

Jönköping University, School of Health and Welfare

Children with mild intellectual disability and
their families – needs for support, service
utilisation and experiences of support

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JÖNKÖPING UNIVERSITY

School of Health and Welfare

DISSERTATION SERIES NO. 67, 2016

DISSERTATION SERIES NO. 77, 2016

JÖNKÖPING 2016

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Publisher: School of Health and Welfare
Print: Ineko AB, Göteborg

ISSN 1654-3602, 1650-1128
ISBN 978-91-85835-28-7

“Every child is a different kind of flower, and all together, they make this world a beautiful garden.”

Author unknown

“One person can make a difference, and everyone should try.”

John F. Kennedy

Abstract

This thesis focuses on service utilisation among children with mild ID and their families, their needs for support and their experiences of support.

Aims

The overall aim of the thesis was to explore and describe service utilisation patterns among families of children with mild ID from a systems perspective.

Methods

A cross-sectional, descriptive and comparative quantitative design was used to describe the extent of service utilisation among 84 children with mild ID and their families (paper I and II). The types and number of services utilised were investigated in relation to the child's age, gender and school setting. Data concerning the services utilised were collected from the organisational records of social services and paediatric habilitation units. In paper III, a descriptive questionnaire design was used to describe the support needs of families of 38 children with mild ID. A confirmatory design was used to examine the relation between family needs for support and (a) parental self-efficacy and (b) parents' control over services. A confirmatory design was also used to examine the relation between parents' experiences of the helpfulness of the support and (a) parental self-efficacy and (b) parents' control over services. In paper IV a longitudinal, comparative and confirmatory design was used to investigate whether social service utilisation patterns differ over time when children with mild ID in self-contained classes are compared with those integrated into mainstream classes (n=405).

Results

In total, 60% of the families utilised paediatric habilitation services, and 40% of the families used disability-related services provided by social services. The most commonly utilised services were services concerned support outside of the home, such as respite care and services to improve children's participation in society. Approximately 25% of the families utilised social problems-related services provided by social services. The most commonly utilised services concerned those to support parents in their parenting roles and financial assistance. In contrast to older children, younger children were more likely to utilise paediatric habilitation services. Older children utilised a higher number of disability-related service types provided by social services. Few differences were found between males and females. The majority of families did

not utilise such services that are provided by social services. It was rare for families to use both disability-related services and those that address social problems during the same year.

Commonly reported family needs concerned information about what services are available for their child, their child's impairment, how to respond to their child's behaviour and how to teach their child skills. Other common needs included access to parent support networks, to find suitable leisure activities for the child, and more alone time for parents. In contrast to families with mothers who did not participate in paid work, families with mothers who were employed expressed a lower requirement for support such as counselling, contact with other parents of children with impairments, more friends and more alone time for parents. Similar results were found for families with mothers with higher levels of education. Parents with higher levels of perceived self-efficacy reported a lower need for information, as did also parents with higher levels of control over services. Parents with higher levels of control over services experienced the support as being more helpful.

Children with mild ID who attended self-contained classes were more likely to utilise paediatric habilitation services than children integrated in mainstream classes. The same pattern was found for utilisation of disability-related services provided by social services. Integrated children who changed school setting to attend self-contained classes were more likely to begin to utilise disability-related services in comparison with those children who continued to be integrated. The former also had a higher likelihood of increasing the number of disability-related service types utilised.

Conclusions

In addition to disability-related problems, families of children with mild ID may also be at a higher risk of experiencing social problems when compared with the general population. Furthermore, very few families utilised both disability-related services and services addressing social problems. This implies that collaboration flaws exist between those professionals concerned with child welfare services and those concerned with disability-related services. A strong predictor of service utilisation was the type of school setting: children attending self-contained classes had a higher rate of service utilisation than those attending mainstream classes. This indicates that service systems outside of school are designed to collaborate with groups of pupils in special classes rather than individual children in mainstream classes. The strong need for information by families indicates that an ecological framework should be used to identify those factors that affect information availability and effectiveness. To increase

parents' perceived level of control over services, HSO professionals need to work in a capacity-building manner with the explicit goal to enhance parental self-efficacy.

Key words

Children, mild intellectual disability, service utilisation, social services, paediatric habilitation, education policy and practice, integration, inclusion, needs assessment, family needs

Original papers

The thesis is based on the following papers, which are referred to by their Roman numerals in the text:

Paper I

Olsson, L.M., Elgmark Andersson, E., Granlund, M., & Huus, K. (2015). Social service utilisation patterns among children with mild intellectual disability – differences between children integrated into mainstream classes and children in self-contained classes. *European Journal of Special Needs Education*, 30(2), 220-236. doi: 10.1080/08856257.2014.986920

Paper II

Olsson, L.M., Elgmark Andersson, E., Granlund, M., & Huus, K. (in press). Habilitation service utilization patterns among children with mild intellectual disability. Accepted for publication in *Journal of Policy & Practice in Intellectual Disabilities*.

Paper III

Huus, K., Olsson, L.M., Elgmark Andersson, E., Granlund, M., & Augustine, L. Perceived needs among parents of children with a mild intellectual disability in Sweden. Submitted.

Paper IV

Olsson, L.M., Bengtsson, S., Granlund, M., Huus, K., Elgmark Andersson, E. & Kåreholt, I. Integration of pupils with mild intellectual disability in mainstream school settings - good or bad for social service utilisation? A longitudinal study among children with mild intellectual disability in Sweden. Submitted.

The articles have been reprinted with the permission of the respective journals/publishers.

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Acknowledgements

I would like to gratefully acknowledge persons and organisations who have helped to support me in completing this thesis: I could not have done so without your help.

Participants in the thesis

The participating families: thank you for sharing your experiences with me and for improving my knowledge about your everyday life.

Family and friends

My mother *Gull Olsson*: you have been my discussion partner throughout this process and you have supported me in prosperity and adversity. You have accepted my frustrations, concerns, exhaustion, eagerness, confidence and happiness with tremendous patience. You have always had faith in me.

My friend *Johan Eek*: like my mother, you have been a discussion partner throughout this process. You have always told me that I will succeed. Thank you for always being available to share both my joy and sorrow.

My twin sister *Marie Olsson* and her husband *Stefan* and nine-year old son *Hugo*: you have always encouraged me in my work, even though you, Hugo, have questioned why I still go to school although I am 48 years old.

My aunt *Inga Hallström*: you have continuously encouraged me. As a retired teacher you have a special academic interest in my thesis.

My sister *Annika Nygren* and her family *Wilhelm*, *Elvira* and *Linnea*: thank you for being my supporters.

My late father *Stig Olsson*: you always was an inspiration with your positive attitude and optimism. You taught me to be persistent and never give up.

My other friends: no one mentioned and no one forgotten, who have put up with my limited social life during my work with the thesis. I will be available again soon!

Contributors of scientific expertise

Main supervisor *Mats Granlund*, Professor in Disability Research: for your invaluable scientific knowledge of impairments and disability, for always being available and for your prompt responses. I especially want to thank you for your extreme prescience in the final phase of this thesis.

Co-supervisor *Elisabeth Elgmark Andersson*, Senior Lecturer in Occupational Therapy: for your expertise in disability and performance of activities in daily life and for your encouragement and emotional support.

Co-supervisor *Karina Huus*, Associate Professor in Nursing Science: for your expertise in children's issues, your encouragement and for helping me in statistical issues.

Co-supervisor *Staffan Bengtsson*, Senior Lecturer in Social Work: for your theoretical contributions, especially concerning social policy and human service organisations.

Co-author *Ingemar Kåreholt*, Associate Professor in Gerontology: for your invaluable support with statistics, your positive and encouraging attitude and your remarkable patience.

The examiners in my final seminar: Professors *Anna Hollander* and *Arne Gerdner*, and PhD student *Jenny Hallgren*. Thank you for your expertise and invaluable comments.

The examiners in my half-time seminar: Professor *Gerd Ahlström*, Senior Lecturer *Staffan Bengtsson* and Lecturer and PhD *Inger Ahlstrand*. Thank you for your expertise and invaluable comments.

Others

The Public Health Agency of Sweden, the Foundation Sävstaholm and the Foundation Sunnerdahl's Disability Fund: thank you for financing the research included in this thesis.

The professionals from social services, paediatric habilitation units and school authorities: for your support in the data collection process.

PhD student colleagues at The Research School of Health and Welfare: for both scientific and emotional support. I will miss you and our wonderful working environment.

The Research School of Health and Welfare, the School of Health and Welfare, Jönköping University, especially *Bengt Fridlund* and *Kajsa Linnarsson*: for your invaluable contributions of structure and clarity.

Gunilla Brushammar: for your expertise and invaluable support with EndNote.

Lisa Andersson: for your expertise and invaluable support with tables and figures.

My colleagues at FoUrum, Municipal Development, Region Jönköping County: for being such kind and positive colleagues.

Stefan Österström: for supporting me to become a PhD student.

Nerrolyn Ramstrand: for your support with language proofreading.

Katrin Nilsson, for your expertise in legal matters.

Last but not least, the dogs *Smulan* and *Bamse* and the cat *Murre*: for giving me positive energy and unconditional love.

Jönköping, Sweden,
February 2016

Lena Olsson

Swedish legal instruments

Legal instruments that are referred to in the thesis.

Act concerning Support and Service for Persons with Certain Functional Impairments. (1993:387)

Act concerning the Ethical Review of Research Involving Humans. (2003:460)

Care of Young Persons (Special Provisions) Act. (1990:52)

Education Act. (2010:800)

Government bill 1992/93:159. About support and services for persons with certain functional impairments

Government bill 1996:97:124. Amendment in the Social Services Act

Government bill 1999/2000:79. From patient to citizen - A national action plan for the disability policy

Health and Medical Services Act. (1982:763)

Information and Secrecy Act. (2009:400)

Patient Act. (2014:821)

Personal Data Act. (1998:204)

Regulation on jurisdiction and certification of teachers and preschool teachers. (2011:326)

Social Insurance Code. (2010:110)

Social Services Act. (2001:453)

SOSFS 2008:20. Regulations: Amendment of the regulations and guidelines (SOSFS 2007:10) concerning coordination of habilitation and rehabilitation services.

Definitions

Child welfare services

Services provided by social services to children to protect them from a negative development.

Children

A person under the age of 18 years.

Compulsory school for pupils with intellectual disability

A special school form for pupils with ID who are judged to not be able to achieve the knowledge requirements for mainstream compulsory school. In Swedish this is defined as “*grundsärskola*”.

Disability

A limitation that occurs for a person with an impairment when he/she performs an activity in an environment that is not accessible.

Human service organisations

Organisations that control access to and provide services.

Impairment

A reduction of intellectual, mental or physical function.

Inclusion

Equality in living conditions and full participation in the society. This definition applies to all life domains, including education.

Integrated

A pupil is *physically* placed in a mainstream class, although enrolled in compulsory school for pupils with intellectual disability.

Mild ID

Refers to an IQ score between 50 and 69 and significant limitations in adaptive skills.

Needs

The means that are required to handle problems, such as different kinds of support and services.

Problem

The difference between a present state and desired state.

School setting

The type of class a child with ID is educated within; a self-contained class or a mainstream class as an integrated pupil.

Self-contained class

A class in which every pupil has ID.

Services

Individually adapted formal interventions provided by social services or healthcare paediatric units.

Social problems-related services

Services provided by social services because of social problems.

Social services

Municipal social authorities.

Support

All kinds of informal and formal support

Introduction

Sweden's disability policy states that children with impairments - on an equal basis with other children - shall be able to fully participate in the life of the community. To achieve this, society must accommodate all citizens and customised services should be provided when needed (Swedish Ministry of Health and Social Affairs, 2011). Children with intellectual disability (ID) face considerable limitations in intellectual and adaptive functioning (American Association on Intellectual and Developmental Disabilities, 2013). They often experience a higher incidence of various disorders compared with children without impairments, which may result in reduced participation and relatively poor health in adulthood (Allerton, Welch, & Emerson, 2011). Furthermore, they are also more likely to experience maltreatment (Lightfoot, Hill, & LaLiberte, 2011) and violence (L. Jones et al., 2012). Thus, it is imperative that they receive sufficient support and services to ensure appropriate development.

Because a child's development occurs via interactions with people and objects in his or her environment, of which the family is the prime setting (Bronfenbrenner, 1979, 1986), stress and coping among family members will inevitably influence the child. Therefore, when supporting a child with ID, the child's family must also be included in the service provision; that is, practices must be family-centred. Family-centred practices stress the importance of a child's family as a constant in the child's life and the parents' role as experts regarding their child's and the family's functions and strengths. Thus, families should be involved in decision-making processes concerning service provision (Rosenbaum, King, Law, King, & Evans, 1998).

While most families of children with ID require some services, these needs typically differ between families. For example, a child with mild ID may require fewer services than a child with more severe ID. The latter frequently involves co-morbidity and lower levels of adaptive functioning (Haveman, van Berkum, Reijnders, & Heller, 1997). This may mean that mild ID is not as easily detected as one that is more severe, and services may therefore not be provided at an early stage. Children with mild ID are usually identified during their early years at school, when their learning difficulties are first noticed (Lindblad, 2013). Parents of children with mild ID report that they are unlikely to apply for services if they perceive their child's

problems as minor (Weiss & Lunskey, 2010). Families of children with ID are more likely to have a lower economic status (Emerson, Shahtahmasebi, Lancaster, & Berridge, 2010), especially families of children with mild ID (Emerson, 2013; Leonard & Wen, 2002; Strømme & Magnus, 2000). Experiences of pronounced financial hardship are related to poorer well-being (M. B. Olsson & Hwang, 2008). Furthermore, mild ID is more likely to be hereditary than more severe ID (David et al., 2013), for which bio-pathological causes are the likely cause (Strømme & Hagberg, 2000). Thus, parents of children with mild ID may themselves face cognitive deficiencies. Parents of children with ID repeatedly report difficulties in acquiring knowledge about available services (Douma, Dekker, & Koot, 2006; Nowak, Broberg, & Starke, 2013). Parents with cognitive deficiencies may find it even more difficult to identify child-related problems, to learn about the welfare service system, how to gain access to services and to advocate for their child. Because both knowledge about service systems and how to gain necessary access influence service utilisation (Andersen, 1995; Andersen & Newman, 1973), there is a risk that these families will not receive the required services. Of course, this also relates to the nature of the service system, that is, the accessibility of the services and the responses of the various professionals to service applicants (Lipsky, 2010).

Parents of children with impairments report being more satisfied with services when they are included in decision-making processes; this in turn strengthens their parental self-efficacy. Such service provision practices improve both parental and child well-being (Dunst & Trivette, 2009; Trivette, Dunst, & Hamby, 2010). The provision of services is also influenced by collaboration among different service providers (Lipsky, 2010). For instance, it has been observed that healthcare specialist services may be organised around special school settings for children with cerebral palsy, implying that children in mainstream school settings may have fewer opportunities to utilise such services (Parkes, Hill, Dolk, & Donnelly, 2004). In Sweden, children with mild ID can either attend self-contained classes specifically for children with ID or be integrated into mainstream classes (Education Act, 2010:800). Whether these two school settings influence service utilisation patterns outside of the school has not been previously investigated. Service utilisation among children with mild ID have been observed to differ in relation to children with more severe ID (Haveman et al., 1997). However, studies concerning children with ID often fail to distinguish between the levels of ID. Thus, there is a need for greater knowledge about children with mild ID (Ellem, O'Connor, Wilson, & Williams, 2013). This thesis concerns service utilisation patterns among families

of children with mild ID. The thesis takes a systems perspective with a special focus on service utilisation in relation to children's school settings; that is, self-contained classes or integration in mainstream classes.

Background

Disability

Disability is a multidimensional concept that has been defined and conceptualised in various ways, including from medical, socio-political, economic and administrative perspectives. In some contexts disability is seen as a dichotomy; that is, a person either has a disability or not, whereas from other perspectives, disability is seen as occurring on a continuum. There is no consensus about the definition of disability. The definition is dependent on the context in which it is used (Altman, 2001). The traditional perspective of disability is the medical model, which infers that a disability is a deficit or some sort of damage within a person's body that complicates the performance of activities. According to this perspective, services should be provided to cure or prevent the "illness" (G. Williams, 2001). As a reaction against the medical model, the social model of disability was developed in the United Kingdom. From this perspective, disability originates from societal structures that oppress persons with impairments, and they become discriminated against and excluded from full participation in society (Oliver, 1996, 2009). In contrast to these models, the social constructionist model of disability claims that disability is an expression of people's understandings and ideas about it. It is a social construct that has been formed within a local context (Gustavsson, 2004) and based on values and attitudes about deviance and normality. Cultural features differ between contexts, as do perceptions of disability (Bhaskar & Danermark, 2006).

The relative definition of disability is an attempt to combine the medical and social model of disability. Two examples of the relative perspective are the view of disability in accordance with terms of critical realism and the World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF) (Gustavsson, 2004). According to the ICF a disability may occur when a person with an impairment is situated in an inaccessible environment that reduces opportunities to perform activities and to participate in society. A person's environment involves both the individual level (e.g., home, school and family) and societal level (e.g., legislation, attitudes and available support and services). Inadequate services may restrict participation, whilst individually adapted services may simplify the performance of activities and promote participation. Appropriate services may eliminate the disability even though the impairment remains (World Health Organization, 2001). The ICF accords with critical realism in the sense that disability is seen as the result of collaborative

mechanisms that exist at diverse levels of reality. A critical realist believes that reality consists of hierarchically stratified levels that are autonomous and mutually interact with each other. Mechanisms at different levels (e.g., biological, psychological, psychosocial and socioeconomic) may collectively produce a phenomenon such as a disability. Therefore, to gain holistic knowledge about disability, it must be studied from different levels, including the individual, micro, meso and macro levels, and to then integrate the results (Bhaskar & Danermark, 2006). Thus, critical realism can be seen to conform to Bronfenbrenner's bioecological model of child development, in which development is seen as a result of reciprocal interactions in various milieus and subsystems (Bronfenbrenner, 1979). The models take into account both the individual characteristics of the persons involved and environmental features in the creation of a phenomenon.

Disability research in Sweden was originally dominated by the medical model of disability but today the relative model of disability, which was introduced in the 1970s, is the foundation for Swedish social disability research (Söder, 2013). Thus, this thesis is based on a systems perspective with the aim to avoid a reductionist understanding of the studied phenomenon. In this thesis, impairment is defined as a reduction of intellectual, mental or physical function (Swedish National Board of Health and Welfare, 2007b) and disability as a limitation that occurs for a person with an impairment when he or she performs an activity in an environment that is not accessible (Swedish National Board of Health and Welfare, 2007a; World Health Organization, 2001)

Intellectual disability

Intellectual disability (ID) includes both intellectual impairment and adaptive functioning deficits in conceptual, social and practical domains. All of the following three criteria must be met before a person is said to have ID:

- A. Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning and learning from experience, confirmed by both clinical assessment and individualised, standardised intelligence testing.
- B. Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of

daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community.

- C. Onset of intellectual and adaptive deficits during the developmental period (American Psychiatric Association, 2013) (p.33).

In the United States, a child's developmental period is defined as lasting until the child reaches 18 years of age (criterion c) (American Association on Intellectual and Developmental Disabilities, 2013). Conceptual (academic) adaptive skills refer to reading, writing, math, numbers and time. Social skills concern interpersonal communication skills, empathy, awareness of others' experiences and feelings, social judgment, gullibility and avoidance of victimization. Practical skills concern activities of daily living, such as the use of money, use of telephone, personal care, occupational skills, transportation and safety (criterion b) (American Association on Intellectual and Developmental Disabilities, 2013; American Psychiatric Association, 2013). To be diagnosed with ID, the deficits must be apparent in at least one of the three domains of adaptive skills and be so limiting that continuous support is required to manage daily life. Persons with ID generally have an IQ about two standard deviations below the mean of the population; that is, an IQ below 65 -75. The score on an IQ test is an estimate of conceptual functioning, but clinical judgments are also needed to assess a person's intellectual and practical ability in real life situations, as IQ test scores are not adequate measures of these features (criterion a) (American Psychiatric Association, 2013). Although ID is considered to be permanent, continuous support and services provided at an early stage may improve adaptive behaviour. ID can be caused by pre-, peri- and postnatal variables and comorbidity is common, including cerebral palsy, epilepsy and mental disorders (American Psychiatric Association, 2013).

Levels of ID

The World Health Organization (2009) categorises ID into four severity levels:

- Mild (IQ 50 -69)
- Moderate (IQ 35 -49)
- Severe (IQ 20 -34)
- Profound (IQ < 20).

For persons with severe and profound ID, IQ has been found to correlate with adaptive behaviour; however, for mild ID, such a correlation has not been validated (Reschly, Myers, & Hartel, 2002). Tiekstra, Hessels, and Minnaert (2009) studied the correlation between learning ability and IQ among adolescents with mild ID attending a special education school in Switzerland. They were unable to find a significant correlation between the variables. Arvidsson and Granlund (submitted) studied the correlation between IQ and everyday functioning among persons with mild ID aged 16 -40 living in Sweden. No correlation was found with IQ, either for self-rated or proxy-rated functioning. The authors concluded that IQ is not a suitable predictor of everyday functioning among persons with mild ID (Arvidsson & Granlund, submitted). On the basis of these findings, there is no ground to assume that children with mild ID in the upper range of the IQ interval for mild ID (IQ 50 -69) automatically have better adaptive functioning and a lower need for services than children with mild ID in the lower range of the interval. According to the American Psychiatric Association (2013), a person with an IQ above 70 may have equally severe adaptive deficits as a person with an IQ below 70. In addition to intellectual capacity, adaptive skills are influenced by other factors including personality features, motivation, education and socialisation (American Psychiatric Association, 2013). Thus, an IQ score cannot be considered an appropriate estimate of service needs among children with mild ID.

Prevalence of mild ID among children

The prevalence of mild ID is higher among males than females (American Psychiatric Association, 2013). The overall prevalence of mild ID among children differs according to the definition used, psychometric measures applied, age group of the children and socioeconomic status of the region in which the children live (Lindblad, 2013). A Swedish study found a prevalence rate of 0.85% among school-aged children (Lindblad, Gillberg, & Fernell, 2011).

