

Children with blindness: Developmental aspects, comorbidity and implications for education and support

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Abstract

The overall aim of this research is to deepen the knowledge about developmental aspects, comorbidity and implications for education and support provision, regarding children with blindness. Special focus is directed towards children with blindness and autism spectrum disorder (ASD).

The research comprises three different projects, reported in five papers. The studies adopt different designs; one is record-based and explores clinical characteristics and etiologies of Swedish children with blindness, one has a longitudinal design with collection of qualitative as well as quantitative data, and explores the school outcome for braille reading students in inclusive education; and one has a mainly qualitative design and explores diagnostic challenges and support to children with blindness and ASD and their families. Both children's, parents' and teachers' perspectives are included in the research.

The results show that children with blindness are very rare; in average seven blind children per year are born in Sweden. Moreover, isolated blindness is unusual in children, and the rate of multidisability is high. The comorbidity with ASD and intellectual disability (ID) is high, especially in certain etiological groups. Competence about children with blindness is necessary in assessment and diagnostic procedures, to differentiate between effects of blindness and possible additional disabilities. The results also highlight the fact that the support provided to children with blindness, with and without additional disabilities, is perceived as insufficient and does not correspond to the complex needs of the population. Teachers need more competence in braille and teaching methods, especially regarding blindness and additional disabilities such as ASD. Parents ask for a more coordinated support with a life-long scope, provided by professionals with expertise in children with blindness.

The opinions about inclusive education differ in the studies; both students, parents and teachers point to advantages as well as challenges. However, for the schools to be able provide equal educational opportunities for children with blindness in the inclusive setting, the support must be further developed and the national responsibility for unusual disability groups must be extended.

Keywords: *Blindness, comorbidity, autism, intellectual disability, inclusive education, support, braille, children, parents, teachers.*

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FOR EDUCATION AND SUPPORT

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To Hilma, my sunshine.

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The research comprises three different projects, reported in five papers. The studies adopt different designs; one is record-based and explores clinical characteristics and etiologies of Swedish children with blindness, one has a longitudinal design with collection of qualitative as well as quantitative data, and explores the school outcome for braille reading students in inclusive education; and one has a mainly qualitative design and explores diagnostic challenges and support to children with blindness and ASD and their families. Both children's, parents' and teachers' perspectives are included in the research.

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Stockholm 2018-05-18

Kim de Verdier

Preface

As a clinical psychologist at Resource Centre Vision (RCV) for many years, I have performed developmental assessments of children with blindness, and provided counselling and education to their parents and teachers. In my encounters with the children, I have begun to discover something about what it means to approach the world and try to make sense of it, without the use of vision. I have been introduced to new, exciting ways to perceive the surrounding world through other senses, but I have also gained insight into the difficulties regarding how to fully grasp what everything means, what is really going on, and how to master different skills, without the visual information to clarify and facilitate the process. Blindness has a significant impact on a child's development, and entails specific learning needs. A great responsibility lies on the environment to support the child, and provide opportunities for optimal development. In order to properly shape the support, knowledge about the consequences of the lack of vision for development and learning is required.

Moreover, a significant proportion of all blind children has additional disabilities besides the blindness, which brings further challenges. An especially complex group is children with blindness in combination with autism spectrum disorder (ASD), with or without intellectual disability (ID). These children generally have profound information processing difficulties, and need specifically adapted support and interventions. Teaching methods suitable for blind children, and standard methods applied for sighted children with ASD, are not always compatible. Thus, methods have to be carefully modified to suit the child, and again, this requires adequate competence. Through my work at RCV, I have come to develop a particular interest in this group of children, since it is often especially difficult to find an optimal school placement for a child with this complex combination of disabilities, and provide proper support according to their specific needs.

For more than thirty years, the majority of Swedish children with blindness, with and without additional disabilities, attend inclusive educational settings in local schools around the country. Due to the fact that childhood blindness is unusual, the child is generally the only one in the school, or most often in the whole community, with this specific disability. The Swedish municipal autonomy implies that each school is responsible for creating equal educational opportunities for all children, including a child with blindness. However, in general it is impossible for the communities to build sustainable

knowledge and experience of the pedagogical consequences of blindness, since a child with blindness is perhaps born in the area only once during a period of many years. Therefore, teaching a child with no, or very limited, vision, is generally a completely new experience for the teachers in the local schools, who become responsible for the child's education.

