had questioned the support that the family received. They had criticized the training methods, they had refused to follow written schedules for housework, they had argued or refused to talk to social workers on some occasions, and they had either hired a lawyer to help them assert their rights or they had told their stories to the media.

As a consequence, the system labelled these fathers as troublesome and difficult. Mothers in these families were considered to be cooperative, but the fathers were considered difficult to work with. Three of these fathers were unemployed and one of them had part-time employment, but also longer periods of unemployment. Only one of these fathers had been diagnosed with intellectual disabilities in childhood. Since the fathers questioned the support they received, they were deemed as non-cooperative by the support staff. In order to improve the family's situation and to provide them with support, a needs test was conducted and a plan was set up to help the families. The parents' compliance with the plan and a willingness to receive help is highly valued among social workers, and is considered by the social workers to be crucial since this shows that the parents are acting responsibly and that they understand the seriousness of their problems as defined by the system. The social workers also felt that compliance would also ensure that the child's situation improved. (McConnell, 2001, Booth 2004, Haugen 2004)

When Sigurjónsdóttir (2005) studied the documents and files concerning parents in her study, she finds that the fathers who are judged to be cooperative by the social workers also had jobs and had no diagnosis of intellectual disabilities. And they did not question the authority of the social services or their support for the family.

When Sigurjónsdóttir listens to the family support staff talking about their work, it soon becomes clear that they see support for the mother and child as their primary mission. This is understandable given that in our western culture, laws, practices and debates focus on the relationship between mother and child.

Even though gender roles in today's society work to promote equality, the mother is still considered to have the main responsibility for the care of the child, and the father is still seen as the breadwinner. (Van Driel, 2004)

If we accept these traditional beliefs and cultural expectations, then this means that the child's welfare depends solely on the mother. A small study shows that families did not receive the support unless both the father and mother (and not *just* the father) had mental disabilities. This approach ignores the fathers, which in turn, leaves them without support. Fathers feel that they are "dethroned" in their own family and that the support staff is making decisions about the home and the family. (O'Hara & Martin, 2003)

Sigurjónsdóttir, (2005) clearly demonstrates that social workers preferred to work with mothers. It may have been a contributing factor that the mothers were already in the system and had the support of social workers, when they met the men who then became part of their lives. The women had learned to adapt to the role of being in need of help and being the recipients of support. They matched the view of impairment that was predominant among social workers. In order to strengthen existing capabilities and to support the child and the parents and the family's competencies, the support must be directed towards both the family as a whole and towards each individual in the family. (Dunst, 2000) In order to develop and strengthen the family it is necessary to understand and see both parents' skills and build on them, rather than focusing on their shortcomings and questioning the attitude of some

fathers. Some social workers said that the fathers were jealous of the attention that the social worker pays to the mother and child. They could see that the father felt left out unneeded in his own family. But this did not mean that social workers changed their approach in order to include fathers. Instead there was a discussion about whether the fathers were cooperating or not, within the scope of the support services.

The fathers can be broken down into three categories based on how they are treated by the system. (Sigurjónsdóttir, 2005)

The first category is the cooperative fathers. In these cases, the family lived according to a traditional family model. The couples had met, moved in together and had not previously had any formal support from the community. It was not until the couples were expecting their first child that they came in contact with social services, since someone close to them had deemed them in need of support. Social workers met these people when they were already a family and also saw that they had the ability to cope in society. Therefore the support they received was the kind that all first-time parents can receive. When the child was born, the mother stayed at home and the father worked. Social workers provided support during for the mother the day and respected the father as breadwinner.

Fathers did not interfere with the support and were therefore seen as responsible breadwinners. However after a period of time, one of the mothers felt that she could no longer trust her support staff and refused to accept further help. This situation was solved by asking the father to stay home part-time and receive compensation from the social insurance system for the lost income. In the second instance, the family lost custody of the child when it was discovered that both parents abused alcohol.

The second category is the fathers who were deemed to be non-cooperative. These fathers caused major problems for support staff. (Sigurjónsdóttir, 2005) One father was never home, he was constantly running out to help people other than his family. He squandered the family money, putting the family in debt and his wife was left to pay the debt.

When he was confronted, he minimized the problem and put the blame on his partner. Such a situation shows how difficult it can be to support an entire family. If all focus is put on support for the mother and child, then the father's problems will not be solved.

The other fathers who were considered to be non-cooperative had all met their partners when the women were already living on their own and were receiving some form of formal support from the social services.

None of these men had previously received support of any kind. They had been expelled from school, left home in their teens and lived a precarious existence while they fought to survive. Some of them had lived in rented rooms or in shelters. One of the fathers was tested in connection with his wife's pregnancy and at the age of 50 was diagnosed with a mild intellectual disability. Now he was expected to receive assistance in their home and follow the schedule that the social worker had put together. He was offended by being asked to clean at specific times, because he always managed to keep himself and his home clean, under much more difficult living conditions.

Another one of the fathers left his family when he was 15 years old because a stepmother came into the family who he did not get along with. He ended up living on the street and drank and abused drugs. At sixteen, and then again when he was eighteen, he travelled to the United States alone and lived there a few months. Both times he lived at a school for young people at risk and studied the Bible.

He returned to Iceland and became a member of a religious group that ran a home for homeless young people who abused drugs an alcohol. With the help of the religious group, he became clean and sober. He had been so for several years when he met his wife.

These fathers had lived hard lives with low incomes, but escaped from drugs, abuse and a life on the streets to more settled conditions. They felt offended by the attitudes of support staff, and the support staff was quick to underestimate the fathers' ability to fend for themselves. Fatherhood was the fathers' first adult male role. The fathers received the same status of other men in society. The fathers felt that their autonomy was snatched away from them by social workers, and that social workers deemed them incapable. Social workers saw

the men as being difficult to work with and they caused great concern. Fathers saw their role as standing up for and defending his family. The fathers' unemployment did not improve the situation. The fathers were not traditional breadwinners, and they were also at home when the social worker arrived. Two of these men lost custody of their children. The third father was told that the system required that his wife leave him, otherwise she would lose custody of her child. Another one of the fathers lost custody of his daughter three times.

Sigurjónsdóttir (2005) called the third category of fathers "worthless". This is a father who did not contribute anything to the home. He sat most of the time at the computer, didn't work or do any chores in the home and didn't help with the care of the child. The mother took care of everything. After a few years, the couple divorced and the couple had joint custody of the child. The father found another woman who had no disabilities, and moves to another municipality. When it's time for the child to start school both parents apply for sole custody since schooling is otherwise difficult. The mother loses custody in favour of the father, who is considered more qualified since he lives in a relationship and not alone.

These life stories from the fathers perspective, show how institutionalized support, when based on a traditional gender views and traditional gender roles, puts the fathers at a disadvantage. The system has a fixed idea and perception of how both families and clients should be. The fact that the non-cooperative fathers did not fit the image of the ideal family or were not grateful and obedient clients, caused a power struggle between them and social workers.(Sigurjónsdóttir, 2005)

Fatherhood - success factors and obstacles
According Sigurjónsdóttir, there are clear factors that can be identified as the basis for successful fathering and for the ability of the parents to retain custody of their children. Likewise, clear obstacles that inhibit this are described in the thesis. (Sigurjónsdóttir, 2005)

The success factors that the researcher discusses are:

- Support should be home-based, flexible, non-threatening, adapted to family needs and carried out in collaboration with parents. The support staff's attitude should be characterized by understanding and empathy.
- Support should be given in a way that allows parents to maintain their dignity and independence within reasonable limits
- The relationship between the support person and the family is more important than how the support is adapted
- The support person's attitude towards the family determined what actions where taken prior to making the decisions about whether the family would lose custody of the child.

Inhibiting factors discussed by the researcher are:
- Shortcomings in legislation
- Negative attitudes and stereotypes that focus on the parents' weaknesses and not on their abilities
- Lack of coordination in support measures for the families
- The support staff's lack of knowledge and expertise on disability
- The assumption that people with intellectual disabilities can not make their own decisions, leads to a situation where others make decisions for them.

Sigurjónsdóttir (2005)

Method

Introduction

In this chapter, I present the purpose of Our Father and present the methodology I used for data collection and data analysis. Since I have chosen to work with fathers as subjects of research in a phenomenological study, and data collection has been done through interviews and observation, I describe what considerations I have taken, given that the research subjects have an intellectual disability. In particular, I lift dilemmas such as phenomenology and previous knowledge, the factor of time, and the narrative and ethical considerations in relation to fact that the research subjects have intellectual disabilities. The section begins with a presentation of the different perspectives on disability that can be found in current research. These different approaches affect the researchers' choice of methods and interpretations of results.

Purpose
To seek knowledge about fathers with intellectual disabilities and the support that society offers them in their role as fathers.
To find the factors that have a positive effect on fathers with intellectual disabilities in their role as fathers and that enhance their parenting skills.

Approach to disability
In research on disability within the Nordic region and internationally, three perspectives or approaches to disability can be found. (Gustavsson & Tössebro and Traustadóttir, 2005), *the medical or functional approach, the environmental approach and the relative approach.*
Two of these approaches focus on what disability really *is.*
One of them, usually known as the medical or the functional approach, assumes that disability is an individual characteristic.
Two directions can be distinguished depending on whether one focuses on medical factors or on functional factors, but both factors are related to the individual.
The first perspective- *the medical or functional approach* - sees an intellectual disability as having low intelligence and poor social skills that can be identified in childhood. It focuses on the individual's lack of abilities and seeks to offset these individual shortcomings by support and training. This approach has led to "experts" taking the power over how people with intellectual disabilities are met and treated. (Atkinson, 1997)
This narrow approach to people with intellectual disabilities has been challenged and questioned for almost 30 years, since it ignores the environment or the social context that people live in. (Atkinson, 1997; Tössebro & Kittelsaa, 2004)
The second perspective is *the environmental approach* which takes into account the complex interplay of factors within an individual, in the physical environment and in the social environment.
The social model is inspired by the vision of society that Marxists used, as did Goffman (1963) in his theories of stigma. It has emerged as a protest against the medical approach. The disability movement in Britain formulated much of the thinking behind this model during 1960-1970's. It pointed to the social, economic and cultural factors as explanations for the how a disability becomes an impairment. The barriers can be a question of physical accessibility - narrow doors, high thresholds, high counters in shops, but they can also be of

an institutional and organizational nature, such as the welfare system and the organization of work in a society.

Oliver (1996) argues that an impairment is anything that is an obstacle that is put "on top of " the disability. The social model does not deny the value of individual measures but fights for the idea that society is created *by* people without disabilities *for* people without disabilities.

In an article, Shakespeare (1996) has described a theory of how one can regard persons with disabilities as a group, i.e. how an identity is created that stems from the disability. The disability occurs in five different types of social processes, where the social model is the first. The view discusses people with disabilities as a minority, as a group created by social policy, as a group created by the diagnosis and finally as a cultural group.

The third perspective, *the relative perspective* sees disability as a social construction based on a complex interaction of individual factors as well as factors in the physical environment and factors in the social environment. This approach is referred to as postmodernist or poststructuralist. South (1999: p 33) has developed this approach and called it *the relative perspective* on disabilities.

South says (1999: p 33) that it is impossible to understand the processes which create disability that leads to exclusion and discrimination, without simultaneously studying the interaction between the individual and the context the individual exists in. To understand this interaction, we must not stick to the notion that people have certain shortcomings or problems and that these should be in focus. Nor should one decide in advance that the context has certain characteristics. South says that the relative perspective requires a respectful approach to the reality that competent and reflective people have created and that the researcher wants to study. (1999: P33)

The social construction of disability occurs in the relative perspective, both in the relationship between the individual and the environment and the relationship between different individuals.