Children with ID and their families

As research about children with ID commonly fails to distinguish between the levels of ID, knowledge about those with mild ID is limited (Ellem et al., 2013). Thus, the term *children with ID* is frequently used in this thesis when presenting previous research. *Mild ID* is only used when it is clearly stated that the research concerns this level of ID. Children with ID have, in comparison with children without ID, an increased prevalence of various disorders, such as epilepsy, obesity and psychiatric disorders (e.g., depression, Attention Deficit

Hyperactivity Disorder (ADHD), Autism Spectrum Disorders and conduct disorders) (Allerton et al., 2011). Approximately 30% -50% of children with ID have a mental disorder in addition to ID (Einfeld, Ellis, & Emerson, 2011). These health inequalities may be the basis for relatively poor health in adulthood (Allerton et al., 2011). The health of such children may also be negatively influenced by lower levels of physical activity (Shields, King, Corbett, & Imms, 2014). Furthermore, children with ID are more likely to be victims of violence (L. Jones et al., 2012) and maltreatment (Lightfoot et al., 2011). They have been observed to have a heightened risk for neglect and emotional, sexual and physical abuse (Spencer et al., 2005; Sullivan & Knutson, 2000). Children with mild ID are at risk of being manipulated because of deficits in social judgment and their unawareness of potential risks in social situations. This gullibility makes them vulnerable to victimisation, exploitation and sexual and physical abuse (American Psychiatric Association, 2013). In comparison with children with more severe ID, children with mild ID have been found to have a higher incidence of anxiety, depression and antisocial behaviour (Dekker, Koot, van der Ende, & Verhulst, 2002). A Swedish study observed a high incidence of co-existing developmental-neuropsychiatric problems in the areas of executive function, motor function, social skills and emotional/behavioural problems among children with mild ID. Close to 50% of the children in that study met the criteria for ADHD (Lindblad et al., 2011). In addition, children with ID are more likely to live in families facing low financial resources (Emerson et al., 2010), particularly children with mild ID (Emerson, 2013; Leonard & Wen, 2002; Stromme & Magnus, 2000).

Parents of children with ID spend much time caring for their child and interacting with service providers. They also report reduced opportunities to participate in paid work and recreational activities (M. B. Olsson & Hwang, 2003). Their levels of well-being are lower than those of parents of children without ID (Emerson, Hatton, Llewellyn, Blacher, & Graham, 2006; M. B. Olsson & Hwang, 2006, 2008). If a child with ID also expresses behavioural problems, parental stress is likely to increase. However, parental stress and adaptation differ between families and are influenced by several variables, e.g., parental, family and environmental features, in addition to child-related features (Hassall & Rose, 2005). These variables include parental locus of control (Hassall, Rose, & McDonald, 2005), parents' marital and employment status (Eisenhower & Blacher, 2006), health, the family's financial situation (M. B. Olsson & Hwang, 2008) and whether the child's service needs are met (Bourke-Taylor, Pallant, Law, & Howie, 2012).

Common needs among families of children with impairments concern knowledge about the child's impairment and how to effectively support child development, information about the family's rights and services available and how to advocate for services and ensure appropriate collaboration with professionals (Bailey et al., 2006). Possessing knowledge about child-related domains refers to parenting competence, which is related to parental self-efficacy (T. L. Jones & Prinz, 2005). Knowledge about services and how to collaborate with professionals refers to parents' control over services (Bailey et al., 2006). The utilisation of formal services may decrease the perceived burden of caregiving among parents of children with ID (Haveman et al., 1997). However, parents of children with ID experience difficulties in acquiring knowledge about services and in gaining access to needed services (Nowak et al., 2013). All families in Nordic countries are entitled to generic allowances such as subsidised childcare and children's allowances, and education and healthcare are primarily free of charge. However, to obtain access to individually adapted services, the families of children with impairments often find it challenging to navigate the bureaucratic processes that precede a decision about service provision (Tøssebro & Wendelborg, 2015). Public service provision aims to contribute to human development and improve well-being among citizens (Lipsky, 2010), and is guided by various policies (Lundberg et al., 2008).

Swedish disability policy

The United Nations' (UN) Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006), and the UN Convention on the Rights of the Child (United Nations, 1989) are important benchmarks for Swedish disability policy. The purpose of the CRPD is to *"promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity"* (Article 1). The Swedish government has, in a national action plan, described a number of national goals and detailed measures for the country's disability policy. The plan has a clear focus on human rights, democracy and citizenship, emphasising equality and every citizen's right to equal opportunities (Government bill 1999/2000:79). The objectives of Sweden's disability policy are:

"to ensure a society based on diversity, a society designed in a way that enables people of all ages with disabilities to participate fully in the life of the community, and that ensures equal living conditions for girls and boys, and women and men with disabilities. Barriers to people's participation in society must be torn down. This is a matter of

equality and justice. Women, men, girls and boys with disabilities must be able to lead active everyday lives on equal terms as regards participation and accessibility” (Swedish Government, 2015).

To implement the above disability policy the Swedish government's stresses the application of various general measures including creating a society adapted for diversity. Furthermore, individually adapted services should be provided when needed. Disability policy concerns society as a whole and is therefore a shared responsibility between government agencies, county councils, municipalities and civil society. The Swedish government has highlighted ten policy fields that have a special responsibility in the implementation of the disability policy including social policy, health policy and education policy (Swedish Ministry of Health and Social Affairs, 2011). These policy fields are discussed in this thesis.

Legislation and practice

Policies are often reflected in legislation that states the policy aims and objectives (Brodkin, 2010). In Sweden, legislation is used as an important tool to realise social policy goals (Åström, 2005). Sweden's disability policy is based on a number of legal statutes. Important statutes regarding individually adapted services to persons with impairments include the Social Insurance Code (2010:110), the Social Services Act (2001:453) and the Act concerning Support and Service for Persons with Certain Functional Impairments (1993:387). The Education Act (2010:800) and the Health and Medical Services Act (1982:763) also play crucial roles in the provision of services to persons with impairments. Thus, this thesis concerns such services that are provided by social services, by paediatric habilitation units and school authorities. Legislation in relation to these is described below.

Social services

Social services are municipal social authorities that provide various support and services. Their responsibility is primarily regulated in the Social Services Act (2001:453), shortened SoL in Swedish, and the Act concerning Support and Service for Persons with Certain Functional Impairments (1993:387). The objectives of the SoL are regulated in Chapter 1, Sections 1-3. The first section expresses the general goals and values for social services:

Public social services shall, on a basis of democracy and solidarity, promote people's

- economic and social security,
- equal living conditions, and

- active participation in the life of the community.

With due consideration for the responsibility of the individual for his or her own social situation and that of others, social services shall be aimed at liberating and developing the inherent resources of individuals and groups.

Activities shall be based on respect for people's self-determination and privacy (1:1 SoL).

The aims of the first section shall be used in the interpretation and implementation of the act. The local social authorities have the discretion to apply the services to people's different needs and wishes. In many chapters of the act the regulations are quite detailed. An example of this is Chapter 4, which concerns entitlements to services. The first section in this chapter explains the conditions for individually adapted support:

Persons unable to provide for their needs or to obtain provision for them in any other way are entitled to assistance from the social welfare committee towards their livelihood (livelihood support) and for their living in general.

Through the assistance, the individual shall be assured of reasonable standard of living.

The assistance shall be designed in such a way as to strengthen his or her resources for independent living (4:1 SoL).

The right to support is not without restrictions. In the first instance individuals have to support themselves or obtain such support from their families. It is not until individuals have no further possibilities to live on their own as a result of their unemployment, disability or other valid reason that they may be entitled to support. For instance, an unemployed person must be actively searching for work and has to accept any work that is deemed suitable (Government bill 1996:97:124). Although the SoL applies to all people living in Sweden, it is also focused on several groups for special provisions. These groups are children and young persons, older persons, persons with impairments, substance users, carers and victims of crime (5:1-11 SoL). The social welfare committee has to ensure that persons who, for physical or mental or other reasons encounter difficulties in their everyday lives are able to participate in the life of the community and to live like other members of society (5:7 SoL).

Children and young persons may need services because of impairments, but they may also be in need of care because of social problems. A child is, according to the SoL, any person under

the age of 18 years (1:2 SoL). Children and young persons at risk of a negative development shall be provided the necessary protection and support to meet their needs in close cooperation with their parents (5:1 SoL). According to the Care of Young Persons (Special Provisions) Act (1990:52), shortened LVU in Swedish, such risks include a child's exposure to physical or mental exploitation, abuse, neglect or some other circumstance in the home where there is a substantial risk of detriment to the young person's health or development. Under the LVU a care order can also be made if the health or development of the young person is exposed to a substantial risk of injury through the abuse of addictive substances, criminal activity or some other socially harmful behaviour (Sections 2-3 LVU). The LVU is defined as a complement to the SoL. Support and services provided by social services to children and young persons shall in the first instance be decided in agreement with the child and his or her guardians in accordance with the regulations in SoL (3:5 SoL). If any of the situations specified in the LVU, Sections 2 or 3, are present and it can be assumed that the necessary care cannot be provided to the child with the consent of his or her guardians and, when the young person is 15 years old, by him and herself, care shall be provided under the LVU (Section 1 LVU). Care according to the LVU is a placement outside the child's home (Section 10 LVU). Examples of child welfare services that can be provided under the SoL are help from a personal contact, contact family and family treatment/family pedagogue.

For persons with impairments, including children, services can also be provided under the Act concerning Support and Service for Persons with Certain Functional Impairments (1993:387), shortened LSS in Swedish, which complement the SoL. The aim of the LSS is to provide services to persons with certain extensive and enduring impairments. Persons with ID are, in general, entitled to services pursuant to the LSS, based on their diagnosis as persons with functional impairments as listed in the act (Section 1 LSS). The LSS is designed to ensure good living conditions for the relevant persons, ensuring that they receive the support they need in daily life while also enabling the individual to have a voice in the support and services they receive. The LSS expresses the fundamental principles of Sweden's disability policy; namely, accessibility, influence, self-determination, participation, holism and continuity. The overall aim of the act is to ensure that persons with extensive and enduring impairments are able to fully participate in the life of the community; that is, that they have the opportunity to live like others despite their impairments (Government bill 1992/93:159).

Persons who are eligible for services under the LSS are entitled to up to ten different services. For children there are eight services. These are:

1. advice and other personal support that requires special knowledge about problems and conditions governing the life of a person with extensive and enduring impairments,
2. personal assistant or financial support for reasonable costs for such help,
3. companion service,
4. help from a personal contact,
5. relief service in the home,
6. short stay away from the home,
7. short period of supervision for schoolchildren over the age of 12 outside their own home in conjunction with the school day and during the holidays,
8. arrangements for living in a family home or in residential arrangements with special service for children and young people who need to live away from their parental home (Section 9 LSS).

By specifying the services that can be granted under this act the legislator aimed to guarantee that persons who are eligible for services will receive these particular services (Government bill 1992/93:159).

The key aims of the LSS for children and adults with impairments are *good living conditions* and *full participation* in the life of the community (Sections 5 and 7 LSS). Services must be provided if an applicant require the service in his or her daily life and if this need is *not satisfied* in some other way (Section 7 LSS). In contrast, the conditions for services under the SoL are based on the fact that the individual's needs *cannot* be met in some other way. The SoL can only guarantee a *reasonable standard of living* and *active participation* in the life of the community (4:1 SoL). Therefore, the LSS is considered to be more favourable for applicants with certain functional impairments. An application should consequently be assessed under the LSS and not the SoL assuming that the application concerns services that can be provided under the LSS (Government bill 1992/93:159). One advantage of the SoL in contrast to the LSS is that services pursuant to the SoL are not regulated in detail and are therefore more adaptable to individual problems and needs (Åström, 2005).

As mentioned above, personal assistance or financial support for reasonable costs for such help can be provided under the LSS (Section 9 LSS). However, if a person's need for personal

assistance is high, decisions about and the provision of financial support for costs for personal assistance are made by the Swedish Social Insurance Agency under the Social Insurance Code (2010:110), shortened SFB in Swedish. When such a decision is made, social services in the area where the person lives is always responsible for meeting some of the cost of assistance. Social services shall also make decisions if an individual has temporary needs of increased personal assistance, and to provide an assistant or reimburse costs when the usual carer is on sick leave (Swedish Government Official Reports, 2008). Therefore, also decisions concerning personal assistance made by the Swedish Social Insurance Agency are included in this thesis. All other allowances and benefits that can be provided to persons with impairments under the SFB are excluded.

In this thesis, services granted under the SoL, the LSS or the SFB to children with mild ID because of disability are defined as disability-related services. Services provided by social services under the SoL or the LVU to children with mild ID because of social problems are defined as child welfare services. These services are means-tested; that is, entitlements to services under the acts are based on an individual assessment of the child's needs (4:1 SoL; Section 7 LSS, 51:2-6 SFB). Decisions denying services can be appealed at county administrative courts (16:3 SoL; Section 27 LSS; 113:10 SFB).

Paediatric habilitation units

According to the Health and Medical Services Act (1982:763), shortened HSL in Swedish, the county council shall offer citizens habilitation and rehabilitation services (Section 3b HSL). Specialised paediatric habilitation units within county councils provide medical, social, psychological and educational services to children with severe impairments (e.g., ID) aged 0-20 years and their families. The services include diagnostics, treatment, counselling and assessments and are provided by teams consisting of occupational therapists, physiotherapists, special educators, dietitians, counsellors, physicians, psychologists and speech therapists. A child must first be referred to a paediatric habilitation unit from a healthcare unit (e.g., school health clinics) to receive services (Bjerre et al., 2004; Thylefors, Price, Persson, & von Wendt, 2000). Habilitation services aim to maintain or develop the functional ability as far as possible among persons with an early acquired or congenital impairment. In Sweden the terms habilitation and rehabilitation are not synonymous. Rehabilitation services are provided to persons with an acquired impairment as a mean to maintain or regain the best possible functional ability (SOSFS 2008:20).

Compulsory school education

According to the Education Act (2010:800), shortened SkoL in Swedish, Swedish municipalities are responsible for organising compulsory school (2:2 SkoL). In Sweden, the majority of children with impairments attend mainstream school settings with the exception of children with ID (Michailakis & Reich, 2009). Children with ID who attend compulsory school can either attend mainstream school or be enrolled in compulsory school for pupils with ID. A decision about the latter is made by the municipality in which a child lives and is preceded by a pedagogical, medical, psychological and social assessment. The child's guardians shall be consulted during the assessment process and their consent is required regarding such an enrollment (7:5 SkoL).

Children with mild ID are often initially educated in mainstream school settings. They are typically identified as having ID during their early years at school when their learning difficulties are first noticed (Lindblad, 2013). Children with mild ID are educated in accordance with a reading-based curriculum, while those with more severe ID follow a life-skills based curriculum (Roll-Pettersson, 2003; Swedish National Agency for Education, 2011). When children are enrolled in compulsory school for pupils with ID, they can either be integrated into a mainstream class or join a self-contained class, in which all pupils have ID (7:9 SkoL). In this thesis, these two types of classes are defined as types of school settings. Approximately 80% of all pupils with ID in Sweden are educated in self-contained classes, but the numbers vary greatly between municipalities because of organisational variations (Swedish Schools Inspectorate, 2011). A child's guardians can request an integrated school setting, but they have no legal right to claim such a placement (Swedish National Agency for Education, 2014a). Teachers in self-contained classes must have a teaching certificate in special education specialising in ID. This is not required for the teachers of mainstream classes, even though they may also educate children with ID (Regulation on jurisdiction and certification of teachers and preschool teachers, 2011:326).

Children with impairments with special educational needs are entitled to support to achieve the required knowledge requirements (3:3 SkoL). In addition to teachers, support can be provided by student assistants (Swedish National Agency for Education, 2014a), special teachers and special educational needs coordinators. Special educational needs coordinators focus on eliminating any obstacles in the environment that may limit children's learning (Isaksson & Lindqvist, 2015). A student health team, which includes a nurse, physician, psychologist and social counsellor, provide services to promote health and facilitate learning

for all pupils (2:25 SkoL). The team may refer pupils with impairments to special healthcare units such as paediatric habilitation units (Swedish National Board of Health and Welfare & Swedish National Agency for Education, 2014).

The best interests of the child

Social services, paediatric habilitation units and compulsory school authorities are all obliged to act in the best interests of the child. Regarding social services, this is regulated in the SoL and the LSS and for educational authorities in the SkoL. Concerning healthcare authorities, this is regulated in the Patient Act (2014:821), shortened PL in Swedish. This act aims to strengthen and clarify the position of the patient as well as to promote the patient's privacy, self-determination and participation within the healthcare industry (1:1 PL). The statutes stress that in actions concerning children, the best interests of the child shall be given special consideration (1:2 SoL; Section 6a LSS; 1:8 PL). For educational authorities this is given a greater emphasis, stating for all actions concerning children, the best interests of the child shall be the first consideration (1:10 SkoL).

Theoretical framework and previous research

The theoretical framework used in this thesis is based on Bronfenbrenner's bioecological model regarding child development (Bronfenbrenner, 1979). This model is applicable to both social services and healthcare authorities when providing services to children (Baldwin & Walker, 2005). To gain a further understanding of service utilisation in particular, the following frameworks are also used: Lipsky's theoretical framework of street-level bureaucracy (Lipsky, 2010), Hasenfeld's theoretical framework of human service organisations (Hasenfeld, 2010a) and Andersen's Behavioural Model of Health Services Use (Andersen, 1995). The latter model includes societal, community, organisational, family and personal determinants in relation to service utilisation, and is considered a system-based model. Although Andersen's model has been extensively used in research on healthcare service utilisation (Babitsch, Gohl, & von Lengerke, 2012), it has also been applied in other contexts, including social services (Aroian, Wu, & Tran, 2005) and special education services (Zima, Bussing, Yang, & Belin, 2000). Lipsky's theoretical framework has been widely used in Swedish research concerning social service organisation (Uhnöo, 2012). A short description of these frameworks and models is presented below, and a more detailed description will follow under Bronfenbrenner's structured systems levels: macro, exo, meso and micro levels. Previous research in relation to the research questions in this thesis will also be presented under each level.

Bronfenbrenner's bioecological model

According to Bronfenbrenner's bioecological model a child's development occurs through the child's reciprocal interaction with the surrounding environment. The development takes place on different levels and in different milieus in a system consisting of several subsystems, which continuously interact and affect each other. In the microsystem, for instance at school or at home, the child interacts directly with persons and objects. The mutual interactions between different microsystems such as school and home are defined as mesosystems (Bronfenbrenner, 1979). Mesosystems may also include interactions between a family and healthcare authorities (Bronfenbrenner, 1986). Systems that interact with microsystems and affect a child even though the child is not an active agent in the system are called exosystems (Bronfenbrenner, 1979). Such systems include parents' employment, parents' workplaces and parent support networks (Bronfenbrenner, 1986). A child is also affected by societal structures and

ideologies, for example legislation and regulations, which are factors that fall under the macrosystem. Thus, a child's development depends on a variety of interconnected variables (Bronfenbrenner, 1979).

A child intermingles with and internalises other people, symbols and objects in external settings and reacts and responds to them, thereby influencing the external settings, such as parents and caregivers, who in turn respond to the child. Such transactional formational processes become more and more complex. If these processes occur regularly and over time a child's functioning will develop effectively. Such processes are called proximal processes and may occur in several ways, for instance in activities involving child and parent, child and child, but also child and object, e.g., during play or reading. Thus, environmental circumstances influence child development outcome, both in the sense of available resources and how stable these are over time (Bronfenbrenner & Ceci, 1994). Using an ecological framework is fundamental for professionals to catch complexity and to be able to assess and judge what support and services a child need to develop appropriately. Thus, factors such as child and family characteristics and resources, neighbourhood and community resources, social networks, cultural aspects and legislation have to be taken into account (Baldwin & Walker, 2005).

Bronfenbrenner's bioecological model is described in Figure 1 below.

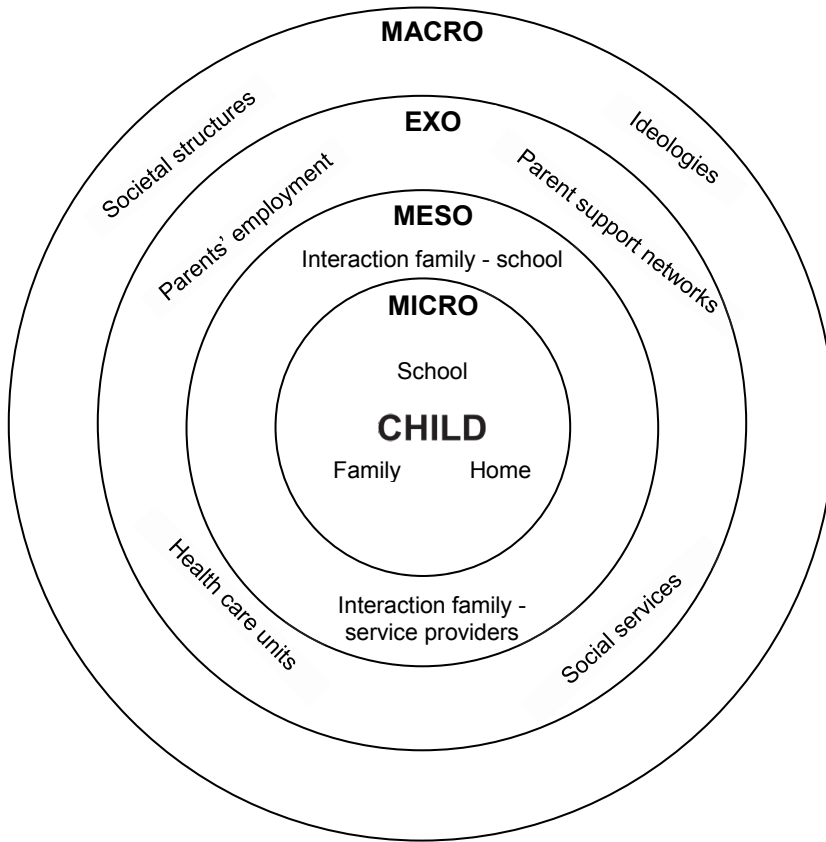


Figure 1. Bronfenbrenner's bioecological model, adapted from Bronfenbrenner (1979, 1986, 1999)

Hasenfeld's theoretical framework of human service organisations and Lipsky's theoretical framework of street-level bureaucracy

Human service organisations (HSOs) such as social services, healthcare authorities and educational authorities, are organisations that control access to and provide services and support. HSOs aim to improve people's lives and play a central role in their lives. Thus, people are often very dependent on HSOs (Hasenfeld, 2010a). In contrast to the HSO definition, Lipsky (2010) uses the term street-level bureaucracies when describing public service providers that are mandated to decide the distribution and provision of resources. Professionals in these authorities, such as social workers, are called street-level bureaucrats and have a considerable discretion when making decisions about eligibility to resources. Street-level bureaucrats are responsible for implementing legislation and policies and aim to contribute to development and autonomy among citizens. Making decisions about eligibility

to services is a complicated process in which street-level bureaucrats have to take several factors into account, including the individual needs of clients, the collective needs of clients, organisational needs, conflicting role responsibilities and conflicting goals (Lipsky, 2010).