Over the years, I have come across many stories about blind children's situation in and out of school. Some have had positive experiences, both pedagogically and socially, but too many have described unsatisfactory outcomes, with poor support as well as poor social inclusion. Many children, parents and teachers seem to share similar experiences of challenges regarding the school situation, and support issues within the inclusive setting. However, despite several years of inclusive education for children with blindness in Sweden, no systematic research has been performed regarding these children's specific needs, how they experience their school situation, how families and teachers experience the support provided on different levels, and to what extent the children receive equal educational opportunities. Overall, the research field focusing on children with blindness in relation to developmental aspects, education and support needs and provision, is still very limited, both nationally and internationally.

In the light of the above, through this thesis, I want to make children with blindness, with or without additional disabilities, more visible in the discussion about education and support provision. The thesis is about all children's right to education, adequate support, and the opportunity to develop their fullest potential. It is also about the necessity of recognizing the specific needs of children with unusual disabilities, who are far too often expected to "play the game" according to rules that were not set up based on their prerequisites.

Note on terminology:

In the thesis I alternate between using person-first language; i.e. "*children with blindness*" and disability-first language, i.e. "*blind children*". The reason behind this is that the participating families used both expressions. Some emphasized putting the child before the disability, while others felt that putting "blind" first felt natural and clarifying. By using both expressions, without weighing them against each other, I wish to reflect the families' choice of language.

Projects and research groups:

The thesis was based on three research projects, reported in five papers: Project A (study I), project B (studies II and III), and project C (studies IV and

V). Each project was carried out in collaboration with different research groups:

- In project A, data collection was performed by Kim de Verdier (KDV), psychologist at Resource Center Vision and PhD student at Stockholm University. Analysis was performed by KDV, along with Ulla Ek (UE), psychologist and professor emerita in special education at Stockholm University, principal supervisor; Elisabeth Fernell (EF), MD and professor at Gillberg Neuropsychiatry Centre, Institute of Neuroscience and Physiology, University of Gothenburg, and co-supervisor; Stefan Löfgren (SL), MD, Associate Professor, Senior Consultant Pediatric Ophthalmology at St. Erik Eye Hospital.
- Project B was carried out in two phases. In the project's first phase, data collection and analysis was performed by KDV, together with Anders Rönnbäck (AR), special needs advisor, and Annica Winberg (AW), social worker, at Resource Center Vision. In the second phase, data collection was performed by KDV and analysis by KDV and UE.
- In project C, data collection was performed by KDV and the analysis by KDV, UE and EF.

In the thesis, the researchers will be referred to with the above abbreviations.

List of publications

The thesis was based on three research projects, reported in the five following papers (I – V):

Project A

- I. de Verdier, K., Ek, U., Löfgren, S., & Fernell, E. (2017). Children with Blindness – Major Causes, Developmental Outcomes and Implications for Habilitation and Educational Support: a two-decade, Swedish Population-based Study. *Acta Ophthalmologica*. Epub ahead of print. doi: 10.1111/aos.13631.

Project B

- II. de Verdier, K., & Ek, U. (2014). A Longitudinal Study of Reading Development, Academic Achievement, and Support in Swedish Inclusive Education for Students with Blindness or Severe Visual Impairment. *Journal of Visual Impairment & Blindness*, 108, 461-472.
- III. de Verdier, K. (2016). Inclusion in and out of the classroom: A longitudinal Study of Students with Visual Impairments in Inclusive Education. *British Journal of Visual Impairment*, 34(2), 130-140.

Project C

- IV. de Verdier, K., Fernell, E. & Ek, U. (2018). Challenges and Successful Pedagogical Strategies: Experiences from Six Swedish Students with Blindness and Autism in Different School Settings. *Journal of Autism and Developmental Disorders*, 48, 520-532. doi: 10.1007/s10803-017-3360-5.
- V. de Verdier, K., Fernell, E., & Ek, U. Blindness and autism: Parents' perspectives on diagnostic challenges, support needs and support provision. *In manuscript*.

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Abbreviations

AD/HD	Attention Deficit/Hyperactivity Disorder
AIF	Average Intellectual Functioning
AS	Asperger Syndrome
ASD	Autism Spectrum Disorder
BIF	Borderline Intellectual Functioning
CVI	Cerebral Visual Impairment
DSM	Diagnostic and Statistical Manual of Mental Disorders
ECC	Expanded Core Curriculum
ICD	International Statistical Classification of Diseases and Health Problems
ICF-CY	International Statistical Classification of Functioning, Disability and Health – Children and Youth Version
ID	Intellectual Disability
LCA	Leber Congenital Amaurosis
LS	Klassdiagnoser i Läsning och Skrivning för högstadiet och gymnasiet [Diagnostic test of reading and writing skills for senior and high school]
VI	Visual Impairment
O&M	Orientation and Mobility
ONA	Optic Nerve Atrophy
ONH	Optic Nerve Hypoplasia
PVL	Periventricular Leucomalacia
RCV	Resource Center Vision
ROP	Retinopathy of Prematurity
SDQ	Strengths and Difficulties Questionnaire
SNASNE	Swedish National Agency for Special Needs Education and Schools (English abbreviation corresponding to SPSM, below)
SPSM	Specialpedagogiska skolmyndigheten
TRC	Tomtebodas Resource Center
WHO	World Health Organization