Gustavsson (2004) describes five variations within the relative perspective.

The first two share a basic realistic assumption about disability as a phenomenon, while the other three variations stress more that disability is a construction. All five variations stress that disability can only be understood against the background of relations between the individual and contextual factors.

In my work I have used the relative approach, but I have also been inspired by the social model for understanding disability and its consequences. It has also meant that I have not focused on disability as stemming from the individual. I have searched for phenomenon in society that encompass all parents, all fathers and therefore fathers with intellectual disabilities, in order to learn how these phenomenon affect fathers with intellectual disabilities in his pursuit of fatherhood.

Concepts and definitions used in Our Father

In the research and the reports that I have read for my study, many different terms are used, making interpretation of results a difficult process. The discussion of concepts and definitions is complex because there is not a single group of people that we are able to separate from the rest of us. Rather, they are individuals with abilities and difficulties that are shaped by the environment and the ability to make use of the knowledge and information, as is the case for all members of society. In Sweden, the group "people with intellectual disabilities" is usually defined by an administrative definition – i.e. they have a diagnosis that makes them eligible for support under the law on Support and Service for Persons with Certain Functional Impairments (LSS) (Lag1933: 387). Not all individuals with intellectual disabilities need special assistance under LSS, and they live their lives without a diagnosis. In my work, the fathers' own experiences and their own definitions of their disability have been the determining factors – not an official diagnosis or whether or not they receive LSS support of some kind. None of the fathers have denied having an intellectual disability.

My choice of terminology is based on the instructions of the terminology council at the National Board of Health and Welfare. When I use other terms or concepts in my work, it is the term or concept used by the particular researcher whose work is being referred to. Mental retardation and intellectual limitations are examples of Swedish terms used, and learning difficulties, learning disabilities and intellectual disabilities are examples of English terms used in international research.

Methodological choices

Since the purpose of my work is to seek knowledge about fathers with intellectual disabilities and the support that society offers them in their roll as fathers, as well as to identify factors that influence

fathers with intellectual disabilities in their roll as father in a positive way and strengthen their parenting skills - qualitative methods are more appropriate than quantitative methods, which focus on establishing the occurrence and frequency of certain phenomena. (Denscombe, 2009)

Three methods of data collection were used. The first method was data collection via documents dealing with society's support to fathers in general and to fathers with intellectual disabilities in particular.

The second method used in-depth interviews with conversations of a narrative nature and the third method was in the form of observations.

Denscombe (2009) highlights the need for researchers to distance themselves from their own beliefs and experiences, and instead, maintain a neutral position in relation to the interview subjects, who will themselves describe the world of their daily life and their perception of it.

Booth & Booth (1996) maintain that in the case of narrative interviews with people with intellectual disabilities, previous knowledge and expertise on the consequences of the disability can be used to facilitate the interview subjects in providing relevant information. It is more important that the individuals themselves have the opportunity to tell their story than that the researcher be concerned about the quality of their statements. I have followed this principle in the interviews with the fathers. I have chosen a phenomenological approach to my study.

The advantage of the phenomenological approach is that it is a humanistic research approach with a built-in respect for people. Descriptions of experiences can make an interesting narrative and make the results more comprehensible to the research subjects. (Denscombe, 2009). Since the purpose of my work is to draw attention to fathers with intellectual disabilities, it is also my goal to make the results intelligible to them.

Denscombe, (2009) notes that the disadvantages of the phenomenological approach is that it lacks scientific stringency, and it is more associated with descriptions and less with analysis, making it difficult to generalize the results. These drawbacks do not affect my study to any appreciable degree, since the aim is descriptive and so few studies or reports about fathers with intellectual disabilities exist.

Interpretation and analysis of data

The method that is used is much like hermeneutic phenomenology, where hermeneutics is used to interpret the data that is made up of the information gathered in narrative interviews, the observation that has been carried out, and the information gathered from previous research, as well as legislative documents and the contents of various support services that are targeted towards parents.

The interpretation of society's information about fatherhood has given me new ideas and a new understanding of fatherhood when the father has an intellectual disability.

I have anchored my interpretation in a gender perspective, in the British social model of disability (Shakespeare, 1996) and in the Swedish environment-related approach. To understand a phenomenon, it must be placed in the context where it occurs. The interpretation of the collected material develops in a spiral motion, in which new experiences and ideas affect the previous understanding and lead to a new understanding. (Gadamer, 1997)

In order to understand my data, the analysis progressed from the fathers' experiences to the social support for fathers and evaluations of how they worked in practice, to a better understanding of fatherhood and intellectual disabilities.

Kvale (1997) takes up an interesting discussion about the validity of the interviewee's statements. He maintains that it can be viewed from two perspectives, one of which is that the interviewee is a witness and informant, and the second being that the interviewee is a representative and subject to analysis. In the former perspective, one seeks to determine the truth of the statements, while the latter perspective is more interested in the interviewee's own experience of what is described – a symptomatic interpretation. My perspective has been the symptomatic interpretation. I want to convey their fathers' own experiences and I interpret the partisan elements of their stories as indicators of how the fathers regard their life situation. An example of this is the description of contacts with social workers and agencies, which can be seen as an attempt by the fathers to show their strengths and thus convey a stronger self-image to me, as the interviewer.

There are various methods of interview analysis. (Kvale, 1997) Concentrating sentences can be used to express more concisely what the respondents said. Sentence categorisation encodes the interview into

categories, so that a large body of text can be reduced and structured in a way that can be expressed in tables and figures.

Narrative structuring means that a text is organized in terms of a time line and a social context, in order to reveal its meaning. Narrative structuring can mean either a reduction in the interview text, or a development of the potential meaning of the story.

The form of analysis that I have used is the narrative analysis, which expands the interview text into a more developed story. This choice of the form for analysis is based on the desire to allow the fathers' own stories to remain as untouched as possible. My previous knowledge about the disability and its consequences, my visual observations during the interviews, what the persons conveyed through body language and eye movements, tone of voice, smiles, laughter, wrinkled brows and silences, all form the basis of my analysis.

In the study however, the printed interview texts reflect what was said in the interview as closely as possible.

Methodological considerations

Ethical considerations

Kvale (1997) points out that the interviewers should be extra vigilant so as not to damage the individual's self-image or arouse worry or anxiety. This is especially important when research subjects have low self-esteem from the outset and may have experienced social exclusion.

With the subject of the interviews being fatherhood, one touches on private topics such as pregnancy, the reactions of one's surroundings, being confronted with the skepticism of the social services and others concerning their parenting ability, possible loss of custody of one's child and all this can create anxiety and agitation for the interviewee. It is therefore particularly important for the interviewer to be aware of the subject's reactions during the course of the interview.

I perceived these types of reactions in the fathers who later chose not to participate in the interviews. During the initial discussions it became clear to me that these topics were very sensitive and that fathers did not want to talk about them when the interview did not benefit them in any particular way.

That the aim of my work was to raise awareness concerning fathers with intellectual disabilities and find success factors for fatherhood in cases of intellectual impairment, was too abstract for them. When participation didn't directly benefit their situation, they chose to abstain.

I was careful not to exert pressure or attempt to persuade the fathers to participate. My approach was to give them as much time as was available to me and be objective and clear about what their participation would entail. In the interaction with the fathers who chose to participate, I was aware that there were many sensitive areas.

I dealt with this by starting out with questions of a general nature, approaching the more private topics in stages. For instance, I would tell the interviewee that I knew a father who had lost custody of his child. Then I asked "Do you know someone who has experienced this"? And I then asked "Have you felt worried about losing custody of your children"?

If I felt that the father wanted to avoid the question, I let it go, remained silent for a moment and then moved on to another question.

The narrative approach when the research subjects have intellectual disabilities

In my study, I use my previous knowledge about the disability and its consequences, and my experience in conversing with people with intellectual disabilities to encourage the research subjects to use their own words to describe their experiences in narrative interviews. Due to my previous knowledge about intellectual disability, I have been able to help the interviewees find in their own words and images to describe their experiences. In this way, I have increased the research subjects' opportunities to be heard.

Very few studies on people with intellectual disabilities have been carried out using narrative techniques. Researchers should find ways to overcome the difficulties involved, instead of avoiding the use of narrative methods, thereby reconfirming the limitations of the research subjects. (Booth & Booth, 1996)

Four challenges face researchers who want to interview people with intellectual impairments. (Booth & Booth, 1996)

The first challenge is a lack of ability to communicate with verbal fluency.

For the fathers in my study, this was a minor problem, because their disability did not significantly affect their ability to communicate, even if it was noticeable. It was difficult for them to describe the emotions associated with fatherhood. Emotions were usually described using one-syllable words. I interpreted this more as not being accustomed to talking about feelings rather than as having difficulties in experiencing and understanding emotions.

The second challenge is a limitation in the ability to answer certain questions.

Questions with open-ended responses are difficult to answer. I avoided this difficulty by dividing the major issues in specific sub-issues. I also repeated some questions, by reforming the respondent's answer into an assertion and then ask if this expressed how he felt.

The third challenge is the difficulty that people with an intellectual disability have in generalizing based on their own experiences and abstract thinking. Being able to look back on one's life and think about the meaning different have had is difficult. By creating a concrete framework for considering something in retrospect, I have helped the fathers in my study to remember and recall.

Finally, the fourth challenge is the difficulty in understanding the concept of time. It can be difficult to comprehend the passing of time in a life cycle, since people with intellectual disabilities have fewer significant events in their lives that help create a sense time and facilitate remembering dates. People with intellectual disabilities tend to have a less varied daily life, with fewer events that would help them in remembering dates. (Booth & Booth, 1996)

Compared to those who participated in the survey that the researchers refer to, people with intellectual disabilities in Sweden have more opportunities to participate in society and therefore have their own experience of the passage of time in their lives. Yet, I could sense this kind of difficulty in the research subjects in my own study when we talked about the future. The future is less tangible than that which has already occurred and therefore it is more difficult to picture.

The aspect of time

One difficulty I encountered in my work was the amount of time available for of data collection. I was prepared for the fact that it would take time for the fathers to understand the purpose of the study and consider if they wanted to participate or not. Despite this, time began to run out and I had to abandon the fathers who were hesitant. This may have affected the result since it was fathers who did not have custody of their children, who left the study. My opinion is that people with intellectual disabilities need more time to come to a decision; they need to return with more questions and then think about their decision again.

One of the fathers returned and wanted to participate in the study, but there was too little time left for me to be able to include him. This reinforces my belief that it takes more time for people with intellectual disabilities to make decisions.

This process is necessary, even if the information is adapted so that it is easy to read or if one speaks in a clear and concrete manner. It is the actual thought process and practical matters that take longer. Reading an email, making a phone call and scheduling an appointment involve many steps where we use our intellect. The slightest difficulty has a great impact. The process can not be accelerated without the researcher risking influencing the informant to participate without him/her having a complete understanding of the purpose of the study.

One effect of the intellectual disability is that it can be difficult to prioritize different activities. This means that an agreed time for the interview may change for reasons beyond the researcher's control. The daily routines of these people help their daily lives function and disrupted routines created chaos and uncertainty. Therefore, the reason why an interview is cancelled, or that a response does not come as planned, may be incomprehensible to the researcher, but crucial to the informant.

The follow-up interviews, to confirm the transcript that the researcher has prepared and the different ways the information will be processed, require more time than in studies where the research subjects did not have intellectual disabilities.

I am aware of the shortcomings in that section of my work, where I sent written information to the fathers, printed on paper. If I had been able to choose another method, I would have chosen to have a meeting with them to go through what was in the written text and get their verbal consent. In this case, I interpreted their silence as approval. However, I took particular care to follow up our conversations in conjunction with the interview.