Andersen's Behavioural Model of Health Services Use

According to Andersen's Behavioural Model of Health Services Use, a person's utilisation of healthcare services is a function of his or her need for care, predisposition to use healthcare services and factors that enable or hinder service utilisation. The need for care includes perceived and evaluated health and functional status. Perceived health is the experiences and judgements of one's own health and symptoms, and it will influence whether service application and utilisation will occur. Evaluated health relates to the professionals' evaluations of a person's health status and the need for healthcare services. Examples of predisposing characteristics are gender, age, education, occupation and knowledge about healthcare services. Enabling resources refer to knowledge about how to gain access to and utilise healthcare services, family income, extent of social relationships and whether healthcare services are available. In addition, healthcare service utilisation is influenced by societal determinants, such as technology and norms. Technology applies to techniques used in healthcare to reach desired outcomes, whilst norms may concern legislation and prevailing societal values regarding healthcare. Furthermore, the organisation of the healthcare service system, national health policies, resources and accessibility (e.g., how citizens gain access to healthcare services and conditions that qualify for services or not) may act as barriers to healthcare services (Andersen, 1995; Andersen & Newman, 1973).

Andersen's Behavioural Model of Health Services Use is described in Figure 2 below.

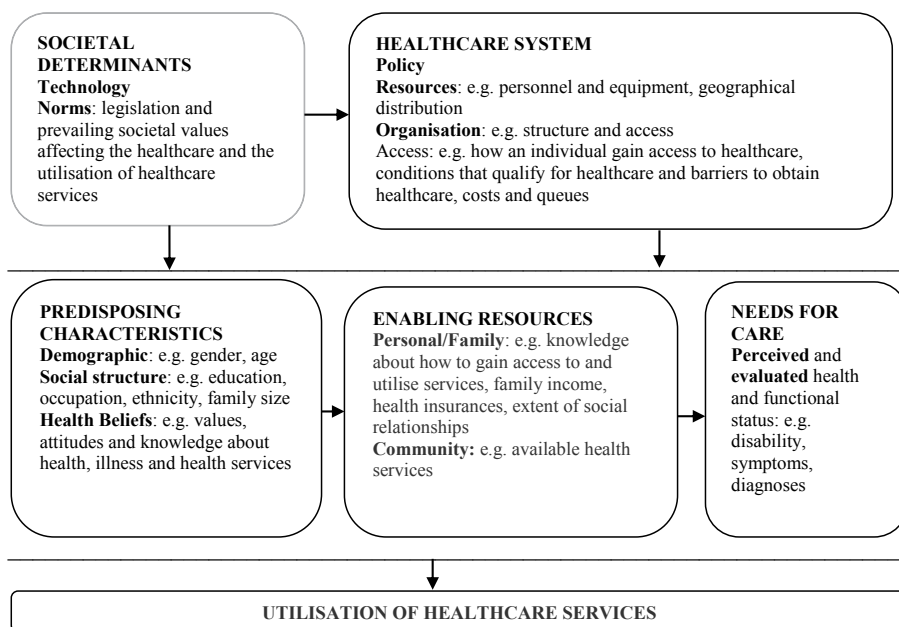


Figure 2. The Behavioural Model of Health Services Use, adapted from Andersen (1995) and Andersen and Newman (1973)

Integration of theoretical frameworks and models structured according to Bronfenbrenner's bioecological model: macro, exo, meso and micro levels

Macrosystem

Child development is influenced by societal structures and ideologies (Bronfenbrenner, 1979) including prevailing policies. Sweden's disability policy seeks to ensure that children with impairments are able to lead active everyday lives and fully participate in the life of the community (Swedish Government, 2015). Political ambitions are reflected in the legislative texts that signal the overall aims and objectives (Brodin, 2010). As described above, several acts in Sweden aim to ensure that children are socially and financially secured, with good health and are well educated so that they can actively participate in society. Concerning education, international policy such as that declared in the Salamanca Statement (United Nations Educational Scientific and Cultural Organization, 1994) and the CRPD (United Nations, 2006), favour that children with impairments with special educational needs should be educated in mainstream school settings. Sweden has signed both these documents. National policy emphasises equity and inclusion, which is expressed in the concept "a school for all" (Berhanu, 2011). The ideological reasoning behind integrating children with ID into mainstream classes is to enable inclusion in school and society (Michailakis & Reich, 2009),

Social policies guide the provision of services (Lundberg et al., 2008) and together with legislation inevitably influence service utilisation (Andersen & Newman, 1973). However, although legislation expresses the overall objectives and may include eligibility standards and other benchmarks regarding the allocation of services, it is often indeterminate in nature and does not explicitly explain if and how services should be provided (Brodkin, 2010). Furthermore, legislation cannot predict nor include all possible situations and circumstances affecting individuals (Sosin, 2010). Thus, to be practically applicable legislation has to be interpreted, operationalised and implemented by HSO professionals (Brodkin, 2010).

Exosystem

HSOs are part of the community in which children live. According to Bronfenbrenner, the community is one of the most important exosystems that influences child development (Bronfenbrenner, 1986). How service systems are organised in the community, the accessibility of services and available resources all influence service utilisation (Andersen, 1995; Andersen & Newman, 1973). Although the actual need for services cannot be truly known, the demand for services is associated with available services and to what extent citizens are informed about these services. When the available services increase, the demand for such services escalates, providing that citizens are informed about the services and identify themselves as potential recipients. Therefore, the reported demand for services seems to have a greater association with the availability of services than with changes in needs. Thus, the better an organisation is about advertising their available services, the greater the demand for their services (Lipsky, 2010).

When a child with mild ID and his or her family request services, they will come into contact with HSO professionals. Those professionals then gather information about the child's situation and needs, and makes decisions about suitable services. Decisions about eligibility to services are made by HSO professionals such as social workers, physicians and teachers. They possess significant discretion when they make decisions (Lipsky, 2010). Discretion means the making of decisions in individual cases based on general knowledge and professional expertise in accordance with legislation, assessment standards, professional ethics and norms and the delegation of authority (Dellgran, 2015). Service utilisation will be influenced by HSO professionals' evaluations of service applicants' symptoms, impairments and functional capacity (Andersen, 1995; Andersen & Newman, 1973). The work of HSO professionals is guided by practices that rationalise work and consist of belief systems and

moral assumptions about clients and how to respond to them. Such practices represent are shared among co-workers and have been morally legitimised by society (Hasenfeld, 2010a, 2010c). The practices guide the types of services offered, how they are provided and decision procedures, and thus influence service utilisation and outcomes (Hemmelmarn, Glisson, & James, 2010). Furthermore, the services available will inevitably influence the assessments of needs and services provided (Hasenfeld, 2010c).

As a way to gain control over their work HSO professionals use several working strategies, including the categorisation of service applicants. Categorisation means that professionals, based on factors such as the applicant's symptoms and capacities and the organisational context, classify the applicant into existing categories within the organisation. Previously defined categories guide professionals in what to look for, and thereby determine what information they can receive about the applicant and what services that will be appropriate (Lipsky, 2010). For instance, child welfare unit professionals use categories such as neglect, physical or sexual abuse or lack of parenting skills (Hasenfeld, 2010c), whilst healthcare professionals use diagnostic manuals to establish diagnoses (Hasenfeld, 2010a). Categorisation means that attention will only be paid to those characteristics that fit within the category in which the service applicant is placed. Those features that fall outside will be ignored. Categorisation of applicants contradicts their expectations to receive holistically based responses to their needs and demands, as do specialisation. Specialists possess certain training, skills, knowledge and methodologies, which are applied when they observe and assess service applicants. Because the repertoire of possible observations and assessments is limited to the specialised field, it becomes difficult for HSO professionals to respond to applicants with complex needs. Both categorisation and specialisation can lead to fragmented services (Lipsky, 2010).

The fragmentation of services can also result from collaboration problems among different HSOs. Generally, each organisation is only concerned about particular aspects of the service applicant be it health, education or social problems, and thus fails to take a holistic approach (Lipsky, 2010). The HSOs' responses are based on practices used and those differ between healthcare authorities, educational authorities and social services (Grape, 2015). Circumstances that may influence the outcome of the services provided but fall outside of the practices are ignored (Hasenfeld, 2010a). Parents of children with impairments have reported that they have to contact several HSOs to get their needs met. Each HSO has their own

mission, legislation, regulations and processes to follow, which parents find confusing. Parents typically feel like they are being passed between various HSOs (Tøssebro & Wendelborg, 2015). The consequences of collaboration difficulties is that the parents themselves have to provide duplicate information to HSOs and then attempt to coordinate services (Egilson, 2011). Grape (2015) argues that collaboration problems will entail that the services received will likely be determined based on the first HSO an applicant approaches instead of the applicant's complex needs (Grape, 2015). The relevant acts in Sweden state that social services and healthcare authorities shall collaborate when a person is in need of services from both HSOs (2:7 SoL; Section 3f HSL). However, because the welfare system operates to only address one problem at a time, HSO professionals face difficulties when trying to respond to a person with complex needs (Grape, 2015). It is well known that collaboration is often problematic between those social service professionals who deal with child welfare services and those who handle support to children because of disability (Staffan Bengtsson, 2007; Boklund Palm, 1995; Svensson, 2009).

Social service professionals are obliged to follow mandatory legislation and regulations and decisions shall also be in accordance with guiding preparatory work and case law (Erlandsson, 2014). They are obliged to identify those who might need services under the LSS and inform them about the services available. However, outreach work and information dissemination are usually not deemed a priority among professionals. Furthermore, the provided information is not always easily understandable; that is, it has not been adapted to meet the needs of individuals (H. Bengtsson, 2005). The provision of services under the LSS is highly influenced by local characteristics. Even though this act shall guarantee that service provision is the same throughout Sweden, there are significant local variations between municipalities. These variances cannot be explained by differences in needs, but rather by local characteristics such as culture, population density, land area, local government type, population characteristics and whether residential institutions for persons with ID have earlier been situated in the municipality. This implies discrepancies between local level decisions and the aims of the legislation (Lewin, Westin, & Lewin, 2008). Furthermore, decisions about the services provided under the LSS have been found to be guided by local interpretations of the legislation and other legal sources. LSS case workers do use legal instruments, but overall they have insufficient knowledge about legal concepts such as preparatory work and rule of law, and how to use them. Instead they place greater trust in local guidelines. When such guidelines are used in a manner that is in contrast with legislation, they function as barriers to

services (Erlandsson, 2014). Municipal variations are also common in decisions on support for children in need of protection, indicating that local cultures influence such decisions (Forkby, Höjer, & Liljegren, 2015). The significant variations between municipalities in child welfare services and disability-related services indicate that the rule of law is not followed. It also shows that social service professionals need to improve their juridical competence and their ability to use legal instruments (Swedish Parliament, 2009). Decisions about eligibility to services that are not needs driven may prevent needs from being met.

Educational authorities are required to base their actions on children's needs. However, according to the Swedish National Agency for Education, municipal decisions to integrate pupils with mild ID into mainstream compulsory school settings are primarily for reasons other than children's educational needs. Such reasons may include parents' requests, geographical proximity or children's wishes to attend the same school as their friends. Cultural reasons and a lack of information may also make it difficult for guardians to accept that their child with ID need to be enrolled in compulsory school for pupils with ID (Swedish National Agency for Education, 2014a). Further factors that may influence municipalities' decision to integrate such children include practical reasons, municipal traditions and education professionals' perceptions and interpretation of the concept of integration. Integration is most common in sparsely populated and rural municipalities because of practical reasons. It may occur when the number of pupils with ID is too small to form a self-contained class or as a mean to avoid pupils traveling long distances to attend schools with self-contained classes (Swedish National Agency for Education, 2002). Education professionals report that self-contained classes present a number of benefits, including homogenous group structure and specialised teachers, whilst integration in mainstream settings may favour learning opportunities for children with ID, provided that there are sufficient resources to use in that setting. A mainstream setting may also promote relationships between children with ID and children without impairments (Westling Allodi, 2007a). Although integration of pupils with ID aim to enable inclusion (Michailakis & Reich, 2009) inclusion is not clearly defined or established as a definite goal in national educational policy documents. This means that interpretations vary extensively at the municipal level (Göransson, Nilholm, & Karlsson, 2011). In fact, whether children with ID are integrated varies between 0% -100 % between municipalities (Swedish National Agency for Education, 2014b). Teaching arrangements for integrated children also differ as does the time children spend with their classmates and student assistants (Swedish National Agency for Education, 2002).

In addition to community resources, other exosystems such as parents' employment and social networks can influence child development as these influence the processes that occur in the family, e.g., child-rearing practices (Bronfenbrenner, 1986). For families with children with impairments, the effectiveness of their support networks will influence how well they cope (Whiting, 2014). Parents who have opportunities to discuss child health concerns with social support networks are more likely to utilise services for their child (Harrison, McKay, & Bannon Jr, 2004). Swedish parents of children with impairments perceive informal support networks, such as other parents of children with impairments, as highly valuable. Within these networks parents have the opportunity to exchange information with people with similar experiences (Carlhed, Björck-Åkesson, & Granlund, 2003).

Mesosystem

The relationship between a child and his or her family as service users and HSO professionals represents a mesosystem. This relationship influences child development (Bronfenbrenner, 1986) and is the basis for the implementation of social policies and the provision of services (Hasenfeld, 2010a, 2010c). Service applicants are often in a vulnerable situation (e.g., poor health) when they apply for services and hold a weaker position compared with the HSO professionals who make the decisions regarding the provision of services. Therefore, service applicants are likely to experience some kind of anxiety when interacting with HSOs. They are usually non-voluntarily, especially when they have no other option than to apply for the required services. Thus, because they often feel compelled to seek support and are dependent on HSOs, they can feel powerless (Lipsky, 2010). Furthermore, to receive services, applicants are often expected to reveal highly sensitive and private information about themselves. Although adherence to due process is intended to protect citizens' rights, dependence on professionals to ensure the receipt of required services and that their needs are met means that applicants are often vulnerable to the abuse of power (Hasenfeld, 2010a).

How service applicants are treated is dependent on the HSO professional's perspectives of them. When they are treated as objects, their abilities are ignored and they are treated in bureaucratic manner without mutual trust. In contrast, when HSO professionals respond to applicants as subjects, the professionals enable them to be actively involved in the decisions about service provision and work is carried out in a cooperative manner (Hasenfeld, 2010b). The promotion of a service applicant's active participation, alongside genuine listening and mutual respect, will create trust (Hasenfeld, 2010a). For the provision of services to be

effective for children and their families, it has to be available, continuous and responsive. Responsiveness means that services are adapted to address those concerns that are most important to the family (Hemmelgarn et al., 2010). However, parents of children with impairments living in Sweden experience that their problems, needs or requests are sometimes met with inadequate responses, and that they receive insufficient information about services (Carlhed et al., 2003; Nowak et al., 2013). Reports by parents of children with ID reveal that parents may experience resistance from school administrators when they ask that their child be integrated into a mainstream class. Education professionals, however, have reported that they sometimes have to refuse parents' requests for an integrated setting to protect the best interests of the child. This indicates that parents and education professionals may have different views regarding a child's need for support (Westling Allodi, 2007a). Furthermore, reports from parents of children with ID reveal that they are not always sufficiently informed about school setting and are not appropriately involved in the placement decision (Roll-Pettersson, 2001).

Parents of children with impairments request being actively involved in decisions about service provision and that services are individually adapted (Bamm & Rosenbaum, 2008). They seek respectful treatment, competence-building practices, sufficient information about services and coordinated services and flexible responses (Carlhed et al., 2003; Egilson, 2011; Granat, Lagander, & Börjesson, 2002). Parents require services that are flexible and can fit in with their everyday life (Carlhed et al., 2003). When HSO professionals use capacity-building, help-giving practices, i.e. practices that encourage parents to be actively involved in identifying both their concerns, how to meet these and promote the family's existing strengths, the family's ability to get access to services and parental self-efficacy will be strengthened. This will in turn enhance parents' well-being and the interactions between the child and the parents. Ultimately, the child's psychological health and development will be improved (Dunst & Trivette, 2009; Trivette et al., 2010). Parents who perceive high self-efficacy report higher levels of well-being and a lower need for support (Trivette et al., 2010). In contrast, parents who perceive low levels of self-efficacy may be less satisfied in their parenting role (Johnston & Mash, 1989). Parents are more satisfied with services and perceive them to be more helpful if they are provided in a participatory, capacity-building manner. Such practices increase parents' perceived control over the services and their lives. This then reduces parental stress and strengthens parental confidence and competence, and, in turn child development

(Dempsey & Keen, 2008; Dunst, Trivette, & Hamby, 2007). Parents also perceive that such practices increase their opportunities to receive services (Dempsey & Keen, 2008).

Micro system

The prime setting in which child development occurs is the family (Bronfenbrenner, 1986). Service utilisation is inevitably influenced by family characteristics such as knowledge about how to gain access to services and knowledge about health and healthcare services. Whether parents will apply for services for their child is dependent on their perceptions of their child's symptoms, functional status, health, need for care and the child's age and gender. Family income and parents' education are two other family characteristics that influence service utilisation (Andersen, 1995; Andersen & Newman, 1973). Parents who have a restricted educational background may be in need of external resources to acquire the necessary skills to support their child's development (Bronfenbrenner & Ceci, 1994). The family environment and a child's parents greatly influence child development and social competence (Bailey et al., 2006). Parents of children with impairments have expressed the need for practical advice about how to facilitate everyday life and proactive planning to prevent potential problems (Egilson, 2015). Parents repeatedly report the need for information about available services, both in Nordic countries (Nowak et al., 2013; Roll-Pettersson, 2003; Tøssebro & Wendelborg, 2015) and elsewhere (Hodgetts, Zwaigenbaum, & Nicholas, 2014; Sahay et al., 2013). Insufficient knowledge regarding where to request services may prevent parents of children with ID from applying for services (Douma et al., 2006; Weiss & Lunskey, 2010). Furthermore, parents report that when applying for services, they find many are not readily accessible (Nowak et al., 2013; Tøssebro & Wendelborg, 2015).

A lack of information may stem from the fact that parents experience anxiety in meetings with HSO professionals, and therefore information may have to be provided in a non-traditional manner to meet the parents' needs (Steen Bengtsson, 2003). Insufficient knowledge about available services and the disuse of services among families of children with ID have been shown to be related to lower levels of empowerment among the families. The latter was related to lower levels of self-efficacy among caregivers (Wakimizu, Fujioka, Yoneyama, Iejima, & Miyamoto, 2011). Parental self-efficacy and control over services are associated with parental perceptions of family needs (Trivette et al., 2010). Parents who perceive that they have control over services have an increased level of psychological health, which also applies to their child (Dunst & Trivette, 2009). Parents who perceive higher levels of self-efficacy experience less

stress (Wakimizu et al., 2011) and report a lower level of need for additional services (Trivette et al., 2010). The likelihood of utilising services increases when the parents of children with impairments have a positive opinion of the HSOs (Harrison et al., 2004), while negative experiences of formal services may decrease utilisation (Weiss & Lunskey, 2010).

Parents have expressed the need for information about their child's impairment, how to handle the child's behaviour and how to teach the child skills (Hodgetts et al., 2014; Roll-Pettersson, 2003; Sahay et al., 2013). Parents who are aware of their child's impairments, when services are needed and how to gain access to services are more likely to apply for support (Benedict, 2006). In contrast, parents who perceive their child's problems as minor or temporary report that they are unlikely to apply for services (Douma et al., 2006; Weiss & Lunskey, 2010). Children with more severe limitations are more likely to utilise healthcare services than children with milder restrictions, although this may vary depending on the type of services utilised (Benedict, 2006; Weller, Minkovitz, & Anderson, 2003). Among children with ID those with mild ID have been found to be less likely to utilise physical therapy services than children with more severe ID. Furthermore, the proportion of service users was higher among children with ID with comorbid problems (e.g., cerebral palsy or epilepsy) when compared with those without co-existing problems (Chang, Lin, Tung, Chiang, & Hsu, 2014).

A child's age can also influence service utilisation. Younger school-aged children with functional limitations have been found to be more likely to utilise services than older ones (Benedict, 2006). However, the association between age and service utilisation is influenced by the types of services utilised; this may be because care needs differ depending on the level of child development (Haveman et al., 1997; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007; Weller et al., 2003). For instance, the utilisation of mental health services has been observed to increase with a child's age (Witt, Kasper, & Riley, 2003), while the likelihood to utilise habilitation services to decrease with age (Bjerre et al., 2004). The latter has also been observed among children with ID (Chang et al., 2014; Lin, Yen, Loh, Li, & Wu, 2006; Martin et al., 2013), although there may be differences in age-related utilisation depending on what rehabilitation services that are used (Wilkins et al., 2010). In addition to the child's age, utilisation of habilitation services may be influenced by the child's gender. Some findings indicate that males with ID are more likely to use such services as well as a higher number of services (Lin et al., 2006; Martin et al., 2013); there are also those that reveal no gender differences between males and females (Chang et al., 2014). Other studies on service

utilisation among children with impairments have shown that male children are more likely to utilise services (Stein & Silver, 2003; Witt et al., 2003). Others have found no gender differences in service utilisation or unmet healthcare needs (Benedict, 2006; Mayer, Skinner, & Slifkin, 2004). These contradictory results may be associated with the types of services used.

Family characteristics such as parental education, may influence service utilisation among children with impairments. Children of parents with low educational levels have been found to be less likely to utilise services in comparison with children of parents with a higher education (Benedict, 2006; Thomas et al., 2007; Weller et al., 2003). It may be that less educated families have less knowledge about available services (Douma et al., 2006; Weller et al., 2003). According to international research, family income and healthcare insurances influence healthcare service utilisation among children with impairments (Benedict, 2006; Stein & Silver, 2003; Weller et al., 2003; Witt et al., 2003). However, this primarily applies to children living in countries in which healthcare is harder to access. In countries where healthcare is accessible and not dependent on financial capacity, socioeconomic status has not been found to influence the use of services (Zwaanswijk, Verhaak, Bensing, Van der Ende, & Verhulst, 2003). As healthcare services provided to children are primarily free of charge in Sweden, financial capacity should play a minor role in service utilisation.

In addition to family, the school setting represents a further microsystem for the child (Bronfenbrenner, 1979). Parents of children with ID have reported concern about the choice of school setting, unclear as to which will be most favourable for their child. Some parents prefer integration and others self-contained classes, while some acknowledge the advantages and disadvantages of both settings. According to parents, self-contained classes offer appropriate support resources, specialist teachers and friendship with other children with ID (Westling Allodi, 2007a). Those classes are also small and relatively calmer. However, children in these classes may become isolated from children without impairments (Roll-Pettersson, 2001) and teachers may not appropriately challenge the children's educational development. In contrast, an integrated setting may be less stigmatising and friendship with children without impairments may improve the development of a child with ID. However, the support resources may be inadequate (Westling Allodi, 2007a), limiting learning opportunities (Roll-Pettersson, 2001). A child's school setting may influence service utilisation. For instance, children with cerebral palsy who attend special schools have been observed to be

more likely to utilise rehabilitation services than children who attend mainstream schools (Majnemer et al., 2014; Parkes et al., 2004). Whether this also applies to children with mild ID in Sweden needs to be investigated.

In sum, based on theoretical frameworks and previous research discussed here, it is clear that the needs for and the utilisation of services among children with mild ID and their families may be influenced by individual, parental, family, organisational and societal factors and the interrelations between them.

Rationale

Children with mild ID have substantial deficiencies in both intellectual and adaptive functioning and a heightened risk for several health disorders. They are also more likely to come from a socially disadvantaged family. Because of the impairment and social circumstances, disability may occur when activities are performed in inaccessible environments. Disability-related services provided by social services and paediatric habilitation units may be required to enable participation. Children with mild ID also face a heightened risk for violence and maltreatment and therefore may be in need of child welfare services. Like other children, they are supported by their parents and families but demands on parents are typically greater among parents of children with impairments. Consequently, when supporting a child, the child's family must also be included. Needs and service utilisation among children with mild ID and their families differ in comparison with children with more severe ID. However, there is a need for greater understanding about children with mild ID. It may be that children with mild ID do not utilise services to the extent they should, as milder impairments may be more difficult to detect and may not entail pronounced difficulties in family life until the child is of school age. Thus, services are not sought at an early stage. Furthermore, parents of children with ID have reported that they lack knowledge about available services and this lack may be even more pronounced among parents of children with mild ID because mild ID may run in the family. This implies that the children's parents may have cognitive difficulties themselves and this can result in greater challenges in identifying their child's problems and in their ability to advocate for their child. Such difficulties may mean that the child and the family do not receive the necessary services, especially as the formal service system requires that the parents themselves apply for services for their child. According to international literature, professionals may improve parental knowledge about services and how to gain access to them if they work in a capacity-building manner in collaboration with parents. Therefore, it is of value to investigate whether this also holds in other contexts, such as Sweden.

Service utilisation may also be influenced by child characteristics such as age and gender, but this may vary according to types of services utilised. According to some studies carried out in other contexts than a Swedish, a child's school setting may affect service utilisation, at least among children with cerebral palsy. This issue needs to be investigated with regard to children with mild ID living in Sweden. Primarily, discussions about the consequences of integration

of pupils with impairments in educational settings seem to focus on inclusion in the school environment. The discussions do not appear to be related to the services provided by other HSOs and the possible consequences of utilisation of these services for the children and their families. Families of children with impairments commonly require support from several HSOs, but knowledge about concurrent service utilisation among the same group of children is limited (Stein & Silver, 2003). Therefore, it would be timely to investigate service utilisation from different HSOs to obtain a wider view of service utilisation patterns among families.

Unmet service needs among families of children with impairments can negatively influence families, and because families of children with mild ID may be less likely to utilise services, an investigation into their service utilisation patterns is called for. In Sweden, typically social services, healthcare units and schools significantly influence children and thus they require in-depth examination. Furthermore, there is a need for a greater understanding about rehabilitation service utilisation among children with ID (Boulet, Boyle, & Schieve, 2009; Lin et al., 2006). Swedish national statistics on disability-related service utilisation among children with ID do not reveal the various levels of ID (Swedish National Board of Health and Welfare, 2012b) and statistics about child welfare services do not separate children with impairments from other children (Swedish National Board of Health and Welfare, 2012a). For HSOs to provide appropriate support and services to families of children with mild ID it is essential that they possess knowledge about the families' own perceptions of their family's needs and their experiences of support. Because service utilisation is influenced by factors on macro, exo, meso and micro levels, a systems perspective should be applied when studying this phenomenon.

Overall and specific aims

The overall aim of this thesis was to explore and describe service utilisation patterns among families of children with mild ID from a systems perspective.

The specific aims were:

- To describe the extent of service utilisation and the types of services from social services and paediatric habilitation units that families of children with mild ID utilise.
- To examine whether a child's age, gender or school setting influences service utilisation.
- To describe the support needs of families of children with mild ID.
- To examine the relation between family needs for support and (a) parental self-efficacy and (b) parents' control over services.
- To examine the relation between parents' experiences of the helpfulness of the support and (a) parental self-efficacy and (b) parents' control over services.
- To investigate whether social service utilisation patterns differs over time by comparing children with mild ID who attend self-contained classes with those who are integrated into mainstream classes.

Materials and methods

The role of a disability researcher

There is no consensus among disability researchers regarding the researcher's role; that is, activism versus academy. Some researchers emphasise independence, partly motivated by academic rigor, while others base their research on the views and needs expressed by persons with impairments (Roulstone, 2013). In Sweden, although social disability researchers initially, on behalf of the state, commonly acted as evaluators of social reforms, they have been largely neutral in relation to social change. In contrast, activism has traditionally been common in the United Kingdom and the United States. In those countries, research is primarily based on the social model of disability and has been conducted by researchers with impairments who actively strive for political changes (Söder, 2009, 2013). Nevertheless, disability research in Sweden is closely linked to social policy, as is usually justified by aims to improve the living conditions of persons with impairments (Hjelmqvist, 2005). This thesis has been conducted with expectations that the knowledge gained will ultimately have positive influences on children with mild ID and their families.

Study design

In this thesis cross-sectional, descriptive, comparative, confirmatory and longitudinal designs were used. Descriptive research aims to portray the characteristics of the relevant groups and persons, as well as the frequency of a particular phenomenon (Polit & Beck, 2010). This type of design was deemed appropriate to use to gain knowledge about the types and number of service types utilised among children with mild ID (papers I, II and IV). It was also used to describe family support needs among parents of children with mild ID (paper III). By using a comparative design, it is possible to observe any differences in service utilisation between males and females (papers I and II) and between children in self-contained classes and children integrated into mainstream classes (papers I, II and IV). Because the objectives of papers I and II were to obtain an overview of service utilisation patterns without considering changes over time, cross-sectional designs were used. Such designs are appropriate when the aim of a study is to describe a phenomenon or the relations between variables at a fixed time (Polit & Beck, 2010). Results obtained in papers I and II demonstrated the need to conduct a study covering data over time. Therefore, a study involving several years was conducted to test hypotheses, including a longitudinal design (paper IV). Longitudinal research refers to

studies where data are collected several times and is an appropriate approach when studying changes that occur over an extended period (Polit & Beck, 2010). A confirmatory design aims to confirm a generalisation (Vogt, Gardner, & Haeffele, 2012) and was used to test the hypotheses concerning the relation between service utilisation and children's school setting (paper IV). This approach was also used to test hypotheses about the relation between family needs for support and (a) parental self-efficacy and (b) parents' control over services, and the relation between parents' experiences of the helpfulness of the support and (a) parental self-efficacy and (b) parents' control over services (paper III). Data were sourced from archival records and interview schedules (Table 1).

Table 1. Overview of study designs, samples, data collection and data analyses used in this thesis

Paper	I	II	III	IV
Study design	Cross-sectional Descriptive Comparative	Cross-sectional Descriptive Comparative	Descriptive Comparative Confirmatory	Longitudinal Comparative Confirmatory Descriptive ³
Sample	84 children with mild ID and their families ¹	84 children with mild ID and their families ¹	Parents of 38 children with (primarily) mild ID ²	405 children with mild ID
Data collection	Organisational records in social services	Organisational records in paediatric habilitation units	Interview schedules based on closed-ended questionnaires	Organisational records in social services
Data Analysis	Descriptive and inferential statistics Mann-Whitney U-tests, Spearman's rank order correlation, Binary logistic regression	Descriptive and inferential statistics Mann-Whitney U-tests, Spearman's rank order correlation, Binary logistic regression	Descriptive and inferential statistics Cronbach's alpha coefficient, Pearson's Product-moment correlation coefficient Independent-samples t-test	Inferential statistics Binary and ordinal logistic regression

¹ Papers I and II are based on the same sample.

² Of the families included in papers I and II, 16 families participated in paper III.

³ Paper IV had no descriptive design itself. However, since data about service utilisation among the families was collected to answer the aims of paper IV, information about the extent of and types of services utilised are presented in the thesis. This was seen as an advantage because service utilisation in paper IV primarily includes a whole county, whilst service utilisation in paper I and II only includes two municipalities.

Participants

Papers I and II

Papers I and II consist of the same sample of 84 children with mild ID and their families living in a county in southern of Sweden. The studies resulting in papers I and II were parts of a larger research study with an interactive approach in which practitioners participated in the research. Therefore, the county from which the sample was based was selected on the basis of convenience grounded on geographical proximity. All 13 municipalities in the county – the heads of social service departments and heads of childcare and education departments - were

informed about the study and asked to participate. Two agreed. Those municipalities have 100,000 - >150,000 and 20,000 - >30,000 inhabitants (only approximate statistics are used to avoid the identification of the municipalities). Furthermore, the heads of the two paediatric habilitation units responsible for habilitation services for children with mild ID in the county were asked to participate, and both agreed. The sample includes all children enrolled in compulsory school for pupils with ID during the 2011/2012 school year following a reading-based curriculum in public schools. Children who studied in non-public schools were excluded, because more than 95% of all children in Sweden who were enrolled in compulsory school for pupils with ID attended public schools in 2011 (Swedish National Agency for Education, 2014b). The sample consists of 37 females and 47 males aged between 6 and -16 years, with a mean age of 12.8. A total of 56 children attended self-contained classes and 28 were integrated into mainstream classes. Sample characteristics are shown in Table 2.

Table 2. Sample characteristics of Paper I and II, absolute frequencies

Children in self-contained classes	Age 6-13	Age 14-16	Total
Males	16	17	33
Females	10	13	23
<i>Total</i>	26	30	56
Children integrated into mainstream classes			
Males	9	5	14
Females	9	5	14
<i>Total</i>	18	10	28

Paper III

The study presented in paper III was also part of the larger research study mentioned above. Paper III consists of a convenience sample of the parents of 38 children with mild ID aged 7 -17 years. The parents were recruited at parent-teachers meetings at all schools offering compulsory schools for pupils with ID in the same two municipalities as in papers I and II. The researcher provided oral and written information about the project and invited parents to participate. The parents were given forms on which to write their names and contact details, and these could then be returned to the researcher should they wish to participate. Written information about the project and the form mentioned above were also sent, with the help of teachers, to all families with a child enrolled in compulsory school for pupils with ID following a reading-based curriculum in the two municipalities. This included the families of

children who were integrated into mainstream classes. Significantly fewer parents than expected chose to participate. Therefore, the researcher applied for ethical approval applicable to all municipalities in the county, and this was granted. The researcher then visited all schools offering compulsory schools for pupils with ID in all 11 additional municipalities in the county. More than 200 children are enrolled in compulsory school for pupils with ID and follow a reading-based curriculum per year in the county of interest. However, the parents of only 38 children chose to participate, which was far from the researcher's estimate of 80-100 families. Parents' characteristics are shown in Table 3.

Table 3. Sample characteristics – parents, absolute frequencies. Relative frequencies in brackets

	Mother n=38	Father n=38
Educational level		
Compulsory school for pupils with ID	1 (3)	1 (3)
Compulsory school	3 (8)	4 (10)
Upper secondary school	23 (60)	22 (58)
University	10 (26)	5 (13)
Other	0	1 (3)
Missing values	1 (3)	5 (13)
Employment status		
Paid employment	30 (79)	29 (76)
Job applicant	1 (3)	2 (5)
Studying	0	0
Other ³	6 (16)	1 (3)
Missing values	1 (2)	6 (16)
Average paid working time of 100%	84 ¹	98 ²

¹ Of the 30 mothers who participated in paid employment, 28 stated their employment level.

² Of the 29 fathers who participated in paid employment, 29 stated their employment level.

³ Other almost exclusively concerned receiving sickness benefit.

Of the 38 children, 66% lived together with both mother and father, 24% were mother-only families and 8% were father-only families (a missing value for one family). The 38 children consisted of 24 males and 14 females aged 7 -17 years. The mean age was 13 years. During the interviews, the parents rated their child's level of ID. According to parents, there were 33 children with mild ID, three with moderate ID, one with severe ID and one with a suspected ID. Although the study especially concerned parents of children with mild ID, all conducted interviews were included in the study. No comparison were made between the parents' ratings and those of professionals, because professionals' ratings were not the focus of the study and not collected. Information about impairments other than ID was obtained by parents for 37 children. Among them, 68% had at least one impairment other than ID. In total 41% had one additional impairment, 19% two and 8% three. The most common impairments were epilepsy

(18%), autism spectrum disorders (16%), ADHD (11%) and cerebral palsy (11%). The 38 families had on average, 2.3 children per family, and 13% had two children with ID.

Paper IV

The aim was to include all children in a county who were enrolled in compulsory school for pupils with ID and who followed a reading-based curriculum and attended public schools during 2009 -2013. Again, all 13 municipalities in the county - the heads of social service departments and the heads of childcare and education departments - were invited to take part in the study. The former were asked to provide information about service utilisation and the latter to provide class lists of children. Among the social service departments, all those who provide disability-related services agreed, as did all but one of those who provide child welfare services. All but one of the heads of the childcare and education departments agreed to participate. Thus, 12 municipalities were included in the study concerning disability-related service utilisation and 11 municipalities concerning child welfare service utilisation. The municipalities are situated in the same county as the municipalities included in papers I-III. One municipality has 100,000 - >150,000 inhabitants, seven municipalities 0 - >20,000 inhabitants and four municipalities 20 - >40,000 inhabitants. The sample comprise 405 children enrolled in compulsory school for pupils with ID and who followed a reading-based curriculum in public schools during 2009 -2013. The children were aged 6 -18 years. Total sample characteristics are presented in Table 4.

Table 4. Total sample characteristics (n=405)

	2009	2010	2011	2012	2013
	n	n	n	n	n
Children in self-contained class					
Males	90	82	89	88	86
Females	66	57	44	44	48
<i>Total</i>	156	139	133	132	134
Children integrated into mainstream classes					
Males	54	41	38	35	40
Females	36	33	30	34	36
<i>Total</i>	90	74	68	69	76
Altogether	246	213	201	201	210
Number of children who finished school ¹		55	46	49	46
Number of children who became enrolled in school ¹		22	34	49	55
Mean age for children in self-contained classes	12.8	13.0	12.8	12.7	12.8
Mean age for children integrated into mainstream classes	12.5	12.4	12.7	12.9	12.4

¹ Compulsory school for pupils with ID.

As children were only included in the study if they were enrolled in compulsory school for pupils with ID, not all children were included in all years. Among the 405 children, 18% were included for 5 years, 12% for 4 years, 17% for 3 years, 22% for 2 years and 31% for 1 year. Concerning changes in school settings, 27 children shifted from a mainstream class to attend a self-contained class, one child transferred in the opposite direction, and one child shifted from a self-contained class to an integrated setting and then back to a self-contained class. The change from an integrated setting to a self-contained class primarily occurred at 13 years of age; that is, when the child began secondary school. The median age was 13 years for both males and females. Age and gender distributions are shown in Table 5.

Table 5. Change of school setting from being integrated into a mainstream class to attend a self-contained class in relation to the child’s age and gender

Child’s age	Female	Male	Total
11	0	1	1
12	2	1	3
13	8	6	14
14	2	4	6
15	2	0	2
16	0	2	2
<i>Total</i>	14	14	28

Data collection

Papers I, II and IV

Archival data were used for papers I, II and IV, which refers to data that are collected from available sources, for example organisational records, database archives and websites. Such data are not originally collected by the researcher and are therefore referred to as secondary data (Vogt et al., 2012). Data were collected from organisational records in social service departments and paediatric habilitation units. This approach was deemed to be the most appropriate to answer the research questions concerning service utilisation patterns. Class lists of children were provided by school administrators at the childcare and education departments in the municipalities.

Papers I and IV

Class lists of relevant children were collected from educational authorities, including the children’s type of school setting each autumn the actual years, since school years starts at autumn. The researcher visited social service professionals in the municipalities and, based on the class lists, the professionals used their organisational records to collect data about

service utilisation for every pupil on the list. The data were then submitted to the researcher. To guarantee that data were supplied in a manner that allowed research questions to be answered and to minimise possible biases when data were collected from the organisational records, the relevant professionals and the researcher were together when data were gathered, which enabled explanations, verifications and double-checking. Some social service professionals preferred to send the data directly to the researcher without face-to-face contact. This was approved, but was followed by a written description of which data the researcher requested and how they should be provided. Service utilisation was operationalised as all services that were approved by a formal decision (after an individual assessment) and valid during the year/years of interest. The collected data revealed the type of the approved service, under which legislation the service was approved and during which year the service was valid. Both disability-related services and child welfare services were collected. The intention of the descriptive design of papers I and IV was to achieve a comprehensive view of the type and number of services the families utilise from social services. Therefore, detailed data concerning usage characteristics (e.g., hours of use per day, days per month or the number of times the same service type was granted during the same year) were excluded. Each type of service was listed once per year per child with mild ID.

Paper I also includes services granted to the child's siblings and parents to address social problems. This was motivated by the fact that a child's local environment such as the family, has the greatest impact on a child's development (Bronfenbrenner, 1986). For parents, a specific type of service was listed once per family. The same approach was used for siblings, which means that the results reveal that at least one sibling in the family was granted a specific type of service during the year. This approach was chosen because the planned analyses did not require detailed data concerning how many siblings received a certain type of service.

Paper I concerned 2011 and paper IV the period 2009 -2013. It is important to recognise that even though a type of service is primarily granted to a child, it may also be granted to fulfill the needs of family members such as parents. For instance, the aim of respite care is often to relieve parents of their care responsibilities. Services provided in relation to the child's impairment, defined as disability-related services in this thesis, were granted under the Social Services Act (SoL) (2001:453), the Act concerning Support and Service for Persons with Certain Functional Impairments (1993:387) and the Social Insurance Code (2010:110). Services provided to a child because of social problems, defined as child welfare services in

this thesis, were granted under the SoL and the Care of Young Persons (Special Provisions) Act (1990:52) (Table 6).

Paper II

The class lists were submitted to professionals in the paediatric habilitation units together with a written description of the type of data requested and how they should be provided. The professionals used their organisational records to collect data about service utilisation for the pupils on the list and then sent the data to the researcher. The aim of the descriptive part of the study was to achieve a wide-ranging view of the children's utilisation of paediatric habilitation services. Therefore, the focus was on the types and number of different service types. The operationalisation of service types was set as the type of healthcare professional providing services. Details about the kind of support each professional provided were beyond the scope of this paper. Paper II concerned data from 2011. Services provided from paediatric habilitation units can also be provided to a child's family members. However, all service provision is documented in the child's medical record because the services relate to the child's impairment. Services were provided under the Health and Medical Services Act (1982:763) (Table 6).

Table 6. Overview over HSOs and legislation related to service utilisation

Services provided by social services		Services provided by paediatric habilitation units
Disability-related services	Child welfare services	Services provided to the families in relation to the child's impairment
• The Social Services Act (SoL) • The Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) • The Social Insurance Code (SFB)	• The Social Services Act (SoL) • The Care of Young Persons (Special Provisions) Act (LVU)	• The Health and Medical Services Act (HSL)

Paper III

Data for paper III data were collected from interviews with the parents of children with mild ID. Sociodemographic characteristics were gathered concerning family structure, parents' education and employment, their child's age, gender, diagnoses and functioning. In addition two questionnaires were used.

Interview schedules

The parents could choose where they wanted the interview to take place. The majority chose their own home. The few interviews that were conducted outside the families' homes occurred

in a room at Jönköping University. All interviews were structured, which is an appropriate approach when knowledge already exists about what information is required to answer the research question (Polit & Beck, 2010). The interviews were based on two closed-ended questionnaires and the questions were asked face-to-face. The questionnaires were used as interview schedules (Polit & Beck, 2010). The questionnaires could have been handed out to respondents to fill out, but because it can be difficult to understand and fill out questionnaires, it was judged more appropriate to interview the parents. This made it possible to clarify any ambiguities and to check whether respondents had properly understood the questions. Because parents of children with mild ID might have cognitive reductions themselves (David et al., 2013), such an approach was judged necessary. Furthermore, in comparison to questionnaires, response rates are often higher when interviews are used (Mitchell & Jolley, 2013).

The first questionnaire, the *Family Needs Survey* (Bailey & Simeonsson, 1988), concerned parents' perceptions about family needs. The survey was developed in 1988 in the United States to assess family needs as expressed by parents (rather than professionals' perceptions) of children with developmental impairments. The original aim of the questionnaire was to support early intervention program planning. The questionnaire consists of 35 items divided into six categories; *Needs for Information*, *Needs for Support*, *Explaining to Others*, *Community Services*, *Financial Needs* and *Family Functioning* (Bailey & Simeonsson, 1988). Internal consistency has been found to be sufficient, with a Cronbach's alpha of 0.91 for total scores on the questionnaire and 0.65 -0.86 for the subscales (categories) (Sexton, Burrell, & Thompson, 1992). The Family Needs Survey has been widely adopted to identify family needs as prioritised by family members (Shonkoff & Meisels, 2000). Even though the questionnaire was initially designed in the United States for parents of young children with developmental impairments, it has been used to assess the needs of families of children of different ages, ethnicities and with various impairments, see for example Almasri et al. (2012), Bailey Jr et al. (1999), Dalzell, Nelson, Haigh, Williams, and Monti (2007), Hodgetts et al. (2014) and Sahay et al. (2013). The Swedish version consists of six categories and 36 closed-ended questions with the response options *yes*, *maybe* or *no* (Figure 3). An extended version of the questionnaire has previously been used in Sweden, which also included teachers' needs (Granlund & Roll-Pettersson, 2001).