The work done for a master's thesis spans a short period of time and this makes using the method I chose rather complicated. But I felt it was crucial that the fathers themselves had their say, which is why I chose narrative interviews and observation to collect data, despite the difficulties.

Selection

When selecting the fathers who would participate in the study, my ambition was to include both fathers who lived with their children and fathers who did not live with their children. Five fathers were asked to participate. They were between the ages of thirty-five and forty-five. I had met one of the fathers in the network for parents with developmental disabilities that in the past had been organized by the Swedish National Association for Persons with Intellectual Disability (FUB). I had met another father while working on project on civic participation. I had no prior contact with the other three fathers, rather, my network in the field helped me establish contact with them. The fathers come from different cities in Sweden. Two of the fathers live with their children and the mother of the children. The others three have different relationships with their children and the children's mothers, but these three all have in common that the mothers have lost custody of the children. In one of the cases, this happened while the father was living with the mother and in the other two cases the parents' relationships had already ended when the mothers lost custody of the children. I contacted all the fathers by telephone, explained to them the purpose of the study and explained that their participation would mean being interviewed for between one to two hours. I also explained that they would have the opportunity to read my transcript of the interview, before I used it in the study. Initially, all five fathers were positive about participating, but I soon noticed that two of them became increasingly doubtful, and one of them was clearly negative.

This attitude was evidenced by not calling back, by finding reasons for not coming to the planned interviews and by repeatedly asking questions about the purpose of the study. They also expressed irritation about the fact that that the interview would not lead to any concrete change in their situation. I then decided to end my efforts to secure their participation.

The two fathers who were initially doubtful and then negative, do not have custody of their children. One of the fathers has contact with the child and the child's mother, who now lives with another man. Their child is placed in a foster home and the father has very sporadic contact with the child. He feels he is kept from having contact by the foster family, even though he has the legal right to spend time with his child. The other father who declined to participate in the study has no contact with his child or the mother of the child. He said that he did not know where his child was. The two remaining fathers live with their children and the mother of their children. The interview with one of the fathers took place in the family's home, and the interview with the second father took place at the daily activity centre where the father worked. One of the fathers has two children and the other has three children. All the children are between the age of five and a few months old. The support they receive from society varies and is described in the fathers' own narratives.

The interviews

I have used a qualitative approach in the form of personal interviews. The interviews have alternated between being unstructured and semi-structured depending on how the interview progressed.

The interviews were conducted at a location chosen by the informant. In one case it was at home and in the other case it was at the workplace. The interviews began with a verbal briefing of the terms of the interview: that I could record the conversations on tape, and that they could read the printed transcript and approve it before I used it. Ringsby Janson (2002) describes the interviewer's dilemma concerning consent when research subjects are people with intellectual disabilities. The difficulty in understanding abstract concepts and being able to predict the consequences of something they have not previously experienced is the source of the dilemma.

In my study, the fathers were used to being interviewed by various government officials, so the challenge was to get them to understand the purpose of my interview. According to Gustavsson,

(1996:1) dealing directly with research subjects and not with other people in their nearby surroundings is a question of credibility for researchers. Interviews with people with intellectual disabilities can work fairly well. The differences in the experiences and the language of the interviewer and informant creates good conditions for communication since both parties are attuned to the difficulties and therefore strive to express themselves clearly and check to see if they have been understood. One can put forth different interpretations of the interview responses in light of everything one knows about the interviewee and the subject that is being discussed. Additional material is gathered in this manner and this increases the information's ability to understand. (Gustavsson, 1996:1)

How can narrative research work when research subjects have intellectual disabilities? Booth and Booth wrote an article dealing with the issue. (1996, pp 55-69). In the past, these people were regarded as a source of data for the researcher's interviews rather than individuals with their own story to tell. The difference between an interview and a narrative inquiry is that in a narrative inquiry, it is the *research subject* who establishes the framework for the narrative and much of the information is relayed independent of direct questioning. In the case of people with intellectual disabilities, the reverse is more likely. Researchers need to ask more questions and be more observant of how questions are formulated, what language is used and how the interview is being steered. There is a danger that the researcher makes the mistake of assuming that the lack of ability to express oneself verbally during the interview is due to the person's inability to comprehend or have opinions on the matter. There are several useful techniques when working with the narrative method when the research subjects have intellectual disabilities. (Booth & Booth, 1996, pp 55-69)

Eliminating alternatives is one of them. Misunderstandings can be avoided by breaking down a broader question into smaller questions that people can easily answer. Then the interviewer can compile a comprehensive answer and ask if this was what the interviewee meant. This was a useful technique in my work, because the fathers had a tendency to respond monosyllabically with very brief answers, and they were less likely to answer in a fluent manner.

Silence as a response to a question can be interpreted in different ways. One interpretation is that the person does not want to answer the question and another interpretation is that the person, by keeping silent, is conveying agreement, or is pondering the question or is waiting for the researcher to continue speaking. My experience is that silence can also be a time for reflection for the informant. By meeting silence with silence, I was able get research subjects to continue speaking about themselves.

Observation

Observation is a time-consuming and labour-intensive approach to data collection, but it provides the opportunity to understand the people's lives and their experiences and the meaning they themselves attach to these experiences. (Denscombe, 2009)

The observation process is far from simple because it is extremely vulnerable to the risk that the researcher's perception is guided by personal factors and that the data collected then loses its reliability.

Due to my previous knowledge about the disability and its effects, I wanted to observe if the knowledge that was passed on to the parents by their social networks and by the professionals in their support work with the family, had in fact been internalized into the person's parenting.

The father could to explain to me in words, how he handled various situations in family life and could also describe the needs of the children.

But could the father perform practical tasks that he had learned, concerning the children and the children's needs?

People with intellectual disabilities have difficulty in translating knowledge into action and they may have a hard time seeing causality in different situations. (Kylén, 1974)

During my observation, I focused on what was said and how it was said, and what was done and how it was done.

In the analysis of the observation, I wanted to see if there was any contradiction between what was said and what was done.

If there are contradictions, this could be interpreted to mean that the support the father receives is not adapted to his ability to translate words (abstract) into practice (concrete).

Reliability

The reliability of the persons' response is not affected by the disability. (Booth & Booth, 1996) The subjects' inability to place themselves in hypothetical situations makes it difficult for them to lie. Too often, scientists believe that the difficulties associated with interviewing people with intellectual disabilities, are due to latter's lack of abilities, rather than the limitations of the researchers' methods. This attitude leads to people with intellectual disabilities being excluded from participating actively in the research that affects them and their lives. This in turn reflects their peripheral role in society, something that researchers say they hope to counter. Many researchers put forth lack of time and the lack of quality in the stories that are obtained, as reasons for choosing other methods. The result is that people with intellectual disabilities are silenced and prevented from telling their stories. (Booth & Booth, 1996) The quality of fathers' own stories did not have a negative effect on reliability. With my prior understanding of the disability and its consequences, I have been able to interpret their answers, their expressions of emotions and what the fathers wanted to convey. I have reviewed my interpretation together with the fathers, who could then confirm if the interpretation was correct, or protest if it was incorrect.

In the trade-off between using a method that makes great demands on time and preparatory work in order to motivate the research subjects to participate and using a method in which their own involvement is pushed aside in favour of the use of secondary data, I chose to obtain the fathers' own stories.

In my study, the fathers who chose not to participate for various reasons did not have custody of their children. Their life stories would have enriched the study by providing a more multi-facetted picture of fatherhood. Understanding the factors behind failed parenting is equally beneficial in the quest for knowledge as understanding the factors that contribute to successful parenting.

The fathers have been provided with written transcripts of the interviews. I have not received any response from them after they received written documentation. Two factors may explain this. The first factor being that it is a large body of text to read and understand and the second factor being their self-image which may affect their willingness to criticize my text. I was aware this would happen, so at the end of each interview, I summarized verbally what we had talked about and asked if it was in agreement with what they had said. A better method would have been to return after the transcript was completed and go through it together with the fathers. Lack of time and the fact that fathers lived in different cities in Sweden meant that I could not choose this method.

Results

Introduction
I present the result of my study in this section. The result is based on my approach to intellectual disability as expressed in the relative approach, and inspired by the social model. It begins with a short description of all the fathers who were approached to participate in the study. The fathers who did not want to be interviewed in the study have given me permission to include them in my text in this section.

The fathers' names are fictitious. The stories of the participating fathers are presented as narratives, with direct quotes from the interviews. I have also read a letter that was sent to the Swedish National Association for Persons with Intellectual Disability (FUB) and I have permission from the person who wrote the letter to use the contents. However I will not include the letter in its entirety, as I want to protect the identity of the sender. This text is followed by a documentation of an observation I was able to do.

All the fathers that I have been in contact with for my study have a mild intellectual disability, and all but one has received a diagnosis, which entitles them to assistance under the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS).

The fathers who declined to participate
The fathers who chose to not participate in the study and their experiences indicate that the professionals they meet do not see them as fathers or assign them a key role in the lives of the mother and child. Being confronted with this attitude, they may find it difficult to see themselves as fathers and they risk being completely abandoned in their roll as fathers.

Father A
Lives in a flat with support. He does not live with the mother. The mother has an older child with another man in addition to her daughter with this father. The daughter lives with a foster family, and her mother has visiting rights. The foster home has changed the surname of the girl so that her name is the same as the other members of the foster family. When this father got back to me, it was too late, given the schedule I was working on. He said he wanted to participate. I thanked him and informed him that I didn't have enough time to do an interview.

Father B
Lives in an apartment associated with a group home. He has a subsidized job at a grocery store.
He has grown up with his family in northern Sweden. During junior high school he found it increasingly difficult to keep up in school and it was decided that he should start high school in a school for students with learning disabilities. This meant that he had to move to a different school, away from his peers and soon after the move, he lost touch with them.
He had difficulty finding new friends in school, but despite this, he thrived relatively well. However when he moved to the special needs school, he was not aware of what this meant in terms of future educational opportunities or for the possibilities of getting a job.
A few years after leaving school, his father was able to set up an internship at the store where he now works. The internship turned into a subsidized job position, since he could take initiatives and worked independently. He wanted to move away from home at some point.

The solution - an apartment that is associated with a group home - was perfect because he has difficulty organizing his daily routines and planning his economy.
He takes care of most things himself in the apartment, with some outside support. His father is a trustee for him and helps him with his economy by depositing a certain sum of money in an account, so he can withdraw money at ATMs. They pay the rent together, and together they agree on how his money should be spent during the course of the month.
Two years ago he met a young woman on holiday. The woman has no disabilities, but has always had some difficulty with reading and "keeping up", as she puts it.

She lives with her mother and they are relatively isolated since the few relatives they have live in Finland. She got pregnant and both were delighted about child. The father's family was worried, but thought it would work out fine, if he gets the support he needs. She wants to move in with him and they plan to live together with their child.

That's when the difficulties begin. The father lives in an apartment that he received through the Act on Special Support and Service (LSS). The girlfriend, however, is not entitled to support through LSS and cannot live there, according to the LSS administrator.

The girlfriend is told by the midwife that if she does not end her relationship with the father, the social services will take custody of the child. Her mother just cries and cannot handle the problems and his family feels powerless.

Initially, he wants to be included in the study, be interviewed and share his thoughts and feelings, but it quickly becomes very difficult for him and he declines to participate.

"But you can tell my story" he says.

I end my contacts with him and I don't know how the situation developed.

Father C

Has a child with a woman he does not have any contact with.

The mother does not have custody of the child, and he doesn't know where the mother or the child are living. Initially, he says he wants to be included, but then he is not able to meet at the time I suggest. I ask him to suggest a time and place, but then he says that I should call back later. I do that but he is not there, so I leave a message. He does not call back. I interpret this to mean that he is not so keen to be interviewed, so I leave him a message, saying that this is how I interpret his silence, but that he can call if I'm wrong. He does not call.