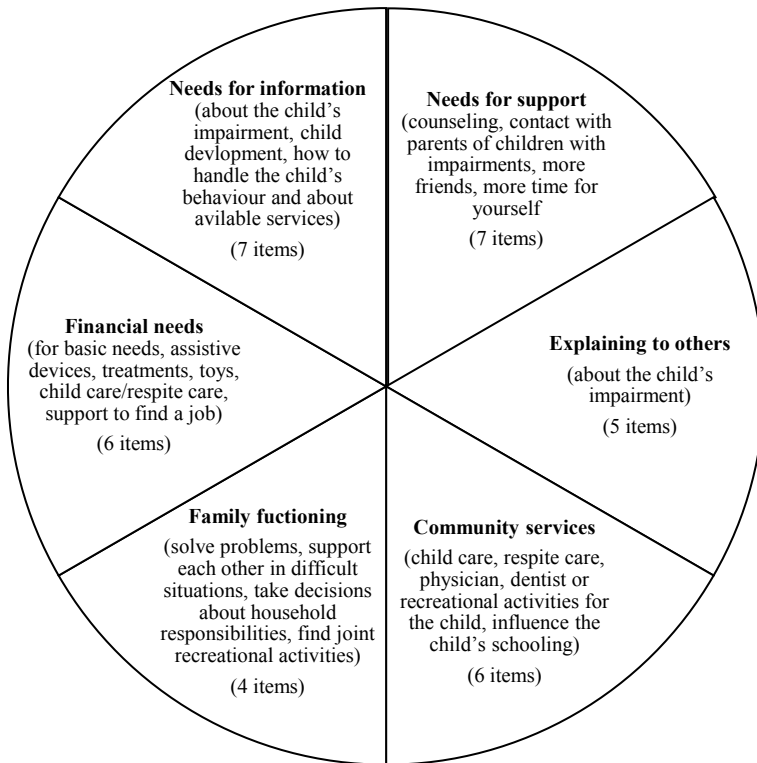


Figure 3. Overview over the Questionnaire *Family needs survey*, adapted from Bailey and Simeonsson (1988)

The second questionnaire, the *Family Outcome Survey*, based on Bailey et al. (2006), measures five outcome domains:

- families understand their child's strengths, abilities, and special needs
- families know their rights and advocate effectively for their child
- families help their child develop and learn
- families have support systems
- families access desired services, programs and activities in their community (operationalised as *accessing your community* and *the helpfulness of early intervention*).

A family outcome is defined as “*a benefit experienced by families as a result of services received*” (p. 228). Thus, it is not received services per se that are an outcome, but the consequences for the family after receiving the services. Services should address the family as a whole because services received by one family member usually influence the whole family as a system, whether the support is provided to the child or parent (Bailey et al., 2006).

The *Family Outcome Survey* contains 18 questions and is available in several languages, including Swedish (The Early Childhood Technical Assistance Center, 2015). The survey was translated into Swedish by Ylvén and Granlund (2009). The Swedish questionnaire was first used 2012. It consists of 18 questions divided into the same domains as the original version, except that helpfulness of early intervention was changed to concern support from paediatric habilitation units. All items in the questionnaire, except one, demonstrated an acceptable distribution of responses (Ylvén, Granlund, & Persson, 2012). In paper III, this version was adapted to also include support from social services and consists of 21 questions. In contrast to Ylvén et al. (2012) who used seven response alternatives, only five were used in paper III, because it was considered easier for parents to respond to. Furthermore, in this version every response alternatives were related to a statement, whilst for those in Ylvén et al. (2012), three had no such attachments, which can make it more difficult to assess the alternative that best corresponds to a family’s situation. Examples of the response used in paper III are as follows: we know almost nothing, we know a little, we know somewhat, we know almost everything, and we know everything about a phenomenon.

To investigate the possible relations between family support needs and family outcomes, 18 of the 21 questions were used to design four indices: parental self-efficacy, parents’ control over services, parents’ experiences of general support and parents’ experiences of specific support. The parental self-efficacy index relates to parenting competence. Parents who experience higher levels of parental self-efficacy seem to be more effective in their parenting role (T. L. Jones & Prinz, 2005) and report a lower need for support (Trivette et al., 2010). The index (four items) refers to how much the family knows about:

- child development
- how ID affects their child
- how to help their child to develop and learn
- how to help their child to work well with others.

The parents' control over services index concerns possessing knowledge about entitlements and available services, being able to advocate for the child and feeling comfortable in meetings with professionals, which are considered as positive outcomes for families (Bailey et al., 2006). Such factors are thought to increase parents' control over services. This index (three items) concerns collaboration with professionals and includes questions about:

- how much the family knows about available support
- how much the family knows about their rights concerning support to help their child and themselves
- how comfortable and involved the family feels in meetings with professionals from HSOs.

The parents' experiences of general support index concerns the difficulty that the families of children with impairments often experience obtaining access to community services (e.g., childcare, healthcare services and recreational activities) that meet their and their child's needs (Bailey et al., 2006). The index (five items) refers to:

- the family's opportunities to talk to someone they have confidence in
- the family's opportunities to get help from someone they have confidence in
- the family's opportunities to engage in recreational activities
- how well general healthcare meet their child's special needs
- how well childcare meet the family's childcare needs.

The parents' experiences of specific support index (six items) concerns the extent that support from paediatric habilitation units and social services have helped the family to:

- gain knowledge about and understand their rights concerning support
- gain knowledge about and understand their child's needs
- help their child develop and learn.

Data analysis

Papers I and II

Descriptive statistics were used to show the extent of service utilisation and the types of services the families utilised. The data did not show a normal distribution and, therefore, non-parametric tests were used for inferential statistics. Mann-Whitney U Tests were used to

examine the possible differences between males and females in the number of utilised service types and between children in self-contained classes and children in mainstream classes. Spearman's rank order correlation coefficient was used to examine the relation between the child's age and number of service types utilised. A binary logistic regression was performed to determine whether the child's age, gender or school setting influenced the probability of utilising services.

Paper III

Descriptive statistics were used to explain sociodemographic characteristics and the families' support needs. Cronbach's alpha was calculated for the six categories in the *Family Needs Survey* and for the four indices created from the *Family Outcome Survey* (Table 7).

Table 7. Cronbach's alpha for categories and indices of the questionnaires

Categories for the <i>Family Needs Survey</i>	Alpha values	Indices for the <i>Family Outcome Survey</i>	Alpha values
Needs for information	0.49	Parental self-efficacy	0.73
Needs for support	0.68	Parents' control over services	0.65
Explaining to others	0.75	Parents' experiences of general support	0.60
Community services	0.61	Parents' experiences of specific support	0.87
Financial needs	0.65		
Family functioning	0.77		

The data showed a reasonably normal distribution and therefore parametric tests were used for inferential statistics. Pearson's product-moment correlation coefficients were used to examine the relation between family needs for support and (a) parental self-efficacy and (b) parents' control over services, and to examine whether parents' experiences of the helpfulness of the support were related to (a) parental self-efficacy and (b) parents' control over services. Independent-samples t-test was used to investigate if there was a difference in family support needs between families of children with mild ID and families of children with mild ID and at least one additional impairment.

Paper IV

Descriptive statistics were used to describe the extent of service utilisation and the types of services the families' utilised. The data did not show normal distribution and therefore non-parametric tests were used for inferential statistics. Logistic regressions were used to investigate whether service utilisation patterns differed over time between children in self-contained classes and those in mainstream classes. The independent variables included in the model were the child's school setting, age (given a linear representation) and gender. In

addition to school setting, gender and age were included in the analysis because these variables have been shown to influence the service utilisation of other types of services (rehabilitation services) among children with ID (Chang et al., 2014; Lin et al., 2006; Martin et al., 2013). The municipality in which the child lived (given dummy coding) was also included in the model, based on previous research that has shown that there is a wide variation in service utilisation between different municipalities in Sweden (Erlandsson, 2014; Forkby et al., 2015; Lewin et al., 2008). Municipality was controlled for when analysing hypotheses 1, 2 and 5a. However, it was not controlled for in hypotheses 3 and 4 because only 28 children changed from a mainstream class (as integrated pupil) to attend a self-contained class. Furthermore, such changes only occurred in five municipalities (Table 8).

Table 8. Overview over children's changes from a mainstream class to a self-contained class in relation to the five municipalities in which such changes occurred and what year the changed occurred

Municipality	2010	2011	2012	2013	Total
1	1	1	0	2	4
2	0	0	0	1	1
3	2	0	3	0	5
4	1	2	0	4	7
5	2	1	4	4	11
<i>Total</i>	6	4	7	11	28

Neither was municipality controlled for when testing hypothesis 5b because there were too few municipalities in which the children utilised more than one type of child welfare service during each studied year.

Children's IQ scores were not included in the analyses because IQ and adaptive functioning do not seem to be correlated among persons with mild ID (Arvidsson & Granlund, submitted; Reschly et al., 2002). Therefore, IQ was not considered a suitable predictor of service needs.

Binary logistic regressions were used to analyse the following hypotheses:

- hypothesis 1: the relation between school setting and whether disability-related services were utilised
- hypothesis 3: the relation between change of school setting and the likelihood to start utilising disability-related services
- hypothesis 4: the relation between change of school setting and whether there was an increase in the number of utilised disability-related service types

- hypothesis 5a; the relation between school setting and whether child welfare services were utilised.

Ordinal logistic regressions were used to analyse the following hypotheses:

- hypothesis 2: the relation between school setting and the number of utilised disability-related service types
- hypothesis 5b: the relation between school setting and the number of utilised child welfare service types.

Ordinal regression is used when a dependent variable has at least three possible outcomes that can be ordered in rank. The odds ratios obtained in an ordinal regression correspond to the average odds ratio of repetitive binary logistic regressions (O'Connell, 2006). The hypotheses include service utilisation among children who were analysed over several years. Because the repetitive measures of an individual are correlated, a robust variance estimation for cluster-correlated data was performed to minimise the risk of obtaining a false correlation (R. L. Williams, 2000). Hypotheses 1, 2, 5a and 5b are based on repeated cross-sectional analyses. For hypotheses 3 and 4 longitudinal analyses were carried out. Detailed information concerning the respective analyses is shown in Table 9. It was not possible to analyse changes in school settings in relation to change in the utilisation of child welfare services because of too small samples.

Table 9. Overview over analyses of hypotheses

Hypothesis	Independent variables	Dependent variable	Number of municipalities	Number of children	Number of observations
1 ^{1,3}	School setting, age, gender, municipality ⁵	if disability-related services were utilised or not (yes/no)	12	405	1071
2 ^{2,3,6}	School setting, age, gender, municipality ⁵	the number of utilised disability-related service types, tripartite variable; 1, 2 or 3-5 services	12	189	449
3 ^{1,4,7}	School setting, age, gender	the likelihood to start utilising disability-related services or not (yes/no)	10 ⁸	177	344
4 ^{1,4}	School setting, age, gender	if the number of utilised disability-related service types increased or not (yes/no)	10 ⁸	236	548
5a ^{1,3}	School setting, age, gender, municipality ⁵	if child welfare services were utilised or not (yes/no)	12	368	965
5b ^{2,3,6}	School setting, age, gender	the number of utilised child welfare service types, bipartite variable; 1 or 2-5 services	12	52	119

Age was given linear representation.

¹ Binary logistic regressions were used.

² Ordinal logistic regressions were used.

³ The hypotheses were based on repeated cross-sectional analyses.

⁴ Longitudinal analyses were carried out.

⁵ Municipality was controlled for giving dummy coding.

⁶ Only children who utilised services were included.

⁷ Only children who initially did not utilise services were included.

⁸ Two municipalities were excluded since children could not change school setting in these. One municipality integrated all children with mild ID into mainstream classes and the other only offered self-contained classes.

Ethical considerations

Research involving humans must ensure that their human rights and dignity are protected and maintained. The various studies within this thesis were conducted in accordance with the Act concerning the Ethical Review of Research Involving Humans (2003:460) and were approved by the Regional Ethical Review Board in Linköping; Dnr 2011/275–31 (papers I-III) and Dnr 2013/369-31 (paper IV).

When deciding who should participate in a research study, the researcher must endeavour to optimise inclusion to avoid the exclusion of certain groups without good reasons. Vulnerable groups are at risk of being excluded because researchers fear that they may experience some harm if they participate. However, avoiding certain groups undermine their opportunities to

experience the benefits of participation. Examples of vulnerable groups are people with certain diagnoses (Williamson, 2007), children and their parents (Long, 2007). Such participants are included in this thesis. However, it is crucial that the situation of such groups is made visible (Swedish Research Council, 2003). Currently, there is insufficient knowledge about service utilisation among children with developmental disabilities (Boulet et al., 2009). Furthermore, because research rarely differentiates between the different levels of ID, there is a need for a greater understanding of children with mild ID (Ellem et al., 2013). Possible benefits of the studies included in this thesis were considered to be an increased knowledge about the support needs of families of children with mild ID, their service utilisation patterns and experiences of support.

Paper I, II and IV

These papers concern data about the utilisation of such services that address disability and social problems, that is, data that are of a highly sensitive nature and are protected by the Information and Secrecy Act (2009:400). Data were collected from existing organisational records in social service departments and paediatric habilitation units, and concerned more than 400 families. In general, research participants should be properly informed about the study and given the opportunity to decide whether they want to be participants; that is, to provide informed consent (Act concerning the Ethical Review of Research Involving Humans, 2003:460). However, some types of research may not require informed consent (Long, 2007). An example of such research is epidemiologic population studies, which includes a large sample where data are gathered via existing personal registers, and the interest of the study lies in a population, rather than individuals. In such cases, when it may be impossible to inform and receive informed consent from each participant, the Regional Ethical Review Board can decide that informed consent is not required even though the research concerns sensitive personal data (Swedish Research Council, 2003). A prerequisite for such a decision is that the Ethical Review Board considers that threats to the privacy of the research participants are clearly outweighed by the public interest (Personal Data Act, 1998:204). Such a decision was made for papers I, II and IV in this thesis. However, to collect data from organisational records without informed consent also requires approval from the authorities responsible for the records (Swedish Research Council, 2003). Approvals was obtained from the heads of social service departments and paediatric habilitation units.

Before gathering data from the included HSOs, class lists of the pupils enrolled in compulsory school for pupils with ID were collected from school authorities. Names, addresses and phone numbers of pupils are considered as information that can be disclosed, provided that a pupil or his or her relatives are not likely to experience personal persecution or harassment if the information is disclosed (Swedish National Courts Administration, 2006). All but one head of the childcare and education departments in the municipalities disclosed the requested class lists. Data for papers I, II and IV concerned information about the types of services utilised. No personal records (i.e., a participant's medical or social notes) had to be read, thereby protecting the privacy of the participants. The privacy of the participants was further protected by the fact that the aim of the study was to obtain group-level results rather than individual-level findings.

Paper III

Potential research participants were informed orally and in writing about the study at parent-teacher meetings at compulsory schools for pupils with ID, and by letter. They also received letter outlining the same. For ethical reasons, the parents of pupils integrated into mainstream classes were not informed about the study at parent-teacher meetings. Therefore, they only received a letter. When deciding whether to participate in a research study, the privacy of research participants may also have to be protected from professionals with whom they have a dependent relationship (Nygren, 2012). In this study, parents were considered to be in such a relationship with the teachers. To prevent these professionals becoming aware of which parents participated in the study, parents interested in participating filled in their names and contact details on a form included with the letter, and this was sent to the researcher.

The parents who participated in the study were informed about study's aims, research outline, methods, possible benefits and potential risks of participating. Potential risks were considered to be violation of privacy and psychological discomfort. The parents were also informed about the voluntary nature of the study, that they could withdraw at any time and that withdrawal would not result in any negative consequences for them. The parents were informed about the estimated time requirements, the content of the questionnaires and how the results would be presented and the data stored. All participants provided written informed consent before being interviewed.

The interviews concerned sensitive matters such as health issues affecting their children and the family, family relations and family support needs. The disclosure of such information can threaten the privacy and may bring up uncomfortable feelings for participants. In addition, some of the parents may, as parents of children with mild ID, have cognitive limitations themselves (David et al., 2013). When research participants have intellectual limitations it is essential to adapt any communication so that it is understandable (Kalman & Lövgren, 2012). The researcher therefore carefully and explicitly informed potential participants to ensure that they received sufficient information before deciding to participate. During the interviews the researcher made every effort to ensure that participants understood the questions.

Research interviews with humans in vulnerable life situations may induce emotional reactions, such as distress and grief (Long, 2007). Compared with parents of children without ID, parents of children with ID generally experience lower levels of well-being (Emerson et al., 2006; M. B. Olsson & Hwang, 2006). Therefore, humility and responsiveness were required from the researcher. Significant emphasis was placed on informing participants about the right to refuse to answer any question, and to withdraw at any time and about confidentiality. Furthermore, the researcher took great efforts to maintain sensitivity and to respond in an appropriate manner when participants were emotionally affected, for instance when crying. The interviews were based on two quantitative questionnaires, which had been previously used with parents of children with impairments. Because the participants gave answers on a Likert scale, the interviews were considered to be less emotionally strenuous than in-depth interviews, in which participants would have been expected to recount and describe their experiences of family support needs. Most of the interviews took place in the participants' homes, which probably increased their sense of security. Participants were offered the opportunity to contact the researcher if they felt upset after the interview. They also received the name of a professional within social services who they could contact if they needed to further discuss their support needs.

The research project in which papers I, II and III were included has resulted in easily accessible material, managed by the Public Health Agency of Sweden, which can be used by HSO professionals to empower children with mild ID and their families in the service provision process. It aims to strengthen families in their abilities to describing difficulties, to request services and to increase their participation in decisions about required services and the implementation of them. The families who participated in the interview study will be invited

to attend a presentation of the results, as will the various HSO professionals involved in the various studies.

Results

Service utilisation and types of services utilised

Services provided by social services (papers I and IV)

Between 2009 and 2013 (paper IV) the most commonly utilised services were disability-related services. On average, 42% of the children in the county utilised such services during that period. Child welfare services were used by 12% of the families. The percentage of children who utilised both disability-related and child welfare services was in average 7% during these years. This does not necessarily mean that services were provided simultaneously, but rather during the same year. The majority of children did not utilise any services (Table 10).

Table 10. Percentages of children who utilised services 2009 -2013

Services	2009	2010	2011	2012	2013	Average
	%	%	%	%	%	%
Disability-related services ^{1,3}	37.0	43.2	43.3	42.3	44.8	42.0
Child welfare services ^{2,4}	9.4	12.4	12.7	15.0	12.8	12.3
Disability-related services and child welfare services during the same year	4.5	5.7	6.6	8.9	8.0	6.6
No services	58.9	51.8	53.0	52.2	52.4	53.9

¹ 2009: n=246, 2010: n=213, 2011: n=201, 2012: n=201, 2013: n=210.

² 2009: n=224, 2010: n=193, 2011: n=181, 2012: n=180, 2013: n=187.

³ Twelve municipalities were included in the analysis.

⁴ Eleven municipalities were included in the analysis.

The majority of disability-related services (94.5%) utilised during 2009 -2013 were granted under the Act concerning Support and Service for Persons with Certain Functional Impairments (1993:387), shortened LSS in Swedish. Very few (2.8%) services were granted under the Social Services Act (2001:453), shortened SoL in Swedish. Similarly, only a small percentage of services (2.6%) were granted under the Social Insurance Code (2010:110). The most frequently used service granted under the LSS was *Short stay away from the home*, which aims to enable respite care and relaxation for parents and an opportunity for a change of scenery and recreational activities for the child. A *short period of supervision for schoolchildren over the age of 12 outside their own home in conjunction with the school day and during the holidays* was the second most commonly utilised service. This type of service ensures meaningful activities and security for children while their parents are at work. Following these services, *companion service* was the third most popular service, enabling

participation in the community. The other available services under the LSS were utilised to a much lower degree (Table 11).

Child welfare services utilised during 2009 -2013 were almost exclusively granted under the SoL. The most commonly utilised services were *family treatment/family pedagogue*, which include services to support parents in their parenting roles. Other child welfare services that were used were *contact family* and *help form a personal contact*. A *contact family* is a service that is provided to families facing social problems and aims to enhance the child's resiliency, relieve parents and supplement their parenting (Berg Eklundh, 2010). A *personal contact* is someone who assists a child and his or her next of kin in personal matters (Social Services Act, 2001:453). Approximately 2% of the children were placed in a *family home* or *residential care* under the SoL (Table 11).

Table 11. Percentage of children who utilised various service types during 2009 -2013

Service types	2009	2010	2011	2012	2013	Average %
	%	%	%	%	%	%
Disability-related services	n=246	n=213	n=201	n=201	n=210	
Personal assistance (LSS)	0.8	1.9	2.5	2.5	1.9	1.9
Personal assistance (SFB)	2.4	2.8	1.0	1.5	1.4	1.9
Companion service (LSS)	13.4	17.4	15.4	10.4	11.9	13.7
Help from a personal contact (LSS)	3.6	2.3	7.5	9.4	11.4	6.7
Relief service in the home (LSS)	3.6	3.8	3.4	3.0	3.8	3.5
Short stay away from the home (LSS)	23.2	23.5	25.4	24.9	27.6	24.8
Short period of supervision for schoolchildren over the age of 12 outside their own home in conjunction with the school day and during the holidays (LSS)	13.0	16.4	18.9	20.4	18.6	17.3
Help from a personal contact (SoL)	-	-	-	0.5	-	0.1
Home care service (SoL)	1.2	0.9	0.5	1.0	1.4	1.0
Companion service (SoL)	-	-	-	1.0	0.5	0.3
Short stay away from the home (SoL)	0.4	0.5	0.5	1.0	1.0	0.6
Child welfare services	n=224	n=193	n=181	n=180	n=187	
Help from a personal contact (SoL)	2.7	3.1	3.9	2.2	2.1	2.8
Contact family (SoL)	2.2	2.6	2.2	3.3	2.7	2.6
Family treatment/Family pedagogue (SoL)	4.0	5.7	3.9	6.1	3.7	4.7
Financial assistance (SoL)	0.4	0.5	0.6	1.1	0.5	0.6
Family home or residential care (SoL)	1.3	2.6	2.8	2.2	2.1	2.2
Juvenile treatment (SoL)	-	-	0.6	0.6	0.5	0.3
Support by a social welfare case worker (SoL)	-	0.5	1.6	1.7	2.1	1.1
Compulsory care (LVU)	-	0.5	-	-	-	0.1

Compulsory care as provided by the Care of Young Persons (Special Provisions) Act (1990:52) was rare (Table 11).