Fathers included in the study

As defined by Kylén (1974), the fathers that are included in the study have a mild intellectual disability. They can read and write, even if they have difficulty expressing themselves in writing and have difficulty in understanding the meaning of complex texts. One father has problems with numbers, but not with a correct sense of time when he referred to life events. Both fathers could relate to the past, present and future. Both stated that they did not "plan so far into the future", which I interpret as an expression of the difficulties associated with their disability. The shortcomings in causal capacity that I could identify stem more from the fathers' self-image than from the disability. In one of the families, support for the family was provided during the day when the father was at work. He explained that this was due to the staff's work schedule. In my view, the reason was that the father was not considered as an important beneficiary of the support.

Kalle

Kalle is 40 years and has a subsidized job in a mechanical workshop. Kalle grew up in his family with two younger siblings and his parents. Kalle is adopted, as are his siblings who are twins. The siblings do not come from the same country as Kalle.

When he was growing up Kalle found it increasingly difficult to keep up with schoolwork. He did not really understand the work he was supposed to do. He had difficulty concentrating and became a "rowdy" student. At home it became increasingly difficult to keep the peace, since Kalle began hanging out with peers who caused problems. More and more often, he and his mother got angry at each other, and Kalle had temper outbursts. He had difficulty managing his finances and spent a lot of money on the wrong things.

Kalle's mother began to seek help, and she thought he had ADHD. Kalle did not know what that was, and when he asked his mother, she said it was his outbursts.

"What outbursts?" Kalle asked. Out of fear for these fits of anger, Kalle began to go off by himself when he got mad at something or someone.

Kalle didn't receive his diagnosis until after he left school and he received medication. Kalle has not needed the support provided by the LSS act (Act 1993:481) and therefore he has no diagnosis that clarifies his intellectual disability. However, he is aware of his limitations and is a member of an association for people with intellectual disabilities, where he is active.

Kalle and his wife met a decade ago and were married five years ago.

Kalle lives with his wife and their two children, 3 and 5 years old in a three room apartment. Kalle's wife has an intellectual disability and works at a supermarket.

They have help in organizing their daily lives through in-home support. They have attended parent training courses both before and after the children were born. The most recent course dealt with conflict resolution.

Both Kalle and his wife are conscientious about asking for help, they feel they need help and that they are treated with respect by the staff of the social services. Kalle's mother helps them with the children and the home so that they get a break.

Kalle and his wife are active in an advocacy association, arrange meetings and do volunteer work there. They meet friends and relatives, but they miss the wife's father, who died a year ago. He was very supportive of everyone.

Amid

Amid came to Sweden with his mother and two younger siblings when he was six years old. His father had already lived here for a year. Two more siblings were born and he has said that he looked after all four, since both his father and mother worked very hard.

When Amid was going to start junior high school, his teacher decided that that he needed to go to a special needs school. He had difficulty writing and difficulty keeping up with schoolwork. Amid doesn't recall that there was any discussion about him being placed in a special needs school. But he remembers that his parents thought it was strange; however they thought that the teacher probably knew what was best. He had to move to another school and leave his friends. The new classmates had more difficulties than Amid, so it took a year before he made friends in the new environment.

After completing his schooling, he spent a year working in a car repair shop, and for the past eleven years he has worked at the daily activity centre where he still works today. The business is craft-oriented and Amid works as a cabinetmaker. Three years ago he married his wife who comes from his homeland. He has three children, twin boys aged two years and a little girl who is one year old. His wife has no disabilities. He has a big family and many relatives live in Sweden.

Kalle

Kalle's background

Kalle was adopted and his two younger siblings, who are twins, are also adopted. Kalle and his siblings were adopted from different countries.

Kalle says that he did not feel different during his childhood because he was adopted, but the sentence continues.

Kalle: *"I was the most bullied - it was because I had a different skin colour"*

Iren: *"Were you bullied for your disability?"*

Donald: *"No, not at all, because it took so long before they realized that I had it"*

The school years

During his years at school, Kalle felt that he had difficulties. He could not concentrate and he did not really understand the school work that he was expected to do. His parents were involved and tried to resolve the situation, but Kalle felt they were angry, nagging and very demanding and he tried to escape by withdrawing.

Kalle wondered why he had problems and why he did not understand, but no testing and no evaluation was done during his years at school. No one talked to Kalle about it either.

When I asked Kalle if he wondered if he had any disability before he was told about it, he answers.

Kalle: *"No, just that I wondered what was wrong with me, why did I behave so strangely, wasn't I a normal teenager? I was just disobedient, out late at night, just went off without telling my parents, I just couldn't care less."*

Disabilities and Diagnosis

Kalle's parents continued to work for an evaluation and finally Kalle was diagnosed at the age of 25 - 26.

Kalle has difficulty in understanding and explaining his diagnosis. He says that the explanation he got when he asked was that it had to do with the outbursts he used to have.

Kalle: *"What outbursts, I thought.*

"They're all gone now," continued Kalle, "I've had the final tests and they're all gone. You can grow out of it... I've outgrown it now; I don't have any outbursts anymore, now I just leave. I have to handle myself better because there's a family now and everything, and then you can't just ignore everything. I've understand that very many demands were made on me when I was a child. My mother wanted perfect grades in school, and they asked every day what I had learned, and I hadn't learned anything." A long silence follows. Kalle looks down at the table and draw circles with his finger. I'm remain quiet.

Kalle: *"I like my mother."* Another long silence.

Kalle: *"But she thought I ought to do better in school."*

Iren: *"Do you think it's hard to be an adoptive parent?"*

Kalle*: "Yes, the mother role is not there right away of course, and everyone knew who I was when I did something stupid."*

Adulthood

Kalle works as a technician at a company that manufactures flooring, fans and stationery, as well as other products. He has worked there for twelve years and has subsidized employment.

Kalle has been involved in the employment union at his workplace and has been president of the union club. He has taken courses in union work and learned a lot.

He is also an insurance adviser and helps those who injure themselves in the workplace.

He sees no signs of his past problems with understanding and keeping up at school.

Kalle: *"It is important that I learn and understand things since I need to help my co-workers if something happens."*

Iren: *"What have you learned about unions?"*

Kalle: *"I've taken courses, different courses. About insurance and such."*

Iren: *"Was it difficult?"*

Kalle: *"Nah, it was exciting and interesting. Afterwards, I could help someone who hurt himself on the job. "*

Kalle met his wife eleven years ago. When I asked Kalle about when he met his wife, he answers first:

Kalle: *"Five years ago,"* then he thinks for a moment and says

Kalle: *"Wait, I got that wrong. We got married five years ago, so it must be ten years ago. And Eric, our son, is of course almost six years old, so it was eleven years ago."*

I asked how old the kids are.

Kalle: *"Soon six years and three years - nine days difference."*

I don't quite understand the answer, and I wait for Kalle to continue with an explanation of what this means.

Kalle explains "*three years too."*

Role Models

Kalle tells how it was when they found out that they were going to have a baby. He says that he was very happy, but that he wasn't sure how he would cope with fatherhood. His own father was away a lot when he was little so it was mainly his mother who took care of the children. He had no friends that he could talk to about becoming a father. But he says that his father-in-law and his father-in-law's wife stood in the window and waved and looked happy when he came home from work on the day when his wife had received the news. Kalle's own parents were also happy.

Kalle: "It was maybe more so-so for Dad. There was not much talk about feelings with my dad, mostly when we talked about skiing and sports."

Kalle's father-in-law continued to be a strong support for Kalle and his wife. The father-in-law had raised his children after he divorced his wife, so he and Kalle's wife were close. This father-in-law became a role model for Kalle.

On fatherhood
Kalle says that neither he nor his wife felt that anyone was worried about how they would manage parenting due to their disabilities.
They themselves were unsure about how they would become comfortable in their role as parents, but they always had confidence in each other. They talked a lot about how it would be.
Both Kalle and his wife are conscientious about seeking help and they talk openly about their concerns about not being good enough parents.
During the pregnancy, they both participated in a parent group for expectant parents at the maternity clinic. No one asked about their disability at the clinic, rather they were the ones who brought it up. Kalle feels they got a positive response and that they received the support and help they needed at the time.
Kalle: *"When we said that we had disabilities, no one said anything at all." Nah, it didn't seem like they thought it was strange."*
The period after the baby's birth went well, but Kalle felt that his wife worried about how she would handle being a mother.
Kalle: *"The role of being a mother isn't completely there, it must come of itself. You learn over time, and she learned quickly."*
Iren: *"The role of being a father - did you learn over time?"*
Kalle: *"Yes, we learned at the same time since I was at home for a while just after the baby was born. You need the support of each other, I think."*
"But as time passed, it became more difficult, I think. You know – teaching right and wrong, feeding the baby, schedules and everything. We didn't know how to set up schedules."
Iren: *"You mean schedules for practical things like when the baby should sleep, when the baby should have food, when to change diapers and such?"*
Kalle: *"Yeah, exactly. We didn't know anything then and we had to ask all the assistants and then they said different things. But one of them said that we should write everything down. So we did that and it went better because then, like, we knew. "*
Iren: *"What did you write down?"*
Kalle: *"We wrote down when he ate and when he slept, and when we changed diapers. Sometimes we wrote when he cried, too. Then we could we answer when she asked, that is. Because then we knew! "*
Iren: *"Who read what you wrote down?"*
Kalle: *"She works at the children's health clinic - what was her name now?"*
Iren: *"Did you and your wife read what you had written down, too?"*
"No," says Kalle and laughs *"we had written it so we knew!"*

I understand from this exchange, that Kalle and his wife were not able to provide answers when the paediatric nurse asked about the baby. Therefore she had helped them make a schedule of times and other details so that they could fill in it in and write down details about the child – when he ate, how much, when he slept and when they changed his diapers.
Filling in the schedule and writing things down took a lot of time and energy for both parents who have difficulty reading and writing. They didn't feel that all the writing down helped them personally; rather they did it for the staff at the children's health clinic. It also took a lot of time for them to write down all the details about the baby.
Both Kalle and his wife stayed at home after their children were born. Kalle thinks that both should be at home since there is so much to deal with, especially with the first child.

Iren: *"Do you know anyone who is not allowed to take care of their child?"*
Kalle: *"Yes, but he doesn't live around here, and I do not know why."*

Iren: *"Did anyone speak to you and your wife about that you might not be allowed to take care of our child?*
Kalle: *"No, nobody. We asked for help of course and so on, because we knew we must ask for help. I think it worked out well for us."*

Support for the family
Kalle has not been worried that they would not be allowed to take care of their children, and no one from the social services has talked to about their disabilities or raised questions about it.

I repeat the question:
"Hasn't anyone talked to you about your disability?"
This time he replied:
"It was mostly about the support. We needed it, we asked for it and wanted it. But if they had said we need help with this and this and this - well, then I wouldn't have accepted help. I can make decisions by myself. No one should go and decide, you know, what I should be doing here and what I should be doing there."

Kalle feels that they received help with everything they asked for. For example, Kalle's parents, especially his mother, helps them with their children, she baby-sits so they can get out sometimes, and she helps them with practical things at home if necessary.
Kalle has a trustee and guardian to help with personal finances, and Kalle thinks this is very good, since then he doesn't have to worry that there won't be enough money for the family's needs. Kalle's wife works four days a week and is home one day a week. She gets in-home support and help with organizing the household work, making schedules for the children and all the things to be done. Kalle doesn't know if any more support is provided, since he is not at home during the day, but he thinks it's good for his wife who becomes calmer when she gets support.
Iren: *"Why can't the in-home assistance come when you are also at home, so you can get support too?"*
Kalle: *"They don't work in the evenings, you know."*

Kalle is anxious to convey that both he and his wife accept help and support, and that they are aware of the difficulties that may arise as their children grow older.

Division of labour
Both parents are involved with the care of the children who are enrolled in a day-care centre. Kalle's wife drops off the children at day-care since she starts work later than Kalle, and Kalle picks up them up in the afternoon so that his wife can go home and start cooking dinner so that it's ready when the kids get home and are tired and hungry.

Thoughts on the disability and paternity
I asked Kalle if he ever thinks – "it wouldn't have to be like this if I didn't have my disability."

Kalle: *"Well, I probably wouldn't have had to ask for all this help, maybe. I wouldn't have to have all these people around in my family; I could have decided things myself, maybe. There are many people in my family now."*
Iren: *"Who are they?"*
Kalle: *"Well, my mother and the social services as well - if more don't come."*
Iren: *"Are there many people who make decisions?"*
Kalle: *" My mother and I have disagreements. I just don't accept certain things; things just go in one ear and out the other. You shouldn't just have to accept things; you should be able to disagree and she'll just have to accept that. "*
Iren: *"It can be difficult to protest, when you also need help, right?"*
Kalle: *"People have their good sides as well; you should be allowed to speak up and you should be allowed to use your own words when you say things and people should understand. They think you have a handicap and well, I think that's difficult. "*

Iren: *"Explain what you mean about your own words"*
Kalle: *"Well, they speak too fast and just make decisions over my head and say how it's going to be. Then I just get angry. I can't handle just sitting around and arguing back and forth. Forget it, then. I just go off somewhere or I just keep quiet."*
Iren: *"What happens when you keep quiet?"*
Kalle *"Well they think they've won, but hey, they are wrong about that."*

Kalle doesn't feel that the professionals disregard him or his wife. He thinks they understand him better and that they understand what he says and how he thinks.
Kalle: *"They keep working like nothing had happened. It's as if I were a regular person, in fact. Nothing else but!"*

The future
Kalle feels that his family has a good life; it's hard to have enough time for everything, but it's fun with the kids. He is an active father, doing a lot with the children, taking them out in nature, playing at the playground and sometimes visiting friends. He is a bit worried that they live in one-bedroom apartment and hopes that in future they are able to live in a house outside of town so that children can be in the garden and have their own rooms. Kids need that if they are going to bring friends home, says Kalle.
Kalle isn't worried that his children will have disabilities or have trouble in school. He says that Eric has outbursts occasionally, but that he didn't think that was odd.

Kalle: *"He's growing up and wants to decide things sometimes, and of course it's like that, but he can't always decide."*
Iren: *"Do you have any favourite dream?"*
Kalle: *"Well, it would be about the house. To move by the time Eric starts school and take care of the garden. Otherwise I don't look so far ahead. Mostly I take one day at a time."*

Observed

In connection with one of the interviews, I had the opportunity to spend a day with the family.
With the family's permission, I use an account of this day in my paper, in the form of an unstructured observation where I observed and was known as an observer.
This observation has helped me to achieve a greater understanding of the father and the father's daily life with the family.
It gave me important background information that has helped me expand my questions in the interview and it contributed to my interpretation of the research subject's comments.
The goal of the observation was to see the interaction between the parents when dealing with the children, to see if the father and mother had different roles and to see the children's contact with the parents.
The observation took place on a Saturday, when the parents were home from their jobs and the kids were home from day-care. Everyday activities such as shopping, cleaning, cooking and washing do not occur during the observation.
My main interest is the parents' contact with children and the father's role in contact with the children.
I have agreed with the father that we will meet on a Saturday and that I would like to interview him for about an hour and a half. I also expressed the wish to have time to meet his wife and two children.
We decide to meet at a gas station in the town in southern Sweden, because I don't know my way around so well that I can find their residence.
It is in the middle of January and at least 22 degrees Celsius below zero outside.
When Kalle arrives, he has the two children with him in the car. They sit in separate car seats in the back seat, looking at me curiously and happily. They say hello and then return to their small boxes of "Saturday" candy.
They have lots of clothes on because it's so cold, and they seem curious about me.
Kalle opens the car door for me, clears the front seat and we drive off. It takes about 10 minutes to drive to the area outside the city where they live.

Kalle parks the car, helps the kids out and carries his daughter into the apartment where Kalle's wife is waiting with coffee. The children take their jackets off by themselves, calling for help when something gets stuck. They hang the clothes up on hooks in the hallway. Two cats also sneak up and the children pet one of them and then run off into the apartment.

The apartment is nice and tidy, even if the children's things are not put away in their rooms. It is crowded in the hall. Since it's January and very cold, many sweaters, mittens, caps and jackets take up lots of space.

Kalle's wife shows me around the apartment and excuses the mess in children's rooms. There is a lot of furniture, but Kalle's father-in-law has recently died, and they would like to keep some of his furniture. They hope to move to something bigger soon.

Kalle's wife shows me that the playground is right outside their kitchen window so that children can be out there sometimes without their parents, who can oversee from the kitchen window. The children are given glasses of juice and sit with us at the table in the kitchen while we drink coffee. Both father and mother are active in overseeing the children, answering their questions and correcting them when they do something wrong.

Pretty soon, the kids get tired of our conversation and go off into a smaller room to play video games. I note that the mother puts on a timer while the father puts on the video game.

They tell us that their son only gets to play for a certain amount of time and that they keep track of the time with a timer. When time runs out, he may not play anymore. The son protests and together the parents agree that it's not a big deal if he plays a little longer since it's a special situation with me being there.

Then it's time for the younger child to take a nap. She is just about done with using diapers. The father takes her to the bathroom, despite her protests, and I hear how he praises her in there.

He then takes her to the children's bedroom and stays there until she falls asleep. She does this after just ten or fifteen minutes, and the father comes out again. She is a bit of a daddy's girl, he says, not without pride in his voice.

Meanwhile, the son drew a picture for me - a clown. It is a very detailed and skilful drawing. I praise it, and he looks proudly at his mother. I ask who usually draws with him, and he says that it's mostly his dad. The mother confirms this and says that her husband is more artistic than she is. While the father is putting the daughter down for her nap, the mother tells me a bit about their daily life, that they have friends, but the friends do not have children, so they don't get together very often.

She misses her father very much, because he was a great support to her and her family, but she looks forward to having better contact with her mother. They have not had much contact since the parent's divorce, since her father took care of her and her sister.

She also takes time to tell me that she is very fond of her mother-in-law, but she can get sad and upset because she meddles too much. She also worries over that her husband doesn't get along so well with his mother and this upsets him.

When the father returns, we talk about their daily life and that they help each other out with everything. Kalle takes care of the kids more when he's home and the wife does more of the housework since she is home one day a week. They both feel that they help each other with most things and that they rarely disagree on how children should be raised. Given that it may become more difficult to set boundaries and handle conflict as the kids get older, they have registered for a course at the local family centre on how parents can handle conflicts.

They are very open about their need for help and are also aware of what kind of help they want. They feel they can handle practical chores themselves, if they get help with structure and planning.

Their son comes and goes during our conversation, asking questions and getting answers, getting a glass of water, being allowed to sit for a while and watch a movie on TV.

When the daughter wakes up after approximately one hour, her father picks her up and takes her to the toilet.

Then the father and I were left with the children while the mother goes into the bathroom to do some laundry. It is not enough to do the laundry according to the previous schedule now that the daughter is trying to stop using diapers. Accidents happen even though we try to watch her all the time, the mother says.

I ask if the father can drive me back to the gas station where my car is parked. Yes, but not immediately, since he needs to help his wife with the meal first. By interacting, they make the dinner

together and look after the kids. The two children are hungry and also a little bored since both parents chose to be with me and the kids played second fiddle during my visit.

The parents handle this differently. The mother has less patience; she is clearly annoyed and raises her voice to the children. The father tries to shift their focus instead, by giving them bits of food to taste, assuring them that dinner will soon be ready and by advertising a car ride after dinner if they behave better.

In this noisy and distracting environment, the mother succeeds without particular difficulty, in making spaghetti, meat sauce and grated carrots for us all. Dad and the kids set the table and peace descends when the food arrives.

The mother corrects the children's table manners a few times during the meal, but both children eat without help.

After dinner, the father does the dishes while the mother gets the children ready for our departure.

The children's good mood has returned and I notice that the mother is less stressed than when she was making dinner.

Taking the children in each hand, the father walks over to the parking lot in the flat complex.

The mother walks beside me and says that she hopes that I got the information that I wanted from the father and that maybe we will meet again soon. She sits with the children in the back seat and we drive off.

We say goodbye at the gas station, with the children calling and cheerfully waving goodbye. Mom and dad in the front seat, the children in separate car seats in the back - a family just like any other family.

Amid

Amid's background
Amid is 38 years old and came to Sweden from North Africa about 25 years ago. His father had moved to Sweden some years earlier and his mother and siblings followed a year later.

Amid was initially placed in a regular school, but was later placed in a special needs school. Today he lives in an apartment where he is receiving assistance under the Act concerning Support and Service for Persons with Certain Functional Impairments LSS (Act 1993:481) and is working at a daily activity centre, which is also a part of the support provided under this law.

Three years ago he married a girl from his homeland. His relatives had helped him find a wife. In the spring of 2006 she came to Sweden, and they moved into the small apartment that Amid lived in. The apartment is a so-called satellite apartment connected to a group home. Today the couple have three children, a pair of twin boys who are two years old and a daughter who is one year old.

The meeting
Amid and I met at the daily activity centre where he is employed. It is our first meeting. He works with furniture carpentry and before we begin our conversation, he shows me around the workshop. He proudly shows me a cabinet that is quite handmade - just beautiful. *"This is for the children's clothes"* he says proudly. *"Each child will have his own cabinet, so that we can find things!"* In an album there are pictures of all the things that Amid has made. It shows beautiful cribs that he made for the twins and several cabinets. Amid has been working for eleven years at the furniture shop and has had time to make many beautiful pieces that have been included in various exhibitions.

Childhood and growing up
We are allowed to use a smaller room, and I ask Amid if he wants his supervisor to join us while we speak.

"Nah," he says, *"it will be fine without him."*

Iren: *"Do you remember what it was like to come to Sweden"*

Amid: *"Nah, nothing, I only remember the airplane and what it was like to fly. Otherwise, nothing."*

I wonder how it came to pass that they came to Sweden. It was because her father was here, says Amid. That's why they travelled here - his mother and his two younger siblings. He himself was six years old and I notice that the times and ages do not match so well, judging by Amid's answers about

his siblings' ages and their number. All siblings are younger, he says. He has not had to take care of them so much since they were not very young and didn't have diapers. Then more siblings were born in Sweden.

School

He went to school, but it was hard to write and difficult to learn the Swedish language since most students spoke a different language at home. He felt he fell behind at school. After six years at school, he was transferred to the special needs school. He was not happy about this because he didn't want to change school and lose his friends. But the teachers had made the decision and parents didn't dare to protest.

So Amid had to move to a new school and a class where *"it was a completely different kind people,"* he says. He soon had new friends there and later went on to the special needs high school. After upper secondary school, he worked for a year before he began at the daily activity centre where he is today.

Adulthood

The centre where Amid works has a focus on crafts where one works with carpentry, painting, leather and glass. Amid is a furniture maker.

Iren: *"Did you have any dreams about how your life would be when you grew up?"*
Amid laughs at first and says that he had none at all.
I am silent for a long moment and then Amid continues to speak.

Amid: *I had made a drawing of exactly how the apartment would look where I would live. But it turned out completely different, it's a little better actually."* He laughs again.