To highlight the influence of the home environment of children with mild ID, in addition to services utilised by children with mild ID, paper I also included the provision of services to address social problems experienced by siblings and parents. Slightly more than 25% of all families utilised services to address social problems (children, siblings and parents included) during 2011. Among the 84 families included in paper I, 13% received financial assistance. The services provided to siblings were the same types of services as those termed child welfare services in paper IV. In nearly 11% of the families at least one sibling utilised services because of social problems, and most frequently a *contact family*. Thus, several families faced difficulties relating not only to the child's impairment but also to social problems.

Services provided by paediatric habilitation units (paper II)

Three-fifths (62%) of the children utilised paediatric habilitation services during 2011. The most frequently used service types were services provided by physicians, counsellors and psychologists (Table 12).

Table 12. Percentage of children/families that utilised paediatric habilitation services 2011

Services provided by	n=84
Physicians (HSL)	52
Counselors (HSL)	44
Psychologists (HSL)	31
Occupational Therapists (HSL)	18
Special Educators (HSL)	15
Physiotherapists (HSL)	13
Speech Therapists (HSL)	4
Dieticians (HSL)	4

Services provided by speech therapists and dieticians were rarely used (Table 12). The number of different types of services per child ranged from 0 to 6. The distribution of service utilisation is presented in Table 13. The results show that 68% of the children utilised a maximum of two service types during the year.

Table 13. Number of paediatric habilitation services utilised 2011

Number of services	Number of children n=84	%	Cumulative %
0	32	38	
1	6	7	45
2	19	23	68
3	9	11	79
4	11	13	92
5	5	6	98
6	2	2	100

When studying the overlap of service utilisation in 2011 among different social service departments and different HSOs serving the same children (paper I and II combined), it was found that 30% of the families utilised services from both paediatric habilitation units and disability-related services provided by social services. There was a marked difference in service utilisation among children in self-contained classes and those in mainstream classes. The percentage of utilisers were generally higher among the former. A small percentage used both paediatric habilitation services, social problems-related services and disability-related services (Table 14).

Table 14. Percentage of families who utilised services 2011 in relation to the child's school setting (absolute frequencies in brackets)

Families who utilised:	Of all families (n=84)	Of families with a child in a self-contained class (n=56)	Of families with a child integrated into a mainstream class (n=28)
Habilitation services	62 (52)	71 (40)	43 (12)
Disability-related services provided by social services	37 (31)	52 (29)	7 (2)
Social problems-related services provided by social services	26 (22)	21 (12)	36 (10)
Both disability-related services and social problems-related services provided by social services	8 (7)	11 (6)	4 (1)
Some services provided by social services (disability-related services or social problems-related services or both)	55 (46)	62 (35)	39 (11)
Habilitation services and disability-related services provided by social services	31 (26)	43 (24)	7 (2)
Habilitation services and social problems-related services provided by social services	12 (10)	13 (7)	11 (3)
Habilitation services, disability-related services and social problems-related services provided by social services	8 (7)	11 (6)	4 (1)
No services at all	19 (16)	13 (7)	32 (9)

Child's age, gender and school setting in relation to service utilisation (paper I and II)

Child's age and gender

The results show that the child's age influenced the utilisation of paediatric habilitation services. The likelihood of utilising such services decreased with age ($p = < 0.05$, $OR = 0.74$, $n = 84$), as did the number of service types utilised ($\rho = -0.35$, $p < 0.0005$, $n = 84$). Age explained 12% of the variance in the number of service types utilised. The likelihood of utilising services or the number of utilised service types provided by social services was not influenced by age, neither for disability-related services nor for services addressing social problems. The child's gender did influence the number of disability-related service types utilised from social services. Males utilised a statistically significantly higher number of service types than did females ($U = 624$, $Z = -2.57$, $p < 0.05$, $r = 0.3$, $n = 84$). However, the likelihood of utilising such services was not influenced by gender. Gender had no effect on the utilisation of paediatric habilitation services or the utilisation of services addressing social problems.

Child's school setting

Service utilisation was correlated to the child's school setting, both regarding paediatric habilitation services and disability-related services provided by social services. In comparison with those that attended mainstream classes, children who attended self-contained classes were more likely to utilise disability-related services ($p = < 0.005$, $OR = 12.96$, $n = 84$) and more likely to utilise paediatric habilitation services ($p = < 0.01$, $OR = 4.30$, $n = 84$). Children with mild ID in a self-contained class had 13 times higher odds to utilise disability-related services and four times higher odds to utilise paediatric habilitation services than integrated children with mild ID. Furthermore, children in self-contained classes utilised a statistically significantly higher number of paediatric habilitation service types than children in mainstream classes ($U = 518$, $Z = -2.62$, $p < 0.01$, $r = 0.3$, $n = 84$). The same pattern was found regarding disability-related services. Those who attended self-contained classes utilised more types of services than integrated children ($U = 448$, $Z = -3.70$, $p < 0.001$, $r = 0.4$, $n = 84$). No differences between school settings were observed regarding the number of services addressing social problems used.

Family needs for support

Most of the parents reported the need for information, particularly information about available services for their child. This included both current (79%) and future (92%) services. Other

commonly reported needs concerned information about their child's impairment (63%), how to handle their child's behaviour (63%) and how to teach their child various skills (47%). The majority of parents expressed needing more time for themselves, that is; opportunities for respite from the care of their child (63%), the need to meet and share experiences with other parents of children with impairments (55%) and to read about the experiences of parents with children with the same impairment (58%). Many families (39%) reported the need for regular meetings with a psychologist, psychiatrist or counsellor for advice and support. In terms of community services, parents were most concerned with finding a suitable leisure activity for their child (42%). They also expressed the need for support to find a babysitter or respite carer to enable them the time to engage in their own activities on a regularly basis (26%). The highest need for financial support concerned expenses for basic needs such as food, clothes, transportation, rent and medicine (24%) (Table 15).

Table 15. Overview over parents reported needs, descending order

	%	n
Needs for information about		
Future services for my child	92	35/38
Present services for my child	79	30/38
My child's impairment	63	24/38
How to handle my child's behaviour	63	24/38
How to teach my child various skills	47	18/38
Child development	26	10/38
How to play with and communicate with my child	16	6/38
Needs for support		
More time for myself	63	24/38
To read about experiences of other parents of children with ID	58	22/38
To meet other parents of children with impairments	55	21/38
Regularly meetings with a psychologist, psychiatrist or counsellor for advices and support	39	15/38
More friends to talk to	30	11/37
More time to talk with my child's physician	18	7/38
Someone in the family to talk to about problems	17	6/36
To talk to a priest (or equivalent) to get help with our problems	8	3/38
Explaining to others; need support to explain my child's impairment to:		
His or her siblings	27	10/37
Other children	24	9/38
My parents or my parents-in-law	16	6/38
Friends, neighbors or strangers	13	5/38
My spouse	11	4/35
Community services; need support to:		
Find a suitable leisure activity for my child	42	16/38
Find a baby-sitter or respite care to be able to attend own activities on a regularly basis	26	10/38
Find a babysitter to spontaneously participate in own activities	18	7/38
Find a physician who understands my or my child's needs	16	6/38
Influence my child's schooling	16	6/38
Find a dentist to my child	10	4/38
Financial support needs		
To pay for expenses for basic needs	24	9/38
To be able to buy assistive devices to my child	13	5/38
To pay for treatment or other services me and my child need	13	5/38
To buy toys to my child	10	4/38
Advice and assistance to me or my spouse to find a job	10	4/38
To be able to pay for a baby-sitter or for respite care	3	1/38
Family functioning; the family need support to:		
Learn how to support each other in burdensome situations	24	9/38
Find leisure activities that the family can participate in together	21	8/38
Discuss and solve problems	16	6/38
Decide who should be responsible for child care and other tasks in the home	3	1/38

Family needs for support and experiences of support in relation to parental self-efficacy and parents' control over services (paper III)

A lower need for support (such as counselling, contact with other parents with children with impairments, more friends, more alone time) was associated with the mother's participation in paid employment ($r = -0.364, n = 37, p < 0.05$) and higher levels of education ($r = -0.429, n = 36, p < 0.05$). Mother's participation in paid employment was also associated with lower levels of financial needs ($r = 0.476, n = 37, p < 0.005$). Parental self-efficacy was negatively correlated with the need for information ($r = -0.386, n = 38, p < 0.05$). Thus, as parental self-efficacy increased, the need for information decreased. Parental self-efficacy was not associated with any other needs.

Parents' control over was negatively correlated with the need for information ($r = -0.345, n = 38, p < 0.05$). Higher levels of perceived control over services was associated with a lower need for information. No other associations were found between family needs and parents' control over services. Parents' control over services was related to their experiences of both general ($r = 0.410, n = 29, p < 0.05$) and specific support ($r = 0.561, n = 33, p < 0.005$). Specific support; that is, support provided by paediatric habilitation units and social services, concerned the extent to which the support had helped the family to learn about and understand their rights with regard to support, to gain knowledge about and understand their child's needs and to help their child develop and learn. Parents with higher levels of control perceived the support as more helpful than parents with lower levels of control. However, parental self-efficacy was not associated with experiences of support. Parents' control over services was positively related to parental self-efficacy, with high levels of self-efficacy associated with high levels of control over services ($r = 0.640, n = 38, p < 0.01$).

Child's school setting in relation to service utilisation over time

Children with mild ID who attended self-contained classes were more likely to utilise disability-related services during 2009 -2013 than children who were integrated into mainstream classes. In comparison with integrated children, children in self-contained classes had higher likelihood to utilise such services (OR=7.12). However, the school setting did not influence the number of utilised disability-related service types. In contrast, the number of utilised service types increased with the child's age (Table 16).

Table 16. School setting in relation to utilisation of disability-related services

Independent variables	Disability-related service utilisation (yes/no) ¹		Number of utilised disability-related service types ²	
	Number of pupils	Number of observations	Number of pupils	Number of observations
	405	1071	189	449
	<i>p</i>	OR	<i>p</i>	OR
Children in self-contained class (ref. integrated school setting)	.000	7.12	.738	.85
Child's gender (ref. females)	.121	1.40	.540	.82
Child's age	.065	1.08	.000	1.34

¹ Number of observations for integrated children were 377, and for children in self-contained 694.

² Number of observations for integrated children were 94, and for children in self-contained classes 355. For more detailed information about the analyses see Table 9 in this thesis.

Changes in school settings influenced changes in service utilisation patterns during 2009 - 2013. Among integrated children with mild ID, those who changed their school setting to self-contained classes had higher likelihood to begin to utilise disability-related services (OR=6.13) in comparison with those children who remained in mainstream classes. Change of school setting was also related to whether the number of service types utilised increased. Integrated children with mild ID who changed to self-contained classes had higher likelihood (OR=5.35) to increase the number of service types they utilised compared with those who remained in mainstream settings (Table 17).

Table 17. Change in school setting in relation to change in utilisation of disability-related services

Independent variables	Likelihood to start utilising disability-related services (yes/no) ¹		Increase in the number of utilised disability-related service types (yes/no) ²	
	Number of pupils	Number of observations	Number of pupils	Number of observations
	<i>p</i>	OR	<i>p</i>	OR
Integrated children who changed to self-contained classes	.006	6.13	.002	5.35
Children in self-contained classes who stayed in self-contained classes	.000	5.81	.003	2.82
Child's gender (ref. females)	.982	1.01	.652	1.10
Child's age	.443	1.05	.825	1.01

Reference category were integrated children who remained integrated.

Since too few children changed school setting, municipality was not controlled for in the analyses.

¹⁾ Number of observations for integrated children who remained integrated were 126. Number of observations for integrated children who changed to attend self-contained classes were 21. Number of observations for children in self-contained classes who remained in self-contained classes were 197.

²⁾ Number of observations for integrated children who remained integrated were 148. Number of observations for integrated children who changed to attend self-contained classes were 28. Number of observations for children in self-contained classes who remained in self-contained classes were 372.

For more detailed information about the analyses see Table 9 in this thesis.

School setting was not related to the likelihood to utilise child welfare services nor to the number of utilised child welfare services during 2009 -2013.

Discussion – methodological considerations

Internal validity

The greatest threat to internal validity is non-random sampling because there may be differences between groups that are not controlled for (Kazdin, 2010; Polit & Beck, 2010). None of the samples in papers I-IV were randomly collected. However, the sample in papers I and II included all children enrolled in compulsory school for pupils with ID following a reading-based curriculum in public schools 2011 in the two municipalities included. Paper IV included all relevant children in the county except those from one municipality. According to statistics from the Swedish National Agency for Education, only an average of four children per year were enrolled in compulsory school for pupils with ID following a reading-based curriculum in the excluded municipality. Thus, because very few children from the county were excluded from the study, the results can be generalised to the county. However, selection bias may occur even if the samples include intact groups of participants from schools, because variables that relate to different schools may influence the results (Kazdin, 2010). To minimise this threat to validity, controls for municipality were performed in the regression analyses, where possible. Furthermore, it is likely that the teaching arrangements of pupils with ID integrated into mainstream classes differ between pupils, for example, there may be differences in the amount of time an integrated child spends with classmates (Swedish National Agency for Education, 2002). However, all of these children are defined as integrated pupils by school administrators and they are not members of self-contained classes.

A threat to internal validity in a longitudinal study is the loss of participants, as differences may exist between those who remain in a study and those who drop out (Kazdin, 2010; Polit & Beck, 2010). In paper IV, which has a longitudinal approach, the loss of participants was related to the age of participants; that is, they dropped out when they finished compulsory school. Furthermore, new participants were added each year; when they were enrolled in compulsory school for pupils with ID. Thus, not all participants were included in all years (2009 -2013). Age and gender were controlled for to minimise such threats. There were no other types of internal dropouts in papers I, II and IV, which can be considered a strength. Regarding external dropouts, the head of a social service department providing child welfare services in one municipality refused to participate in the study presented in paper IV.

However, disability-related services were included for this municipality. Because controls for municipality were included the threat to validity was minimised.

Archival records are secondary data; that is, data that are not originally collected by the researcher and therefore the researcher has no control over what was originally documented. However, Swedish legislation requires that HSO professionals document all decisions concerning individually adapted services on an individual basis (Social Services Act, 2001:453). This is considered to increase validity.

When interviews are conducted, as in paper III, there is always a risk that the respondents do not express their true opinion, which is a threat to validity. For instance, bias may occur owing to self-protection or self-enhancement (Kazdin, 2010; Polit & Beck, 2010). Interviews are not anonymous and because our interview schedules concerned family support needs, it can be assumed that questions may have been perceived as sensitive. To minimise these risks, the researcher strived to achieve a pleasant interview environment and to fully inform participants about the aims of the study, the content of the questions, confidentiality, the right to refuse to answer questions and the right to withdraw from the interview at any time. In addition, the interviewer stressed that they were not associated with HSOs.

External validity

Papers I and II included two municipalities, which is considered a limitation and therefore the results can hardly be generalised to a broader setting. In paper IV all but one of the municipalities in the county were included. Therefore it can be suggested that the results can be generalised to the whole county. The sample is too small to enable a generalisation to a national context, because local variations may exist. Paper III included parents of 38 children with mild ID selected using convenience sampling, which is a limitation in relation to external validity. Furthermore, the parents were recruited at parent-teachers meetings at school. Since those meetings are not mandatory it may be assumed that the parents who participated in those, were more actively involved in their child's schooling and development than parents who did not participate in those meetings. This might have influenced the results obtained in paper III. However, the expressed support needs of the families with mild ID is in accordance with previous research concerning families of children with various impairments. For example, parents' need for additional information about available services and their child's impairment are frequently reported. Furthermore, that parents' control over services likely are related to experiences of support has been previously reported by international literature, as has the

association between parental self-efficacy and family support needs. Thus, the results in paper III can likely be generalised to parents of children with mild ID.

Content validity

When developing an instrument it is important to base the conceptualisation of the construct on existing knowledge (Polit & Beck, 2010). The Family Needs Survey was designed to be a comprehensive measure of parental perceptions of family needs. The questions included in the questionnaire are derived from a comprehensive review of the literature and broad discussions among professionals working with early interventions for children (Bailey & Simeonsson, 1988). The instrument has been found to have clinical utility in service planning for families of children with impairments, both in the original and adapted versions (Bailey & Simeonsson, 1988; Dalzell et al., 2007; Sexton, Snyder, Rheams, Barron-Sharp, & Perez, 1991). The Family Outcome Survey (Bailey et al., 2006) has been carefully designed and is based on an extensive research of the literature and in collaboration between parents, researchers, policy makers and program administrators (Bailey et al., 2006).

Construct validity

Construct validity refers to what extent a measure corresponds to the phenomenon being measured; that is, does the operationalisation of the construct exclusively reflect the underlying theoretical construct (Polit & Beck, 2010). In papers I and IV service utilisation/service types utilised were operationalised as services that were ability-tested and approved by a formal decision and valid during the years of interest. This operationalisation was used to obtain knowledge about the different services the children were entitled to, independent of whether the approved services had been executed. Such an approach was taken because municipalities occasionally fail within a reasonable time to execute approved services (Swedish County Administrative Boards, 2009). If only data concerning executed services were collected it would not have been possible to obtain an overall picture of what services the families of children with mild ID were entitled to utilise.

In paper II, the operationalisation of service utilisation/service types utilised were defined as the types of healthcare professionals providing services. This measurement approach is rather broad and does not include details about what kind of service that was provided by each professional. However, because there is a rather distinct difference between the kinds of services each type of professional provide, and because the study aimed to obtain an overview of service utilisation among families, the approach was deemed sufficient.

In paper III the interviews were based on two questionnaires. The Family Needs Survey (Bailey & Simeonsson, 1988) was designed to be used with families of children with developmental disabilities and concerns support needs related to the child's impairment; that is, such support needs that may follow in addition to general support needs that all families may be expected to have. The survey focuses on family needs and not solely on the child's needs, following Bronfenbrenner's theoretical framework, which states that a child does not live in isolation but is included within an ecological context such as the family (Bailey & Simeonsson, 1988). In this thesis a problem is defined as the difference between a current and preferred state (Ylvén, Björck-Åkesson, & Granlund, 2006), while needs are defined as the tools or resources required to solve the problem (Ylvén & Granlund, 2015; Ylvén et al., 2012). The questions in the Family Needs Survey questions are formulated as "Do you need...". The focus on needs, rather than problems, is based on the assumption that it is easier for parents to respond to such questions than to answer questions about problems, which can be solved with different types of services. The questionnaire was designed to be used as a base for planning services (Bailey & Simeonsson, 1988). In summary, the construct validity is deemed to be suitable.

A further aspect of construct validity is the operationalisation of the population (Polit & Beck, 2010). In papers I, II and IV children with mild ID were operationalised as enrolled in compulsory school for children with ID and following a reading-based curriculum. This was based on the fact that children with mild ID follow this curriculum, while children with more severe ID follow a life-skills based curriculum (Roll-Pettersson, 2003; Swedish National Agency for Education, 2011). The IQ values of the children were not collected by the researcher, therefore there is a possibility that the samples in these papers include participants who fall somewhere between mild and moderate ID. However, this is not considered a threat to construct validity because these children were assessed by school administrators as having sufficient ability to follow a reading-based curriculum. Furthermore, Elgmark Andersson, Huus, and Granlund (in prep.) studied adaptive functioning among children enrolled in compulsory school for pupils with ID and did not observe any differences. Of their sample, 12% were included in paper IV in this thesis and all children included in both studies were living in the same county.

Reliability

The internal consistency of the Family Needs Survey used in paper III has previously been demonstrated to be sufficient (0.91 on total scores and 0.65 -0.86 for subscales) (Sexton et al., 1992). When used in paper III, Cronbach's alpha coefficients were 0.49 to 0.77 on the subscales and 0.65 on total scores (Table 14). Ideally, Cronbach's alpha coefficients should be at least 0.7 (Pallant, 2010), but according to Streiner and Norman (2008) an alpha value of 0.5- 0.7 is acceptable. Cronbach's alphas are influenced by the number of items in a scale. Therefore, for scales consisting of less than 10 items it is common to obtain low Cronbach alpha values such as 0.5. In such a case, mean inter-item correlation values may be more appropriate (Pallant, 2010). This value should be between 0.2 and 0.4 (Briggs & Cheek, 1986). The mean inter-item correlation values were calculated and are shown in Table 14. All items below 0.7 were within the appropriate range except for Needs for Information (Table 18).

Table 18. Cronbach's alpha values and mean inter-item correlations values for the Family Needs Survey

Index	Alpha values	Mean inter-item correlation values	Minimum	Maximum	Items (N)
Needs for information	0.49	0.12	-0.19	0.39	7
Needs for support	0.68	0.20	-0.27	0.58	8
Explaining to others	0.75	0.39	0.10	0.74	5
Community services	0.61	0.21	-0.07	0.64	6
Financial needs	0.65	0.23	-0.13	0.50	6
Family functioning	0.77	0.48	0.30	0.87	4

Reliability also refers to how stable an instrument is, that is, self-reports obtained from subjects should be similar when performing a re-test (Polit & Beck, 2010). Test -retests correlations for the Family Needs Survey (total scores) have been observed to be moderate to high ($r = 0.67$ for mothers $r = 0.81$ for fathers and) (Bailey & Simeonsson, 1988). Ten families of those included in paper III were re-interviewed and test-retest reliability was measured. A high degree of reliability was found; the intraclass correlation coefficient was 0.932 (95 % CI 0.798 -0.992).

Discussion of results

This thesis investigated and examined service utilisation patterns among children with mild ID and their families.