On getting married and having children

Together with a relative in their home country, his father arranged with so that he could meet his future wife. She is 25 years old. She is trained as a seamstress and has no disabilities.
They met a few times in their home country before they got married. Then it took a few months before his wife could come to him in Sweden. His wife got pregnant almost immediately.
The first child turned out to be twins! *"Wow, is one more coming!"* tells Amid, laughing as he recalled how it felt at the delivery.
They were so happy - and proud. Everyone in the family was pleased since it was the first grandchild. Amid's father was very proud of the two boys. And so they had another baby, a little girl who is now one year old. Amid took parental leave for six months when the twins were born.
This was not completely uncomplicated since his employment at the daily activity centre is a support measure provided under the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS). This can be difficult, since if the support measures are not used for a period of time, it is not a given that they will be granted again. The family's finances were better when they both had parental leave allowance, than when Amid worked at the daily activity centre and his wife took Swedish language classes. Then Amid had an "activity stipend" and his wife had no compensation at all.
When we talk about this, Amid told me about a letter that he and his supervisor had written.
Iren: *"Tell me more about the letter that you have written."*
Amid: *"It's such a hard question about the letter, let's take it later when Pelle is here!"*
I'm silent for long time, waiting for Amid to say something more about the letter. But he is silent.

Family Life

Iren: *"Tell me about your own family"*
Amid: *"I have a wife and three children, two two-year-olds and a one year old. The two- year- olds are twins. "*
Iren: *"Have you and your wife ever been worried that you will not be able to take care of your children on your own?"*

Amid *"Naäeeeej"* He laughs and shakes his head.

I wonder silently if this is because Amid's wife doesn't have an intellectual disability.

Amid's wife heard about a women's cooperative in another municipality, where women sew and sell their own things. She visited the coop and was so happy and felt that she wanted to join the group and sew and be able to meet other women in the same situation as herself. But the cooperative is not located in the same municipality where the family lives and this turned out to be an insurmountable problem. The home municipality refuses to pay for her participation in the cooperative. The only possible solution was for the family to move, but then they would lose social network and the security that the extended family provided.

Division of labour
His wife is now taking a course in Swedish and the children are attending day-care. They help each other with dropping off and picking up the children. Amid does the housecleaning and the wash. His wife makes the meals. They do the shopping together. Their relatives are working or attending school, so they must fend for themselves during the week. Amid has a trustee and he also has early retirement disability benefits. His wife has no income while she's attending language class. Amid explains that they receive rent subsidy, the child stipends that all parents are entitled to in Sweden, as well as income subsidy from the social services.

The disability
Iren: *"Do you think you would have been a different kind of father if you didn't have disabilities?"*
Amid doesn't hesitate at all before answering.
Amid: *"Yep. I would have worked. Earned my own money. Taken care of my family, without help from the social services."*
No one has teased or been unkind to Amid. And he has no difficulties being with people who have a greater need for support than he has. I noticed this when he showed me around the workshop and we met his co-workers
However a neighbour has said that Amid can't do anything and that he was stupid, and Amid makes a gesture towards his head when he talks.
It is obvious that Amid was hurt by this, he speaks in a lower voice and looks down at the table, when he talks about his neighbour.
Within the family and among his relatives, he's like anyone else. No one treats him differently. Amid seems almost surprised when I ask the question.

The support from the community
Amid is eligible for assistance under the Act on Support and Service for
Persons with Certain Functional Impairments (LSS) as well as under the Social Services Act.
Amid receives no support in his roll as father. I wonder again if this is because his wife doesn't have a disability. Given that the support I have read about in the study so clearly shows a focus on supporting the mother, this is a

reasonable assumption. There were also examples in the Icelandic study on fathers, where the woman in the relationship did not have a disability and the father did not receive any support. (Sigurjónsdóttir, 2005)
When Amid got married and his wife moved to Sweden, he lived in an apartment that was a satellite apartment to a group residence and where he received support in daily life, under the LSS law. In a formal interpretation, the municipality can deny the wife permission to move in with Amid in the satellite apartment, especially since she has no disabilities. There are no clear-cut regulations that apply to this kind of situation.

Amid says there was a lot of confusion and many meetings before everything finally got settled. I ask what he means.

Iren: *"Who made things confusing?"*
Amid: *There were many papers that I had to fill in. Pelle* (Amid's supervisor at work) *helped me, but just said 'no' all the time since the apartment was too small.*

I don't understand, since Amid has not included all parts of the story.

Iren: *"Was it the administrators at the social services who caused problems?"*
Amid: *I don't know; I was upset but nothing helped. I was given an interpreter - you can ask Pelle about the letter later, because we sent it to many people."*

Despite several attempts, I can't get a coherent description of what happened. I ask if I could read the letter after the interview and then Amid says:
"That will be good, it's important.
"I couldn't fill in the forms," he says. *"And I knew nothing. So I got help, but he quit before everything was completed. It's not that hard to read, and now I know the language, but I can't write."*

At this point, I choose not to continue. I notice that Amid is downhearted.
I confirm that I will read the letter later and we continue to talk about what it's like being a father.

Fatherhood
Iren: *"What's most important for you, now that you're a dad? What is a really good dad? "*

Amid thinks for a moment, then he answers:

Amid: *"Show them things and teach them things. Teach them about life. They are so small now, so now they're learning to walk, to eat and to be nice to their little sister. But it's so complicated with three small children. You have to take the bus since they can't walk so far yet. You don't have time to do much else, other than feed them and let them sleep and play."*
Amid explains that they took a course at the hospital when the twins were born and learned to take care of them. Amid has a sister who also has children and who they meet and socialize with. Her children are a bit younger than Amid's children. She helps them sometimes. Amid is openly proud of his wife and thinks she handles everything very well. Amid is also a proud father.
At this point, Amid becomes silent and is quiet for a long moment. I am also silent.
"What happens then when the children grow older and start school?" I ask.
"I do not know, maybe easier." Amid answers.
"What gets easier?" I ask.
"They can do more things for themselves" says Amid.
Then it becomes very quiet again.
"Or else we'll have no help at home at all." Amid says with a proud laugh.

The future
I ask if there is anything Amid dreams of - something he wishes were different. He can't think of anything. He doesn't think that his disability causes him difficulty anymore. He has taken a class to learn about polishing cars, but he has no training as a carpenter. Since he has attended a special needs school, it is impossible to apply for vocational training. His grades don't count.

Iren: *"How do you think about the future?"*
Amid: *"How am I supposed to teach them to read and write? It gets tricky. "*

I see that Amid is pondering.
"It gets tricky," he repeats. He disappears into his own thoughts at this point, thoughts he doesn't really have words for.
"Who can help you if it gets tricky?" I ask.
After a pause, he laughs and answers:

Amid: *"My wife can, when she learns Swedish better."*
"Do you want more children?" I ask.
Here, I see for the first time that Amid thinks I am asking about things that I shouldn't ask about.
"We'll see" he replies curtly. He is quiet and looks at me as if he wants to tell me to take another question.

Iren: *"Would you like to tell what you dream about?"*
Amid then tells about his dream of getting a drivers license and a car so that he can drive the kids to football and school. Amid thinks life would be easier with a car with so many children.
Amid: *"The theory part will be hard; I think it will be hard."*
When I ask if he can drive a car, he laughs again and says that the he can't.
Amid: *"And the driver's license, it costs too much money."*
When we go out, he asks his supervisor to give me the letter.
"Write about this as well," he says. *"It's too hard to explain everything. I think so."*

Contacts with authorities

In the Act on Special Support and Services (LSS) there is nothing written about support for persons covered by this law, in the event they become parents. Support for parents and families is regulated by the Social Services Act. Within the same municipality, there are different administrators for different activities. In addition, parents have contacts with the national insurance authority that regulates parental leave. If a person can't represent himself in contacts with the authorities, and can't protect their own rights, then they can be granted a trustee through both the Social Services Act and LSS.
One of the fathers has described all the difficulties he and his family had, trying to sort out everything when they became parents. He received help with keeping track of what happened from his supervisor at work, because it's too complicated for him to understand and explain.

When Amid's wife is expecting their first child, they find out that they are expecting twins, seven months into the pregnancy. Amid's wife has no disabilities, but had come to Sweden just a year before and hasn't learned Swedish that well yet. The family needs help with contacts with the health insurance office, the maternity clinic and other aspects that are new to expectant parents. They worry that their home is too small and they would like a bigger apartment.
The supervisor at Amid's daily activity centre makes an appointment with a LSS administrator and an interpreter so that Amid can get support in taking care of the family's needs.
The LSS administrator announced at the meeting that she did not know what to do in terms of health insurance and maternal care. However, she gives Amid the job of contacting a doctor, who will make an evaluation of his disability, so they can determine the extent of the support that he is eligible for. She leaves a form with Amid that he must complete and submit to the guardianship authority, where he applies for a trustee.
Both of these tasks are totally impossible for Amid to handle on his own. Due to his disability, he is unable to write and he has limited knowledge of the Swedish bureaucracy and Swedish authorities. Amid's wife can't help him, since she has only lived in Sweden for a year.
The supervisor helps Amid find a trustee who can help him. They find a man who works within the social services and who speaks the same language as Amid and his wife. He happily undertakes being a trustee. But when the formal decision is to be made, his manager says that he may not undertake the

assignment. He could be disqualified on some issues concerning the family since he works in the office of the social services. No other trustee can be found and the LSS administrator does not get in touch with them.

In May, the twins are born and the parents are delighted about the children. There is no doubt that Amid and his wife can take responsibility for the twins. The LSS administrator still doesn't attempt to contact the family even after the birth of the twins.

Amid first takes days off from the daily activity centre to the extent that he is entitled, according to the parental leave insurance - ten days per child, and after that he takes vacation.

The family has a good summer together; they have parental leave stipends and Amid has his disability pension. As the summer draws to an end, Amid wants to continue being at home with family. The daily activity centre sees no obstacles to this plan. The LSS administrator has still not been in contact with Amid.

Amid is at home with the family during the autumn and winter and they often come to the daily activity centre to show off the twins.

During this period, Amid's wife becomes pregnant again and a new baby is expected in May. Amid and his supervisor arrange - with some difficulty - an interpreter and set up some meetings with the national insurance authority in order to sort out issues concerning the parental insurance stipend.

In May, the family's third child is born. The family now consists of the parents, one-year-old twins and a newborn baby. Amid wants to do as he did when the twins were born, stay home for ten days and then take vacation. This request is submitted to the LSS administrator who approves it and it is decided that they will be in touch about Amid's family in August.

The LSS administrator does not get in touch with Amid, but his work supervisor helps Amid get in contact with her. At that point she gets very upset that Amid been away from the daily activity centre for a longer period. Her concern is not directed at the family's situation in the small apartment and not at Amid's need for support in his role as father of three young children. Rather, she is only concerned about what her supervisors will say when they find out that Amid not been attending the daily activity centre.

Amid returns to the centre and later in the autumn, a new LSS administrator calls and wants to meet him to hear how things are going, what support he needs and if there is anything the administrator can assist with. The meeting takes place, and it is agreed that Amid needs a trustee, he needs help to manage the everyday finances of the family and the family needs a larger home. The LSS administrator shall check these issues and promises to get back in touch. He does not.

After a period of time, Amid's supervisor from work meets the LSS administrator by chance on the street. He finds out the administrator has been transferred and has a new job within the municipality. He doesn't know anything about what is happening with Amid's case.

The supervisor from work then helps Amid get in touch with the new administrator. The administrator replies that if the issue is a financial one, then Amid should contact the social services and once again Amid is given a form to fill out and submit to the guardian authority in order to be granted a trustee. The administrator says that a larger apartment would be very difficult to arrange since Amid is only entitled to a small apartment under LSS, and since neither parent has a permanent job, they are not desirable as tenants.

Time passes and nothing happens. Amid still can't complete the form, he doesn't know which doctor he should go to for an evaluation and they don't have enough money to pay for food, rent and diapers for three young children.

The supervisor from work must re-enter the picture again, as he is sincerely worried about the family. The social services launch an investigation about the family's finances and conclude that they have lived for several months on almost four thousand crowns below the poverty level as established by the social services norms. The family receives immediate and retroactive welfare benefits. With the help of the supervisor, Amid also succeeds in contacting the staff of a cooperative that works with housing support for persons with disabilities.

They arrange so that Amid can get practical help in managing the family's finances, and they contact the LSS administrator. The administrator then submits a request for a trustee for Amid, who does not now need to go to a doctor for an evaluation.

The Social Services are now working on finding a larger home for the family.

The family can breathe a sigh of relief and the crisis is over.

Discussion

Introduction
In this section, I analyze the results from the fathers' narrative stories. In the analysis phase, my previous knowledge can - to an extent - explain my attempt to understand the fathers' stories in the context they find themselves in, rather, than in their disabilities.

Based on the success factors for fatherhood and parenting presented by the Icelandic thesis, I compare the results of my own study, outline some success factors that emerge in this study and analyze them in relation to the fathers' situation.

Analysis of results
In my study, I have sought knowledge about fathers with intellectual disabilities and the support that society offers them in their role as father. I have used the relative approach to disability, which means that the disability is not a property of the individual, but must be viewed in relation to the individual's social context. (Shakespeare, 1996) Since I am also influenced by the social model, I describe in more detail what I mean by this. Shakespeare discusses what it means for the person's identity if one's environment views disability as the individual's personal attribute of or if it is seen as the result of political factors, environmental factors and/or material factors. When the environment views the disability as a personal defect, the environment also assumes that the person has a sense of sorrow about their disabilities and shortcomings. This approach obviously affects the person's self-image; he adopts a negative self-image and compares himself with "normality". But what is normal? Since very few people with disabilities tell their own story, they have nothing to compare with. Shakespeare (1996) compares this to when people who are gay and lesbian come forward and tell their story, it then becomes more acceptable for the environment and other homosexuals dare to come forward. Shakespeare says that a negative self-image leads to the classic role of a helpless and irresolute person, and that image arouses sympathy and understanding in their surroundings, thereby increasing helplessness. He also refers to Freire's analysis - that if it is repeated sufficiently often that people are incompetent, helpless and unable to take responsibility for their own lives, eventually the people themselves will also believe this. Shakespeare (1996) concludes the article by pointing out the value of people with disabilities telling their own stories and telling about their lives with all the different components of a person's identity - husband, father, colleague and friend.

It's when the individual himself discovers the various components that make his identity, that he can regard his disability in positive way and see that it is part of a greater whole. Shakespeare quotes Giddens's theory that identity is made up of social and personal factors and is a question of the person putting himself in a collective context. (Shakespeare, 1996)

Because the fathers in my study talk about their lives from the perspective of citizen, family member, father as well as a person with intellectual disabilities, I believe that they are seen as the complex individuals they are. It is not the disability that is important, rather it is part of a greater whole.

This social approach also affects the support measures that the fathers require and how this support can be designed. Several of the researchers in my study talk about support that can have negative effects on families and on the parents' parenting skills and support that can have positive effects on parenting skills and strengthen parents. (Booth & Booth, 1994; Sigurjónsdóttir, 2005) Booth & Booth (1994) argue that one must see the family's entire situation and the life they are living in order to understand how the support will make them stronger and more competent in their parental role. Some of the factors they highlight are stressors that are *not* linked to the disability. Poor education and being taught in segregated schools has meant that parents lack basic living skills – a weak financial situation, little support from social networks, problems with family member and isolation are some of them. (Booth & Booth, 1994) They point out further that social workers have a tendency to explain all the difficulties as being caused by the disability and while neglecting to consider the impact that stressors may have on parents' ability. When Booth and Booth highlight examples of factors that do parents more harm than good, they name threatening the parents that their children can be taken away from them, the social workers' insensitivity to the interference they cause in the everyday lives of families, social workers' exclusion of parents from decision-making about how they can resolve situations at home and with the child and, finally, not being able to provide the parents with help and

support in cases where they lose custody of the child. (Booth & Booth, 1994) When I asked one of the fathers in my study if he thought he was a different kind a father because of his intellectual disability, he answered that there would not have been so many people involved in his family. I interpret this to mean that although social workers are considerate, they do intrude in the family's everyday life. The other father in the study was forced to live with his family far below the poverty line for several months because of poor coordination and the incompetence of the administrators. Major stress factors that Booth and Booth (1994) highlight is the parents' lack of knowledge. In order benefit from the support granted by laws and regulations concerning parents and families, one needs to know about them, their contents and how they are applied.

Where do people with intellectual disabilities get this information? What is the civics curriculum at special needs school and how is it followed?

Booth and Booth (1994) also highlight factors that make help strengthen the parents and give them an opportunity to develop their parenting skills. Some of the suggestions given to increase the parents' confidence are necessary and *adequate practical* help, over a longer period of time, practical training that leads to increased self-confidence, a stipend for furniture, household equipment and other items that the parents may lack, that would facilitate everyday life, knowledge of healthy food and how to prepare it and access to emergency services.(Booth & Booth, 1994) I think that the key words in these proposals are *long term* and *practical.* Sweden has a national strategy that gives all parents the right to support in parenting until the child becomes eighteen. (SOU 2008:131) This strategy should provide an adequate base to plan for the long-term practical support to families where parents have an intellectual disability. The practical aspect is crucial in order for a person to be able to utilise their capacity to the fullest - learning to prepare nutritious food, getting help in the laundry room many, many times, going shopping every day since the person has difficulty planning for weekly purchases, are some examples. Kylén's theory of intellectual capacity (1974) provides knowledge about *how* people with intellectual disabilities learn the practical tasks of everyday life. Kylén challenges the person's environment to understand how it can be made comprehensible by adapting information to the person's way of thinking. It is only when the social workers and support staff become sufficiently competent, that the parents can receive appropriate support.

When different kinds of support for parents with intellectual disabilities are discussed, the discussion focuses on how effective they are in improving the parenting skills of the parents. Rarely does the discussion focus on the fact that the parents will have their disability throughout the child's childhood, and that support must be viewed as a long-term and adapted to the needs of the child and the parents. The lack of awareness of the gender perspective in relation to support measures, affects the design and content of the support to families. This affects the fathers in various ways. One effect is that the support staff views the family in a traditional manner, where the mother has responsibility for the children and care of the home. In my study, one of the mothers receives help in the organization of housework when the father is at work, *even though* the father has pointed out on several occasions that he would benefit from the support because he shares the responsibility for home and children.

Success factors for fathers in their roll as fathers

In the Icelandic thesis that addresses fathers with intellectual disabilities, their view of fatherhood and the support from the surrounding community, the researcher identifies the success factors that allow fathers to strengthen and succeed in their roll as fathers. (Sigurjónsdóttir, 2005) In the section on research on fathers with intellectual disabilities in my study, I describe these success factors that I searched for in the results of my own study.

- Support should be home-based, flexible, non-threatening, adapted to the family's needs, carried out in collaboration with parents, and the attitude of the support staff should be characterized by understanding and caring.

Several research reports from different countries with different social contexts show that these success factors are relevant. (Feldman, 1994, Booth & Booth, 1998; Llewelyn, 2002) These reports highlight not only the importance of a home-based and tailored support, but also support that reduces the parents' stress level. (Booth & Booth, 1998) The support provided to the fathers in my study is not flexible and is not always adapted to the needs of the families. Examples of a lack of flexibility: the in-

home support staff only works during the day when the father is at off at work and discussion groups for parents with small children are arranged in the evenings when children need to be put to bed. This may work for other families, but parents with intellectual disabilities are very dependent on their routines to keep chaos at bay. Discussion groups during the day don't work so well either since the parents are at their jobs. In one of the families, the parents took turns going to the meetings and training sessions. Receiving support in an environment where the fathers and children feel secure, and receiving support in concrete situations within the family, is perceived as positive by the fathers. The intellectual disability make it difficult to generalize and to see the causal connection, which may mean that fathers find it difficult to make use of the other fathers' experiences.

Both fathers feel that the support staffs have an understanding and caring attitude. As one of the fathers expresses it - they talk to him like they talk to anyone else, they just don't come in and say do this and this. The second father receives no special support in fathering skills in his home. I interpret this as meaning that it's thought that he doesn't need any support since his wife did not have any disability. Not having to live under the threat of your children being taken from you or that there is not enough money for everyday life, can determine how you perceive the other support measures. If you don't have money for everyday expenses and you don't receive help in solving this problem, or if the people who are helping you take care of your children, are threatening to take them away from you, it's just not possible to be receptive to any other kind of support.

- Support should be given so that parents can maintain their dignity and independence within reasonable limits.

This factor is confirmed by Shakespeare (1996) and his analysis of identity's impact on self-esteem. In my study, both fathers are respected by the surrounding environment, that doesn't see them primarily as people with disabilities. They are respected on the job as skilled and knowledgeable, they have a social network in their families, they have a warm relationship with their partners and they feel they are an important part of the family and that they contribute. Due to these factors, they have been able to develop an identity that allows them to recognize their shortcomings and accept help, if it is given in a respectful manner.

- The relationship between the support person(s) and the family is more important than how the support is adapted to the needs of the family.

This factor is also supported by Booth and Booth (1994), although they formulate it somewhat differently. But I'm not in complete agreement with Sigurjónsdóttir (2005) and Booth and Booth (1994). With my prior understanding, I want to interpret this as an expression of the family's isolation, lack of friends and a lack of knowledge about how relationships should be handled, as described by Edgerton. (1993). This can also be seen as an expression of the power imbalance that exists between families and support staff. Sigurjónsdóttir (2005) Out of a fear of alienating the support person that family is fond of, the family doesn't dare to complain about their needs not being met. Parents with intellectual disabilities are not people who make demands, especially on the professionals who are there to help the parents. One of the fathers in my study didn't dare to point out to the in-home support staff that he did not receive any support, since his wife felt that she was less stressed if she received the support. She hadn't considered that she may be even more relaxed, if both of them received support.

- The attitudes of the support staff towards the family determined what measures were to be taken, prior to making a decision about whether the child should be taken into custody.

Booth, T (2000) discussed legal decisions concerning custody decisions for children, where one or both parents have intellectual disabilities and he finds that they are often discriminated by the courts, and that the arguments given for taking over custody of the child, would not hold in court, if the parents had no intellectual disability. Olsson and Springer (2006) examined how social workers assess parental capacity and found that there is a no homogenous approach from the professionals' side. The same parents can be judged differently by different professionals. And there is no instrument for

assessing parental ability that is adapted to Swedish conditions and to persons with intellectual disabilities, according to Olsson and Springer. (2008)

Since no custody decisions have been relevant in the cases I studied, I can not comment on this factor in terms of my study. However, I can lift two of the cases among the fathers who chose not to participate in the study. They never even got a chance to attempt to be fathers. They are not encouraged to stay in contact with the child when the state takes over custody, rather quite the opposite. They feel that they meet opposition, and are not allowed to meet the children, even though they are legally entitled to see their children. They are prevented from doing this by the foster family and they don't dare to stand up for themselves, because they feel they are at a disadvantage. Booth and Booth (1994) highlight as an important factor the fact that social workers do not see the families' need for support when they lose custody of the children. Both my experience and the results of the study confirm this.

In my study, I can see the additional factors that could be the key success factors.

- The disability does not dominate the identity or self image.