Service utilisation and types of services utilised

Paediatric habilitation services were the most commonly utilised services among the families of children with mild ID, followed by disability-related services provided by social services. The services offered by these HSOs aim to improve the service user's performance of activities (SOSFS 2008:20) and to promote participation in the life of the community (Act concerning Support and Service for Persons with Certain Functional Impairments, 1993:387). The families were less likely to use services provided by social services to address social problems. However, more than 25% of the families still utilised such services. Most of these services were granted under the Social Services Act (2001:453), with a small number under the Care of Young Persons (Special Provisions) Act (1990:52), that is, compulsory care. In total, 13% of the families received financial assistance. Furthermore, 12% of the children with mild ID utilised child welfare services, that is, services supplied to children at risk for a negative development (Social Services Act, 2001:453). In 11% of the families at least one sibling utilised child welfare services. International literature has previously reported that children with impairments are at an increased risk of needing child welfare services in comparison with children without impairments (Spencer et al., 2005) and that families of children with mild ID may face financial hardship (Emerson, 2013; Leonard & Wen, 2002; Stromme & Magnus, 2000). The results implies that this may also be applied to children with mild ID living in Sweden.

The most commonly utilised child welfare service was *family treatment/family pedagogue*. This type of service is generally provided to families experiencing problems in parenting, unemployment, mental disorders, financial strain, substance addiction, violence and similar. It may also be provided to families in which parents have cognitive deficiencies (Public Health Agency of Sweden, 2012). The service *contact family* was one of the most utilised child welfare services. This service aims to supplement the parenting role of the parents (Berg Eklundh, 2010). The results indicate that professionals in social services relatively frequently assess parents of children with mild ID as having difficulties in their role as parents. Effective

parenting has been observed to be related to parental self-efficacy. Parents who experience higher levels of self-efficacy seem to be more effective in their role as parents (T. L. Jones & Prinz, 2005). The parents of children with mild ID who utilise services aimed to improve their parenting skills may experience lower levels of parental self-efficacy. The above results highlight the need to recognise that parents of children with impairments may face greater parenting demands and feel overwhelmed by their responsibilities. This can be aggravated by their accompanying financial and employment problems and a lack of support (Algood, Hong, Gourdine, & Williams, 2011).

ID entails considerable limitations to both intellectual and adaptive functioning in several domains (American Association on Intellectual and Developmental Disabilities, 2013). Functioning may be limited in several settings without continuous support (American Psychiatric Association, 2013). In addition, children with ID are more likely to experience other disorders and impairments compared with children without ID (Allerton et al., 2011). Paper III in this thesis revealed that almost 70% of the children with mild ID had at least one other impairment. This likely increases these children's vulnerability and need for disability-related services. Therefore, it is noteworthy that the majority of children included in this thesis did not utilise disability-related services provided by social services. How can this be explained? One explanation might be that parents are not well informed about available services and how to gain access to them. Almost 80% of the families in paper III expressed a need for more information about current available services for their child and more than 90% stated the same about future services. When citizens are informed about available services, the demand for them will increase (Lipsky, 2010). Another explanation might be the parents' low socioeconomic status and level of education. Paper III revealed that only 26% of the mothers and 13% of the fathers had a higher educational level than upper secondary school (university degree or other type of education). This can be compared with the national average for those with a 2-year postsecondary education or higher 2012, which was 41% for women and 30% for men (Swedish Higher Education Authority, 2015). This result implies that parents of children with mild ID have a lower educational level than the general population. Therefore, it is likely that these parents will have difficulty in clearly expressing their family's needs in their dealings with HSOs. Douma et al. (2006) found that parents of children with ID with lower educational levels and socioeconomic status reported a lesser need for support (Douma et al., 2006). Higher educated parents may also be more competent in identifying

child-related or family-related problems and acknowledge that services may be needed to address these.

The majority of utilised services fell under the Act concerning Support and Service for Persons with Certain Functional Impairments (1993:387), shortened LSS in Swedish. The most frequently utilised services concerned support outside the home. Such services can have two aims: respite care for parents and facilitating child participation. The aims of the service *short stay away from the home*, which was utilised by 23% of the families, are to provide respite care for caregivers and to provide a change of scenery for the child. The frequent utilisation of this service likely reflects that parents of children with ID devote significant time and effort to take care of their children (M. B. Olsson & Hwang, 2003) and therefore need time for themselves. Respite care can reduce parental stress and improve the well-being of parents of children with impairments (Hastings & Beck, 2004; Robertson et al., 2011). According to the results of paper III in this thesis, 60% of the parents expressed the need for more time for themselves and 26% support to find a baby-sitter or respite care to be able to attend own activities on a regularly basis. This high percentage matches the frequent use of the service *short stay away from the home*, but also indicates that many parents who need a break do not apply for such services. Perhaps these services do not fit in with the families' everyday lives, or they are not provided in a flexible and individually adapted manner.

The use of *short stay away from the home* may also reflect a heightened need for children with mild ID to have opportunities to participate in activities with other children outside the home. It is known that children with ID are less likely to participate in community-based activities in comparison with their peers (Shields et al., 2014). Approximately 40% of the families who were included in paper III expressed the need for support in finding a suitable recreational activity for their child. This need primarily concerns leisure activities outside of school such as sports. This result is consistent with findings from a review investigating participation in out-of-school activities among children with ID, reporting that children with ID are less likely to participate in structured physical or recreational activities than their peers (Shields et al., 2014). The LSS states that the municipality is obliged to ensure that general leisure and cultural activities are available to all persons entitled to services under the act (Section 15). Participation in recreational and sport activities promotes physical functioning, overall well-being and the inclusion of children with impairments (Murphy & Carbone, 2008). Thus, it is

important that children with mild ID have the opportunity to engage in suitable leisure activities.

For children with mild ID, financial constraints may represent a barrier to leisure activities. The results in paper I showed that several families received financial assistance and according to paper III almost 25% of the families reported financial support needs to pay for rent, food, clothes and medicine. When facing financial hardship, it may be difficult to pay for leisure activities. Furthermore, children with mild ID in Sweden have reported difficulties in using public transportation (Granlund, Huus, Elgmark Andersson, Olsson, & Sjökvist, 2014). Insufficient transport options or the lack of skills to utilise public transportation may prevent participation in leisure activities for children with ID (Foley, Dyke, Girdler, Bourke, & Leonard, 2012). Children with mild ID can receive companion service granted under the LSS. However, because of decisions from the Supreme Administrative Court, eligibility to this service has been tightened, with some municipalities now requiring that the service user pay the companion's expenses (Swedish National Board of Health and Welfare, 2015). The utilisation of companion service among the children in this thesis decreased by 5.5% between 2010 and 2013. This may reduce the children's opportunities to engage in leisure activities.

When HSO professionals assess problems and needs for services among families of children with mild ID, it is important to take into account both disability-related problems and social problems, that is, to use a holistic approach. However, the results in this thesis reveal that less than 7% of the families utilised both disability-related services and those addressing social problems during the same year (not necessarily at the same time). This may imply that social services do not take a holistic approach when supporting these families. Previous studies have also revealed collaboration problems between those social service professionals who handle the provision of child welfare services and those who provide disability-related service provision to children (Staffan Bengtsson, 2007; Boklund Palm, 1995; Svensson, 2009). The Swedish National Board of Health and Welfare have stressed that those children with impairments who also face social problems are at risk of missing out on appropriate services because of the structure of Sweden's social services. That is, child welfare services and disability-related services are usually administered by different departments. Furthermore, the board has signalled that child welfare caseworkers need to improve their knowledge about impairments among children and disability-related caseworkers their knowledge about parenting-related factors (Swedish National Board of Health and Welfare, 2014). Also

international literature has reported that child welfare caseworkers require greater knowledge about impairments (Algood et al., 2011; Lightfoot et al., 2011; Shannon & Tappan, 2011). Insufficient knowledge may lead to both under- and overestimation of the risks for children with impairments (Rosenblum & Ross, 2013) and the absence or inappropriate use of services (Helton & Bruhn, 2013). An on-going issue within this context is that statistics on the child welfare services provided to children with impairments are not systematically coded (Algood et al., 2011). In Sweden, statistics about the provision of child welfare services do not distinguish between children with and without impairments (Swedish National Board of Health and Welfare, 2012a). Therefore, there is a lack of knowledge about child welfare service utilisation patterns among children with impairments (Algood et al., 2011).

Furthermore, there is also concern regarding the coordination of the services provided by different HSOs. Less than 33% of the families utilised both disability-related services and paediatric habilitation services during the same year. Utilisation of both paediatric habilitation services and services to address social problems was relatively uncommon, as was the use of all three kinds of services. This implies that a holistic approach was not used in evaluating the families' needs. Additionally, just because some families did utilise services from more than one HSO, does not ensure that collaboration occurred between the different HSOs. From a theoretical perspective, collaboration problems may exist among the different units in the same HSO and between different HSOs because HSO professionals are highly specialised in their own field. Specialists possess knowledge, training skills and methodologies that direct their observations and assessments towards their specialisation. The narrow use of specialisation means that observations and assessments are limited to those practices that the professionals are skilled in (Hasenfeld, 2010a, 2010c; Hemmelgarn et al., 2010; Lipsky, 2010). Social service professionals who make decisions about disability-related services assess whether a child is in need of services to be able to fully participate in the life of the community (Act concerning Support and Service for Persons with Certain Functional Impairments, 1993:387). In contrast, child welfare professionals safeguard children's development and protect them from harm (Social Services Act, 2001:453). Thus, these two groups observe different aspects of a child's immediate situation. A lack of knowledge in fields other than their own may mean that they are less likely to refer a child to other specialists. Organisational theorists argue that the welfare service system is organised in such a way that it only addresses one problem at a time. Thus, each organisation only pays attention to those aspects of a child for which they are responsible, whether it is health, social or

educational problems (Grape, 2015; Lipsky, 2010). This has been confirmed in studies conducted in Nordic countries. Parents of children with impairments have reported that they are passed around many different HSOs and find it confusing that each HSO has its own mission, legislation and processes to follow (Tøssebro & Wendelborg, 2015). It is often the parents themselves who have to coordinate services between different HSOs (Egilson, 2011; I. Olsson & Roll-Pettersson, 2012). A lack of collaboration between different HSOs may result in fragmented services (Lipsky, 2010). This may mean that only some of the child's and family's needs are met, and some go entirely unmet. Furthermore, it could negatively influence the child's development and the well-being of the family.

In summary, to adequately address the complexity of needs professionals should use a holistic approach when assessing children's requirements. If not, they will be unable to provide support that promotes appropriate development (Baldwin & Walker, 2005).

Needs for support among families of children with mild ID

A high percentage of families expressed the need for information about available services for their family, including both current and future services. Such needs have been reported in numerous studies (Granlund & Roll-Pettersson, 2001; Hodgetts et al., 2014; Nowak et al., 2013; Sahay et al., 2013; Tøssebro & Wendelborg, 2015), and continue to be raised, while also applying to children with mild ID. In Sweden, municipal social services are obliged to engage in outreach activities, to inform citizens and offer their services (Social Services Act, 2001:453). Municipalities are also required to conduct regular surveys to ascertain who is covered by the LSS, their support needs and to ensure that they have their needs met (Act concerning Support and Service for Persons with Certain Functional Impairments, 1993:387). However, according to H. Bengtsson (2005) social service professionals do not properly fulfil their obligation to inform citizens about the LSS, and when information is provided it is not adapted to those who need the information (H. Bengtsson, 2005). The results in this thesis confirm that HSOs, such as social services, do not fulfil their obligation to inform citizens about services. Those parents who expressed a need for information in this thesis (paper III) were parents recruited at parent-teachers meetings at school. Because such meetings are not mandatory, it may be assumed that those parents attending the meetings were more actively involved in their child's schooling and development than those who did not. They may be more competent in advocating for their child than those parents not attending such meetings. Therefore, it is alarming that such a high percentage of parents do not perceive that they have

sufficient knowledge about available services. A lack of knowledge about services has been reported to prevent parents of children with ID from applying for needed services (Douma et al., 2006; Weiss & Lunskey, 2010). Furthermore, unmet service needs have been observed to negatively influence parents' well-being (Bourke-Taylor et al., 2012). Similarly, insufficient knowledge about services availability and not using services are related to lower levels of empowerment and self-efficacy among families of children with ID (Wakimizu et al., 2011). This may negatively influence child development. Thus, it is important that HSOs adequately inform families of children with mild ID about available services.

Other needs commonly reported by the families concerned information about their child's impairment, how to handle their child's behaviour and how to teach their child skills. Such needs have previously been reported by parents of children with impairments, including children with ID (Hodgetts et al., 2014; Roll-Pettersson, 2003; Sahay et al., 2013). The results in this thesis reveal that this also applies to children with mild ID. Such knowledge concerns how to handle everyday family life. The management of everyday life is challenging for all families, but may be harder for families of children with impairments. Studies from Iceland reveal that parents of children with impairments require practical advice about how to simplify everyday life and prevent difficulties (Egilson, 2015). Furthermore, parents' perceptions about their child's health and functional status influence whether parents apply for appropriate services (Andersen, 1995; Andersen & Newman, 1973). Insufficient knowledge may mean that parents overlook or underestimate the impairment-related difficulties experienced by their child. In fact, parents of children with mild ID have reported that they are unlikely to apply for services if they perceive their child's problems as minor (Weiss & Lunskey, 2010). Perhaps minor limitations are not recognised by parents as having a negative impact on everyday family life. Parents of children with impairments have also reported that they find the application process burdensome and time-consuming (Nowak et al., 2013; Tøssebro & Wendelborg, 2015). Thus, it is reasonable that parents do not seek formal services until they perceive them as being absolutely necessary. Because individually adapted services may increase participation (World Health Organization, 2001) and decrease parental burden (Haveman et al., 1997), it is important that HSO professionals sufficiently inform families about the child's impairment and appropriate strategies to use to meet their child's behaviour. Such information has to be provided in a manner that family members understand. The information has to be adapted to the needs of each family member, so that they are able to absorb and use it.

The majority of the parents expressed the need to meet other parents of children with impairments and to read about other parents' experiences. Such informal support has previously been reported to be very important for parents of children with impairments (Carlhed et al., 2003). Although, a child does not directly participate in exosystems such as parents' social networks, exosystems do influence child development through their influences on parents (Bronfenbrenner, 1986). The effectiveness of a family's support networks influence how a family of a child with an impairment cope (Whiting, 2014). Parents with opportunities to discuss child health concerns with social support networks are more likely to utilise child-related services (Harrison et al., 2004). Social services are obliged to offer support to persons who care for a related person with an impairment (Social Services Act, 2001:453). One way to offer families such opportunities is to establish parent support groups. Thus, parents can create informal networks and through these networks become aware of available services and their usefulness.

In summary, in addition to information about available services, other commonly reported family needs concerned information about the child's impairment, how to handle the child's behaviour and teach the child skills, contact with parent support networks, respite care, suitable leisure activities for the child, and financial support to cover basic needs. Of the various legislation concerning support services, the LSS is considered to be the most favourable for persons with certain functional impairments such as ID (Government bill 1992/93:159). This is supported by the results in this thesis, which reveal that almost 95% of the disability-related services provided to the families of children with mild ID were granted under the LSS. However, it is important to acknowledge that the LSS only includes certain services. Some of the needs expressed by the families cannot be met by this act. Such requirements have to be met by other legislation, for example the Health and Medical Services Act (1982:763) or the Social Services Act (2001:453). In this thesis, only a small proportion of disability-related services were granted under the latter act. It is important that children with mild ID and their families are not automatically categorised as belonging to the "LSS category", in that their needs are 'made to fit' within the services provided under the LSS. If so, important information about the family and their needs may be ignored, resulting in unmet needs.

Family support needs and experiences of support in relation to parental self-efficacy and parents' control over services

Families with mothers with higher educational levels expressed a lower need for support (e.g., counselling, contact with other parents of children with impairments, more friends and time for themselves). This may be because these parents feel more able to handle everyday life than parents with lower levels of education. Bronfenbrenner and Ceci (1994) argue that parents with a lower level of educational attainment may need external resources to acquire the necessary skills to support their child's development. Another explanation could be that parents with higher level of education are more aware of available services and more competent in advocating for their child and getting family needs met. Families with mothers in paid employment also expressed a lower need for support. It may be that participating in paid employment provides greater access to external contacts and the possibility for mothers to have time for themselves. M. B. Olsson and Hwang (2006) found that participation in paid work was positively related to the well-being of parents of children with ID living in Sweden. This may also apply to children with mild ID. The perceived need for financial support was also lower among those families with a mother in paid employment.

Parents with higher levels of self-efficacy reported a lower need for information, including information about available services. This is consistent with previous findings noting that insufficient knowledge about available services among families of children with ID is related to lower levels of self-efficacy among caregivers (Wakimizu et al., 2011). This may be explained by the fact that the more knowledge parents have about child impairment, its effects and available services, the better they will be at identifying service needs. Decreased informational needs were also associated with higher levels of parents' control over services. Furthermore, parents who perceived higher levels of control over services experienced both general and specific support (i.e., support from social services and paediatric habilitation units) as being more helpful. This is similar to earlier findings in other contexts, noting that if support is provided in a participatory, capacity-building manner, it is experienced as more helpful by parents. It is likely that this makes parents feel more competent and reduces their stress (Dempsey & Keen, 2008; Dunst et al., 2007). Parents have reported that capacity-building practices increase their opportunities to receive needed services (Dempsey & Keen, 2008). The results in this thesis reveal that this also may apply to children with mild ID living in Sweden.

Parents' control over services was also found to be related to parental self-efficacy. This has been found among parents of children with impairments in other contexts. When HSO professionals work in a manner that actively encourages parental participation in identifying their concerns and suitable responses, it promotes existing strengths and increases parental self-efficacy and well-being. This in turn influences child -parent interactions and enhances child development and psychological health (Dunst & Trivette, 2009; Trivette et al., 2010). In summary, to effectively meet the needs of families with children with mild ID, HSO professionals should collaborate with the parents and support their abilities and promote their involvement in decision-making processes. This may improve parents' knowledge about services and how to gain access to them.

Service utilisation in relation to child's school setting

Papers I and II revealed that children with mild ID who attended self-contained classes were more likely to utilise disability-related services provided by social services and paediatric habilitation services than children with mild ID who were integrated into mainstream classes. The former also utilised a higher number of types of services from both types of HSOs. Among families of children who attended self-contained classes, more than 70% utilised paediatric habilitation services and 50% utilised disability-related services provided by social services. The figures for integrated children were 43% and 7% respectively. These figures may be a sign that services are structured around self-contained classes and therefore not as accessible for children who are integrated into mainstream classes. To further investigate service utilisation patterns in relation to the school setting a study with a longitudinal approach was conducted (paper IV). The study confirms previous results:

- Children with mild ID in self-contained classes were more likely to utilise disability-related services during 2009 -2013 than children who were integrated into mainstream classes.
- When children changed their school setting from a mainstream class to a self-contained class, they were more likely to begin to utilise disability-related services than children who remained in mainstream classes.
- When children changed their school setting from a mainstream class to a self-contained class, they became more likely to increase the number of disability-related service types utilised in comparison to children who remained in mainstream classes.

The only hypothesis that was not confirmed concerned the association between school setting and the number of disability-related service types utilised. Children in self-contained classes did not utilise a higher number of disability-related service types than children integrated into mainstream classes. This is in contrast with the results in paper I. The differences are likely owing to the choice of analytical approaches. When analysing the differences in the number of service types utilised all children were included in paper I, regardless of whether they utilised services. In paper IV children who did not utilise services were excluded. The latter seemed an appropriate approach because the analysis concerned the number of services utilised. If those who utilised no services were included, the analysis would partly concern the likelihood to utilise services; that is, the relation investigated in hypothesis 1. Only age was related to the number of service types utilised; as children grew older they utilised a higher number of service types. This is consistent with the fact that as children with impairments grow older and parental responsibility decreases, children usually become more dependent on formal services. Tasks in everyday life become more complex and demanding as an individual gets older and thus it is reasonable that children with mild ID will need a wider range of service types.

One explanation for the higher rate of service utilisation among children attending self-contained classes might be that these children have more profound impairments and therefore experience more pronounced disabilities. For instance, Majnemer et al. (2014) found that among children with cerebral palsy, those who attended special schools were more inclined to utilise rehabilitation services than those who attended mainstream schools. In that study it was explained that children who attended mainstream schools had milder motor and intellectual deficiencies in comparison with children in special schools and therefore had a lesser need for services. However, adaptive functioning and IQ are not highly correlated for persons with mild ID (Arvidsson & Granlund, submitted; Reschly et al., 2002) and most of the children included in this thesis have mild ID. In a study investigating cognitive ability, general health, behaviour and social skills, hearing, communication and ability to use extremities in children with mild ID living in Sweden, Elgmark Andersson et al. (in prep.) found no statistically significant differences in functional abilities between children in self-contained classes and those who were integrated into mainstream classes. The children included in their study lived in the same county as the children included in paper IV. Approximately 12% participated in both studies. Similarly, an Irish study focusing on school settings found no significant differences in social competence between children with moderate

ID in segregated and integrated school settings (Hardiman, Guerin, & Fitzsimons, 2009). Thus, there is no reason to believe that differences in service utilisation between children attending self-contained classes and those attending mainstream classes in this thesis is explained by differences in degree of impairment.

Furthermore, paper IV revealed that children who remained in self-contained classes were more likely to start utilising disability-related services than children who remained in mainstream classes. Furthermore, the former children were also more likely to increase the number of service types utilised than children who remained in integrated settings. This implies that the mere presence in a self-contained class, whether previously attending a mainstream class or not, is more favourable for children with mild ID when it comes to service utilisation outside the school, provided that the services utilised are effective. In terms of Andersen's Behavioural Model of Health Service Use (Andersen, 1995; Andersen & Newman, 1973), a self-contained class can be seen as an enabling factor for service utilisation outside of school. Of the 28 children who changed school setting from a mainstream class to a self-contained class, 50% changed school setting when they began secondary school (in seventh grade). It is unlikely that the needs of those children changed because of problems at that specific age. Perhaps school setting is related to the organisational structure in the education system as well as the utilisation of disability-related services provided by social services.

The Education Act (2010:800) stresses that in actions concerning children, the best interests of the child shall be the first consideration. However, reasons for integrating pupils with ID is commonly based on reasons other than the child's educational needs, such as the size and population structure of the municipality, school administrators' interpretation of the concept of integration and how it should be carried out, or requests from guardians (Swedish National Agency for Education, 2002). Furthermore, the percentage of children who are integrated ranges from 0% to 100 % among Swedish municipalities (Swedish National Agency for Education, 2014b). Thus, in some municipalities all children are automatically integrated, whilst in others, all children are placed in self-contained classes. It is debatable whether all children with mild ID in a municipality have the same needs in terms of school setting. Reports by parents of children with ID reveal that parents are not always sufficiently informed and involved in the decision about school placement of their child (Roll-Pettersson, 2001) and

sometimes they experience resistance from school administrators when they request that their child be integrated into a mainstream class (Westling Allodi, 2007a).

A further explanation of the differences in service utilisation between integrated and non-integrated children might be that the characteristics of parents of children with mild ID attending self-contained classes differ from those of parents of children integrated into mainstream classes. A Polish study observed that children with ID living in families with higher socioeconomic status were more likely to be placed in integrated school settings and that their parents were more engaged in their education (Szumski & Karwowski, 2012). Such patterns may also be evident in Sweden. However, the fact that local municipal factors widely influence the organisation of education for pupils with ID implies that there is a limited opportunity for parents to their child's school setting (Westling Allodi, 2007b). Therefore, service utilisation patterns in relation to school setting are likely influenced by other variables, such as organisational variables within the various exo, meso and micro levels.

Parkes et al. (2004) observed that children with cerebral palsy in mainstream schools were less likely to receive physiotherapy than those who attended special schools. These differences remained after controlling for the severity of both intellectual and motor impairments. Thus, the authors claim that the differences may be a result of system characteristics rather than the children's needs; that is, the provision of paediatric physiotherapy to children with cerebral palsy is structured around special schools. In a Canadian study, parents of children with impairments reported that services from HSOs other than schools (social services and healthcare authorities) were easier to access when the child attended a special school than a mainstream school (Tétreault et al., 2014). It may be that such organisational structures at the exo level can explain the differences found in this thesis. With regard to the meso level, disability specialists from social services and paediatric habilitation units attend parent-teacher meetings for parents of children with mild ID attending self-contained classes to inform them of available services. This approach can hardly be used to inform parents of children attending mainstream classes. Therefore, it is possible that these families have less knowledge about services and how to gain access to them. It is also likely that they do not see themselves as potential service utilisers. With regard to the micro level at school, these parents have limited opportunities to meet other parents of children with mild ID to share experiences and knowledge with, because their child may be the only one in the class with ID. Therefore,

they may lack information about possible support and services, which is an obstacle for service utilisation.

A further explanation of the differences in service utilisation in relation to school setting, might be that teachers in self-contained classes are more knowledgeable about mild ID, its effects and possible support requirements, both in educational and other settings. In Sweden, teachers in self-contained classes are required to have a teaching certificate in special education, specialising in ID; this is in contrast with teachers in mainstream classes (Regulation on jurisdiction and certification of teachers and preschool teachers, 2011:326). Therefore, they may be better at identifying service needs of pupils with mild ID. This explanation is confirmed in part by reports from teachers in mainstream school settings, revealing that they find it hard to fulfil the needs of both a child with ID and the rest of the class (Forlin, 2001). It has also been observed that mainstream teachers prioritise the collective needs of the class rather than the individual needs of pupils with impairments (Hemmingsson, Gustavsson, & Townsend, 2007). Furthermore, reports by parents of children with ID reveal that school practices in self-contained classes seem to be more family-centred than practices in mainstream settings, implying that organisational structures influence collaboration between parents and school professionals (Roll-Pettersson, 2004). Family-centred practices acknowledge parents as experts regarding their own child and involve them in decisions about service provision (Rosenbaum et al., 1998). When teachers collaborate with parents of children with mild ID and involve them in service provision, the child's needs for both educational services and services outside school may become more visible.

On the macro level, international policy advocates that children with impairments in need of special support should be educated in mainstream settings and receive needed support in that context to promote their inclusion (United Nations, 2006; United Nations Educational Scientific and Cultural Organization, 1994). Swedish national policy emphasises equity and inclusion, expressed by the concept "a school for all" (Berhanu, 2011). However, inclusion is not clearly defined or established as a definite goal in national educational policy documents. Therefore, interpretations vary extensively at the municipal level (Göransson et al., 2011), as do teaching arrangements for children with mild ID (Swedish National Agency for Education, 2002). Furthermore, there is no consensus among teachers concerning the most favourable school setting for children with ID (Westling Allodi, 2007a), and the parents of these children have reported uncertainty about which school setting would be most appropriate for their child

(Westling Allodi, 2007b). The integration of pupils with ID into mainstream classes aims to facilitate their inclusion (Michailakis & Reich, 2009). However, the results in this thesis imply that children with mild ID who are integrated into mainstream classes may be at risk of not receiving those disability-related services that promote active participation in society. Integration in school may be counterproductive to inclusion outside school as long as the welfare system is not designed in a way that it can handle more than one problem and/or one living environment at the time.

Comprehensive understanding

The factors that either aid or hinder the provision of services for families of children with mild ID can be identified in the various levels of an ecological system. From a micro level perspective, it can be argued that families do not apply for services and therefore do not receive needed services because of a lack of information about services and how to apply for them (Weiss & Lunskey, 2010). From a meso level, it can be claimed that needs are not met because HSO professionals do not sufficiently inform parents about services and do not provide services in a participatory, capacity-building manner when interacting with parents (Dempsey & Keen, 2008; Dunst et al., 2007). From an exo level perspective, it may be said that family needs are not met because HSO professionals do not use a holistic approach and do not effectively collaborate nor coordinate services when supporting these families (Lipsky, 2010; Tøssebro & Wendelborg, 2015). Regarding the macro level, it can be discussed that the design of the LSS poses a risk that experienced problems among families of children with mild ID are moulded to fit those services provided under this act. This means that although LSS services are provided, they may not accommodate overall family needs, as some needs may not be met by these services. However, to gain holistic knowledge about a phenomenon there is a need to not only study it from various levels, but also to integrate the obtained knowledge to a wholeness (Bhaskar & Danermark, 2006). In this context, such knowledge may promote how better to meet the needs of families of children with ID.

Overview of obstacles and facilitators to meet the needs of families of children with mild ID

Obstacles

- Paediatric habilitation units, social services and educational authorities have different tasks, are regulated by different acts and perform their assignments in accordance with different policies, objectives and goals (*macro level*). Thus, it is problematic to provide services using a holistic approach and collaboration is difficult (*exo level*). The overlapping of service utilisation are relatively uncommon among families of children with mild ID. This may entail that only some of the families' needs are met (*micro level*).

- Few families utilise both child welfare services and disability-related services (*micro level*). This implies that child welfare caseworkers and social service professionals who provide disability-related services do not engage in effective collaboration (*exo level*). Therefore, there is little evidence of a holistic approach in the provision of services to these families (*meso level*), and as a result, the complexity of the families' problems may not be detected. This may lead to inappropriate and/or fragmented services that only meet these families' needs to a certain degree (*micro level*).
- Children who are integrated into mainstream classes are less likely to utilise paediatric habilitation services and disability-related services provided by social services than those who attend self-contained classes. This implies that the provision of out-of-school services is organised around self-contained classes (*exo level*). This may negatively influence child development and reduce the likelihood of children's and families' participation in society (*micro level*).
- Parents of children with mild ID lack information about available services and where to apply for them (*micro level*). This implies that HSO professionals are not fulfilling their mandate to properly inform citizens about available services (*exo level*). Because parents must possess knowledge about services before they can apply for them, service utilisation among these families is likely not exclusively needs-driven. That is, utilisation is not in accordance with needs, implying that families' needs are not fulfilled because of limited knowledge (*micro level*).
- Parents of children with mild ID do not possess adequate knowledge about the child's impairment and how to respond to the child (*micro level*). Because knowledge about the child's impairment and symptoms facilitates awareness of when and how to request services, this may lead to underutilisation of services and unmet needs (*micro level*).
- Parents have difficulty in finding community-based leisure activities for their child (*micro level*). This implies that communities and social services are failing to adequately promoting access to leisure activities for children with impairments (*exo level*).

- A relatively high percentage of families of children with mild ID face financial hardship. Reported difficulty in paying for basic needs, such as rent, food, clothes and medicine (*micro level*), may lead to reduced participation for both children and parents (*micro level*).

Facilitators

- Integrated children who change school setting to attend self-contained classes are more likely to start utilising disability-related services provided by social services than those who remain integrated. Furthermore, integrated children who change school settings also become more likely to increase the number of disability-related services types utilised (*micro level*). This indicates that the provision of out-of-school services is organised around self-contained classes (*exo level*).
- Families in which mothers participate in paid employment (*exo level*) report a lower need for financial support (*micro level*).
- Families in which mothers participate in paid employment (*exo level*) report a lower need for such support that concerns counselling, more friends, contact with other parents of children with impairments and more time for themselves (*micro level*).
- Also families with mothers with higher levels of education report a lower need for such support (counselling, more friends, contact with parents of children with impairments and more time for themselves) (*micro level*).
- Parents who perceive higher levels of parental self-efficacy (*micro level*) have a lower need for information regarding available services and the child's impairment and development (*micro level*).
- Parents who perceive higher levels of control over services (*meso level*) have a lower need for information (*micro level*).
- Parents who perceive higher levels of control over services (*meso level*) perceive both general support and support from social services and paediatric habilitation units as more helpful (*micro level*).
- Parents who perceive higher levels of control over services (*meso level*) perceive higher levels of parental self-efficacy (*micro level*).

- Younger children (*micro level*) are more likely to utilise paediatric habilitation services and also utilise a higher number of service types (*micro level*).
- As children grow older (*micro level*) they utilise a higher number of disability-related services provided by social services (*micro level*).

Conclusions

Less than 50% of the families in this thesis utilised services provided by social services. Approximately 40% used disability-related services and 25% services to address social problems. This relatively high proportion of service utilisation across services indicates that families of children with mild ID, in addition to disability-related problems, may also be at a higher risk of experiencing social problems when compared with the general population. However, families that utilised services provided by social services, rarely utilised both disability-related services and services that address social problems. This implies that collaboration between professionals concerned with child welfare services and those who are concerned with disability-related services need to be improved.

Type of school setting was a strong predictor of service utilisation, with higher utilisation rates for children attending self-contained classes. The result indicates that service systems outside of school are designed to collaborate with groups of pupils in special classes rather than individual children in mainstream classes. Furthermore, it is likely that self-contained classes provide a more information-rich environment for parents concerning services than mainstream environments. Both teachers and parents in this setting are probably more knowledgeable about ID, its effects and out-of-school services.

Service utilisation is partly dependent on age, with younger children being more likely to use paediatric habilitation services and older children using a higher number of disability-related service types. This pattern confirms that children primarily receive diagnoses and skills training at younger ages, whilst the demands of functioning outside the home increase with age.

Family support needs primarily concern three types of needs: a) information about available current and future services, b) information about how to handle child impairments and functioning and c) having time for oneself. The strong need for information highlights the requirement to identify and implement those factors concerning the information dissemination. Important factors include context (school setting), HSO routines (outreach activities) and the characteristics of both the family and child (e.g., parents' educational background, employment, financial circumstances and possible cognitive limitations).

The results indicate that there are statistical relations between parental self-efficacy, parents' control over services and perceived family needs. Parents who consider themselves to have a high level of parental self-efficacy and control over services have lower perceived needs. Interpreted in light of previous research, this indicates that HSO professionals must work in a capacity-building manner with the explicit goal to enhance self-efficacy in parents.

Implications for practice

The overall implication is that HSO professionals need to acknowledge that children's needs have to be assessed using an ecological framework:

- When social service professionals assess the needs of children with mild ID and their families, it is important to take into account both disability-related needs and those concerning social problems and to then coordinate these services. Social services need to establish processes that ensure that a holistic approach is used during both assessments and service provision.
- Social service professionals need to improve their engagement in outreach activities so that families of children with mild ID are informed about services, their needs are recognised and then services provided. The provision of information should concern both current and future services, enabling long-term planning for the families. Compulsory school is mandatory and thus offers a good opportunity to reach all families. Professionals in social services and schools need to improve collaboration concerning the provision of information and services to meet the individual needs of the families. It is especially important that the welfare system is organised in such a manner to include children attending mainstream classes.
- HSO professionals need to inform families of children with mild ID about their child's impairment and strategies to support their child's development and everyday functioning. Information should be adapted to the individual needs of the children and families to ensure that it is accessible and effective.
- HSO professionals need to collaborate with parents of children with mild ID in their provision of services, support parents in gaining knowledge about available services and involve them in decisions about services. This may improve both parents' control over services and parental self-efficacy.
- Social services need to support the families to find community-based recreational activities for their children and to improve their ability to facilitate access to such

activities. Leisure activities for children will also provide parents some time for themselves.

- Social services and paediatric habilitation units should establish parent support groups for families of children with mild ID, so that families can exchange experiences and advice. Through these networks they may become more aware of available services and their effectiveness, as well as building informal networks that may reduce dependence on service systems.

Implications for further research

- Further knowledge is needed regarding barriers to collaboration between social service professionals providing child welfare services and those providing disability-related services. Such knowledge may be used to eliminate obstacles and enable a holistic approach when supporting families of children with mild ID.
- How families of children with mild ID enrolled in compulsory school for pupils with ID come in contact with social services and paediatric habilitation units needs to be examined. This knowledge may be used to improve the development of processes to ensure that these families have the opportunities to utilise services at an early stage.
- Research concerning the motives for the placement of pupils with mild ID in various school settings, and the reasons for changing school settings is lacking. Such research should adopt an ecological framework that focuses on the characteristics of the child, family, school and municipality.
- Because practical teaching arrangements for integrated children with mild ID varies, there is a need for further knowledge about these arrangements, and if and how such structural characteristics influence service utilisation outside of school. Greater knowledge is also required concerning collaboration between teachers and professionals within social services and paediatric habilitation units regarding children with mild ID.

Summary in Swedish/Svensk sammanfattning

Den här avhandlingen handlar om barn med lindrig utvecklingsstörning och deras familjer – deras behov av stöd, användande av stöd och service och erfarenheter av stöd.

Syfte

Det övergripande syftet med avhandlingen var att utforska och beskriva familjernas mönster av serviceutnyttjande utifrån ett systemperspektiv.

Metod

Tvärsnittsstudier med beskrivande och jämförande design användes för att beskriva i vilken utsträckning 84 barn med lindrig utvecklingsstörning och deras familjer använde behovsprövade stödinsatser från socialtjänsten och barn- och ungdomshabiliteringen (artikel I och II). Typer av och antal använda stödinsatser utforskades i relation till barnets ålder, kön och typ av skolform, i meningen om barnet undervisades i en grundsärskoleklass eller var integrerad i en grundskoleklass. Data om användande av stödinsatser hämtades in från register i socialtjänst och barn- och ungdomshabilitering. Artikel III avser en enkätstudie i vilken föräldrar till 38 barn med lindrig utvecklingsstörning intervjuades om vilka behov av stöd de upplever att deras familj har samt deras erfarenheter av stöd. Vidare undersöktes familjernas behov av stöd i relation till (a) självtillit i föräldraförmåga och (b) föräldrars upplevelse av kontroll över stödet. Även föräldrarnas upplevelser av hur hjälpsamt stödet varit studerades i relation till (a) självtillit i föräldraförmåga och (b) föräldrarnas upplevelse av kontroll över stödet. För artikel IV användes en jämförande, hypotesprövande och longitudinell design för att undersöka om användande av stödinsatser från socialtjänsten skiljer sig åt över tid mellan barn med lindrig utvecklingsstörning som går i grundsärskoleklass och barn som är integrerade i grundskoleklasser. I studien deltog 405 barn.

Resultat

Stödinsatser från barn- och ungdomshabiliteringen användes av 62 % av familjerna under 2011. Läkare, kuratorer och psykologer var de professioner som flest familjer fick stöd av. I genomsnitt 42 % av familjerna använde stödinsatser från socialtjänstens funktionshinderomsorg (FO) under åren 2009-2013, inberäknat personlig assistans enligt socialförsäkringsbalken. Sådana insatser har som syfte att minska eller eliminera funktionshinder och därigenom öka delaktigheten i samhällslivet. Majoriteten av insatserna

från funktionshinderomsorgen var beviljade enligt lag om stöd och service till vissa funktionshindrade, LSS. De vanligaste insatserna var korttidsvistelse, korttidsstillsyn och ledsagarservice, d.v.s. insatser som avser stöd utanför hemmet. Sådana insatser kan möjliggöra ökad delaktighet för barnen, men också ge föräldrar möjlighet till avlösning i omvårdnadsarbetet. Drygt 25 % av familjerna använde stödinsatser från socialtjänstens individ- och familjeomsorg (IFO) under 2011, inberäknat barnen, föräldrar och syskon. Sådana insatser ska vara ett stöd vid olika typer av sociala problem. Den vanligaste insatsen var försörjningsstöd till föräldrarna. Under åren 2009-2013 fokuserades helt på sådana IFO-insatser som beviljats av barn- och ungdomsenheterna, d.v.s. sådana insatser som ska skydda barn från en negativ utveckling. I genomsnitt använde 12 % av familjerna sådana IFO-insatser under de studerade åren. De vanligaste insatserna var familjeterapeut och familjepedagog, d.v.s. stöd som avser stöd i föräldrarollen. Majoriteten av familjer använde dock inte stödinsatser från socialtjänsten och mindre än 7 % av familjerna hade insatser från både funktionshinderomsorg och individ- och familjeomsorg under samma år (inte nödvändigtvis samtidigt).

När det gäller barnens ålder så var yngre barn mer benägna att använda stöd från barn- och ungdomshabiliteringen än äldre barn. De förra använde också flera typer av insatser, i meningen stöd från flera typer av professioner. När det gäller funktionshinderomsorgens insatser så använde äldre barn fler typer av insatser. Få könsskillnader hittades gällande användande av insatser.

En hög andel av familjerna uttryckte behov av att få mer information om vad det finns för stöd och service för deras barn, både aktuellt (79 %) och framtida (92 %) stöd. Familjerna uttryckte också behov av mer information om sitt barns funktionsnedsättning, hur de ska bemöta sitt barn och lära det olika färdigheter. De intervjuade föräldrarna efterfrågade också möjligheter att komma i kontakt med andra föräldrar till barn med funktionsnedsättning att utbyta erfarenheter med, samt att få mer tid för sig själva. En annan svårighet som framkom var att hitta en lämplig fritidsaktivitet till barnet och nästan 25 % av familjerna uppgav att de skulle behöva ekonomiskt stöd för att betala hyra, mat, medicin, kläder och transporter.

Familjer i vilka mödrarna förvärvsarbetade uttryckte ett lägre behov av sådant stöd som avser rådgivning, kontakt med andra föräldrar till barn med funktionsnedsättning, att få fler vänner och tid för sig själva, i jämförelse med familjer i vilka mödrarna inte förvärvsarbetade. Samma mönster utkristalliserades för familjer i vilka mödrarna hade högre utbildningsnivåer.

Föräldrar med högre självtillit i föräldraförmåga gav uttryck för lägre behov av information än de med lägre nivåer av sådan självtillit. Även föräldrar som uttryckte högre nivåer av kontroll över stöd och service sade sig ha ett lägre behov av information än föräldrar med lägre nivåer av kontroll över stöd. De förra upplevde också både generellt och specifikt stöd som mer hjälpsamt än de senare. I detta sammanhang avsåg specifikt stöd insatser från socialtjänst samt barn- och ungdomshabilitering.

Vid jämförelse av användande av stödinsatser mellan barn med lindrig utvecklingsstörning i grundsärskoleklass och de som integrerats i grundskoleklass framkom att barn i grundsärskoleklass är mer benägna att använda insatser från FO och insatser från barn- och ungdomshabiliteringen. Integrerade barn som bytte till en grundsärskoleklass blev mer benägna att använda insatser från FO i jämförelse med de barn som fortsatte vara integrerade. De förra blev också mer benägna att öka antalet använda FO-insatser efter byte till grundsärskoleklasser i jämförelse med de som fortsatte vara integrerade i grundskoleklasser. Sådana mönster kunde inte urskiljas när det gäller användande av IFO-insatser.

Slutsatser och implikationer för praktiken

Utöver behov som är relaterade till barnets funktionsnedsättning kan familjer med barn med lindrig utvecklingsstörning också vara mer utsatta för sociala problem än den generella befolkningen. Få familjer använde stöd från både FO och IFO, vilket indikerar att socialsekreterare inom IFO och LSS-handläggare inom FO behöver effektivisera sitt samarbete. Behov bland barn med lindrig utvecklingsstörning och deras familjer behöver bedömas utifrån ett ekologiskt perspektiv. Socialtjänsten behöver beakta både behov som är relaterade till barnets funktionsnedsättning och sådana som avser sociala problem och koordinera insatser som ges. För att undvika att bara vissa av familjernas behov tillgodoses behöver socialtjänsten upprättas processer som säkerställer att ett holistiskt perspektiv används under både behovsbedömning och verkställande av insatser.

Skolklassstillhörighet var en stark prediktor för användande av stödinsatser: barn i grundsärskoleklasser använde i högre utsträckning både FO-insatser från socialtjänsten och insatser från barn- och ungdomshabiliteringen än barn som var integrerade i grundskoleklasser. Det indikerar att servicesystemet utanför utbildningssystemet är organiserat att samverka med grupper av elever i specialklasser snarare än med enskilda barn i grundskoleklasser. Socialtjänsten behöver utveckla sin uppsökande verksamhet så att barn med lindrig utvecklingsstörning får tillgång till behövliga stödinsatser. Då grundskolan är

obligatorisk så erbjuder den en lämplig plattform för att fånga upp familjer som kan behöva insatser av olika slag. Det är av vikt att människovårdande organisationer, så som socialtjänst och barn- och ungdomshabilitering, samarbetar ändamålsenligt kring dessa familjer, och inte minst att även de familjer vars barn är integrerade får möjlighet till behövligt stöd även utanför skolan.

Familjerna uttrycker i hög grad behov av information om tillgängligt stöd och om hur de ska hantera sitt barns funktionsnedsättning, vilket antyder att människovårdande organisationer behöver bli bättre på att informera om tillgängligt stöd och om barnets funktionsnedsättning samt att anpassa informationen så att familjerna kan tillgodogöra sig den. I sammanhanget behöver faktorer på både mikro-, meso- och exonivå beaktas.

Professionella inom människovårdande organisationer bör vinnlägga sig om att involvera och samarbeta med föräldrar vid behovsbedömningar och verkställande av insatser till barnet och familjen. Samarbetet kan stärka föräldrars självförtroende i föräldrarollen och deras upplevelse av kontroll över stöd och service.

Familjer med barn med lindrig utvecklingstörning behöver mer stöd av socialtjänsten att hitta lämpliga fritidsaktiviteter till sitt barn, men också att komma i kontakt med andra föräldrar till barn med funktionsnedsättning.

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