Earlier in this discussion, I have lifted Shakespeare's (1996) ideas on identity and disability. I then used them to motivate viewing disabilities in a social and societal perspective. If you use these ideas to consider disability from the individual's perspective, then I think it is a more defined version of the older Swedish concept of disability awareness. During the eighties, psychologists talked about making people with intellectual disabilities aware of their disability. It could be done in such a way that the person's disability awareness was something positive; they incorporated the disability as a part of their self-image. But there was a possibility that the person could also develop a negative disability awareness, which meant that he/she denied the existence of the intellectual disability or exaggerated the consequences of it, thereby developing a greater degree of helplessness. What makes Shakespeare (1996) ideas more appealing to me is the idea that by telling their own life stories, persons with intellectual disabilities can develop an identity in which the disability does not dominate. The role of others in the surrounding environment will be to listen to the life stories, and through them change their attitudes and preconceptions about people with intellectual disabilities.

The identity of both the fathers in my study may be interesting to dwell on for a moment, since they both came to Sweden from other countries. One was adopted as a small child and the other was six years old when he came with his mother to Sweden, to join his father.

Siers (2003) writes that adopted children wrestle with a special kind of identity problem. He believes that adopted children are both loved and wanted, but also unloved and unwanted. Why do my adoptive parents love me and want me, and why didn't my biological parents want me, are difficult questions to handle. In addition, continues Siers, you must feel gratitude and a debt to the adoptive parents who after all wanted you. Siers takes up a third problem as well, namely the difficulty of linking together a foreign appearance with a Swedish "me" so as to form a coherent and stable identity.

The father in the study who was adopted, describes how he was teased as a child because of his different appearance. He was not bullied because he had intellectual disabilities, he says. This background may explain why the father's self-image is not influenced by the disability.

Neither does the second father, who came to Sweden when he was six years old, have his disability as the focus of his identity. His immediate family has never regarded him as different and he gives no indication that he has been mistreated because he wasn't Swedish-born. To a great extent, he has retained his identity as a man from the family's home country and he lives in that culture with his family.

- To *not* live under the threat of losing custody of the children

Several researchers in my study describe the complex relationship with the support staff and social workers, who both provide help and support in difficult situations and assist parents with the tasks they find difficult, while simultaneously assessing their parenting skills and deciding on a possible loss of custody. (Hindberg, 1993 Llewelyn & McConnell, 2002; Sigurjónsdóttir, 2005)

It is crucial that the social workers who provide the families' support, are not the same people who make decisions about custody. (Sigurjónsdóttir, 2005) If this is the case then the parents, out of fear, won't dare to show their shortcomings and ask for appropriate assistance. I see that the fathers who chose not to participate in this study, did not get the chance to test their parenting. And if the case is so serious that the child is taken into the care of the state even before the mother or father of the child has attempted to be a parent, then support must be provided for the mother and father that addresses their loss of custody and what this means for them as parents.

I return to Booth and Booth (1994) who brought up the factor of the parents' lack of knowledge. Do the expectant fathers with intellectual disabilities know what's to be done in order to confirm paternity, thus becoming an official guardian of the child, together with the child's mother? Who gives them this information and who helps them take the necessary steps?

- The financial situation is secure.

Booth & Booth (1994) state that the stress of not being able to pay their bills or their food costs affect parents' ability negatively. Both of the fathers in the study had a trustee appointed, who assisted them in financial matters and took care of their personal finances. Since people with intellectual disabilities have very little chance of obtaining a paid job, their finances are tight. The disability can be a barrier when it comes to shopping economically and or preparing meals with inexpensive, healthy ingredients. A government inquiry into the activity stipend for young people with disabilities, noted that the economic situation of this group needs to be reviewed and a new and more comprehensive evaluation should be the basis for a proposal on the remuneration structure. (2008:112)

In conclusion, I highlight the single most important factor for success that I can see most clearly in my study:

- That people in the immediate environment show confidence, thus giving the fathers a chance to function in their role as fathers

Both fathers in the study experienced joy and excitement from their surroundings when they found out that they would be fathers. No one doubted that they could take care of the child together with their wives. Both fathers lived in a traditional family model. One was married and one lived together with the mother. According to Shakespeare (1996) Freire argued that if you just keep repeating: lazy, incompetent and ignorant, often enough, then eventually the persons themselves will believe this description. I think the opposite approach works in the same way. By taking note of abilities and good qualities, self-esteem improves and the person becomes better at exercising their parenting skills. Research studies show that child welfare evaluations and custody decisions for children of parents with intellectual disabilities often are based on facts that would not be accepted as the basis for a decision, if the parents did not have an intellectual disability. (Booth & Booth, 1994; Olsson and Springer, 2003; Sigurjónsdóttir, 2005)

In addition, most research on parenting and intellectual disability focuses on the mother and child, and the father is disregarded. And this occurs even though the research about fathers shows that they are the best and most important support for the mother and child. (Booth & Booth, 2002; Sigurjónsdóttir, 2005)

The research that focuses on mother and child, is reflected in the practitioners' focus on mother and child. It's time to see the fathers and fatherhood as a resource.

The influence of the method on conclusions

I have chosen methods for my study that are not usually linked with research about people with intellectual disabilities. Working with narrative tales is quite possible, according to Booth and Booth (1996), even if research subjects have intellectual disabilities. My argument for using a qualitative approach and narrative stories is that no matter which method you use, you need to take into account people's disabilities. If I used a quantitative approach with surveys, I would have reached many more fathers, but the credibility of the responses would not have been any greater. The fathers who took part

in my investigation would not have been able to answer a questionnaire without the help of another person.

Narrative stories provide a good picture of the research person's experiences, but less information about the surrounding social context. I used my prior understanding of intellectual disability and the social contexts that existed during different periods in Swedish society, to put the fathers' life stories in a social context. In this way, I believe that my previous knowledge has helped raise awareness of fathers with intellectual disabilities, but without me influencing their life stories.

The time element has affected my study in two ways.

The first way is the timeframe for my work. The fathers who chose not to participate were the fathers who did not have custody of their children. They would have been able to contribute knowledge about the reasons for the loss of custody of the children, the relationship with the foster family and the role of a father who does not have custody of his child. If I had had more time at my disposal, I would have put more effort into getting these fathers to participate. One of the fathers, who initially declined to participate, got back to me and announced that he was willing join the study, but by then my work was already in its final phase.

The second effect of the time element is more closely linked to the research subjects and their disabilities. The time factor affected the important feedback about the results to the fathers who participated in the study. Getting the narrative stories in written form after the interviews, is not fully satisfactory for people with intellectual disabilities. One or more follow-up meetings after the interviews would have given the fathers a better opportunity to understand my perception of their life stories and also to understand my intentions in terms of how I would use them in my work as a whole. In order to conduct a study with the methods I have chosen, each element must be judged in light of the people's ability to participate with full respect for the consequences that their disability entails. I have not succeeded at every step of the way, but I place a higher value on what I have achieved compared to what would have been achieved if I had chosen other methods. What I value most is that the fathers themselves are heard and that their thoughts and experiences give the world a better understanding of their situation.

The lack of uniform concepts and definitions surrounding intellectual disabilities may have influenced my work. In the international and national research reports, different definitions of intellectual disability form the basis for the results. The differences in legislation, in rights to support and in living conditions in different countries, make it difficult to apply the results from international studies to Swedish conditions and thus make comparisons.

How scientists find their research subjects is a factor that can affect the result. In most research reports that I read in my study, the researcher reached parents through the social services or through the support officer in the municipality. Here, selection is affected because the parents in this group are already receiving support measures of various kinds, or have difficulty in coping with their daily lives, which is a prerequisite for receiving support through the Act on Support and Service for Persons with Certain Functional Impairments. (LSS)

The fathers in my study were in my professional network, which meant that I met fathers with varying needs of support and from different parts of Sweden.

The results of this study can't be generalized to any great degree due to the small number of fathers who participated fully in the study. But given that every father is different, and that research on fathers with intellectual disabilities and their experiences of their paternity is so limited, the study adds important knowledge to the field.

Future use of the results

Despite the limited number of fathers in my study, the results provide insight about fatherhood and intellectual disabilities and the father's important role for the mother and the child/children in the family. Their stories clearly show how the attitudes of persons in their surroundings have a significant impact on their lives as fathers. The life stories of fathers who do not have custody of their children would provide knowledge of how support for these fathers could be designed and how cases of unnecessary loss of custody could be avoided. A number of research reports in my study show that the

underlying factors in state custody cases in families where one or both parents have intellectual disabilities differ from factors in state custody cases in families where there is no intellectual disability.

In Sweden, support for persons with intellectual disability is regulated by the Act on Support and Service for Persons with Certain Functional Impairments (LSS) (Act 1993:387). However there are no guidelines in the act that deal with support for people with intellectual disability who become parents. The support that parents in general receive is regulated by the Social Services Act. Co-ordination between these two laws and co-ordination among local government administrators of the two different laws is not easy to understand for people who are affected by both laws. It hampers their ability to obtain the support they are entitled to.

Lack of knowledge and expertise on gender, on disability and on fatherhood and disabilities within the social services, maternal health services and children's health services affect the fathers' lives.

Proposals for future research, based on the results of my study:

- To focus on the fathers and the fathers' role in families where one or both parents have intellectual disabilities
- To develop approaches and methods of support that includes the father, in families where one or both parents have intellectual disabilities
- To let the fathers themselves be involved in efforts to design support measures
- To increase the competency of professionals (who meet parents with intellectual disabilities) on the topic on intellectual disability and its effects on a person's parenting skills.
- Through increased knowledge about the effects of losing custody of their children, find ways to support parents with intellectual disabilities in their parenting, so that contact between the children and the biological parents can be maintained.

Appendix 1 Data for the interviews – narratives

Background
Childhood, parents, brothers and sisters, growing up

School
Experiences, loneliness, bullying? Special needs school?

Disabilities and Diagnosis
How did the interviewee find out about his disability? What thoughts and emotions did this information arouse – in the interviewee, his surroundings, his friends?

Adulthood
Dreams and reality, meeting his partner, people's views on interviewee as an adult- but in need of assistance? Respect, work life and community.
Roll models among adults and role models in fatherhood? Important people in the social network?

Fatherhood
The experience of being a father, having responsibility for children and partner, earning an income, reactions of others. Contacts with other fathers in the same situation?

Support given to the family
Attitudes of professionals, thoughts and experiences concerning the need for support, what kind of support is needed, how would it look and did the interviewee have any influence?

The division of labour in the family
How do you share the chores, the father's role and the role of the mother? Father's role in the family in terms of the children.

Thoughts on the disability and how it affects fatherhood

The future
Dreams and fears

Appendix 2 The unstructured part of the interviews

I used semi-structured interviews in the narratives due to the special circumstances that I describe in the methodology section, that arise from the fact that my interviewees have an intellectual disability (Car 1).
Some parts of the interviews have been unstructured.

The unstructured parts occur when respondents find it hard to arrange events in time and space, or they make associations between the current conversation and other events or memories.

In my interviews, I have permitted their associations or their perception of chronological order to steer their stories. I have used my ability to sort and arrange in time and space, in order to place the information under the headings set out in the semi-structured interview questions.

An example of this: it can be difficult to start talking about childhood, which is a part of the past. Therefore the interviews began with information about themselves and the current life situation. Because the fathers talk about their work, I can fill in with a question about vocational training, which leads to the subject of school, which leads to the subject of childhood.

When we talked about their thoughts on fatherhood, more information came up about which role models they had and their contacts with other fathers.

The fathers' worry dissipated towards the end of the interview and they were more willing to provide information of a personal nature. This could be in relation to all the topics that we already talked about and had put behind us.

At the conclusions of the interviews, I made a verbal summary of what we had talked about and what the father had told me.
The summary took between forty minutes to an hour, depending on how much his father wanted to add or clarify.

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