Definitions and starting points

Visual impairment and blindness

Table 1 shows the categorization of different levels of visual impairment (VI) that has been established by the World Health Organization, WHO (Socialstyrelsen, 2017). Visual acuity is always measured with the individual’s best presenting vision, i.e. with the use of optimal correction, such as glasses, if used. The table includes measures applied in different countries. Sweden applies the measure 1.0 – 0.01, where 1.0 is considered full visual acuity, 0.1 is comparable to 10%, and 0.01 is comparable to 1% of full visual acuity.

Table 1. Definitions of visual impairment (VI) categories, presenting distance visual acuity (Socialstyrelsen, 2017).

Category:	Lower than:	Equal or better than:
Category 0 No or mild VI		6/18 3/10 (0.3) 20/70
Category 1 Moderate VI	6/18 3/10 (0.3) 20/70	6/60 1/10 (0.1) 20/200
Category 2 Severe VI	6/60 1/10 (0.1) 20/200	3/60 1/20 (0.05) 20/200
Category 3 Blindness	3/60 1/20 (0.05) 20/400	1/60 (counts of fingers*) 1/50 (0.02) 5/300 (20/1200)
Category 4 Blindness	1/60 (counts of fingers*) 1/50 (0.02) 5/300 (20/1200)	Light perception
Category 5 Blindness	No light perception	No light perception

*No perception of objects or shapes, but has the ability to perceive how many fingers are held up, at a distance of 1 meter

Individuals in categories 3 – 5 (table 1), are generally braille readers. In the categories 0 – 2 (table 1) the reading medium is usually ordinary print, enlarged on paper, or through the use of assistive devices or technology.

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by impaired social interaction and communication, and restricted behaviors and interests (American Psychiatric Association, APA, 1994; 2013). Previously, Autism and Asperger syndrome were two separate diagnoses, but since the revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), Asperger syndrome is now included in the ASD diagnosis (APA, 2013). ASD is a multi-determined, genetically and environmentally influenced disorder of the developing brain (Waterhouse & Gillberg, 2014).

Intellectual disability

Intellectual disability (ID) is characterized by significantly impaired intellectual and adaptive functioning. ID is defined by an IQ score below 70 ± 5 , together with deficits in adaptive behaviors which affect everyday living (APA, 1994; 2013). There are several possible causes of ID in children, for example genetic disorders, or adverse events during pregnancy, at birth, or in the neonatal period, affecting the child's development (Daily, Ardinger, & Holmes, 2000).

Attention Deficit/Hyperactivity Disorder

Attention Deficit/Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder that includes difficulties with paying attention, hyperactivity or difficulty controlling behavior, in a way that is not appropriate for the persons age-level (APA, 1994; 2013). The cause of ADHD is believed to involve interaction between genetics, environmental and social factors (Millichap & Gordon, 2010; Thapar, Cooper, Jefferies, & Stergiakouli, 2012).

Impairment and disability

According to WHO (2017), disability is:

an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives (WHO, 2017).

Policies regarding the rights of children with and without disabilities

This thesis takes its starting point in the following international policies regarding children's rights, and the right to education and participation for individuals with disabilities:

The *United Nations Convention on the Rights of the Child* (UNCRC) from 1989, states that all children are equal and that no child should be discriminated against. Children with physical or mental disabilities are entitled to a full and decent life, enabling their active participation in society. The UNCRC also gives all children the right to basic education (United Nations, UN, 1989).

The *UN Standard Rules* from 1993 include 22 default rules designed to ensure that all people with disabilities are guaranteed participation and equality. The right to education implies that member countries should recognize the principle of equal access to education for children, adolescents and adults with disabilities and that the training should be part of the regular education system (§6). The Council of Ministers of the EU has decided that all Member States of the EU shall follow the UN Standard Rules (UN, 1993).

The right to education for students with disabilities within the regular school system is governed by the *Salamanca Declaration* of 1994. The Salamanca Declaration states that: "Integrated education is the most effective means of building solidarity between children with special needs and their peers. Sending children to special schools – or bringing them together within a particular school on a permanent basis should be of an exceptional arrangement, only in rare cases, where the child's needs cannot be met in the regular classroom" (Chapter 1, §18) (United Nations Educational, Scientific and Cultural Organisation, UNESCO, 1994).

In 2006, an additional UN convention, the *Convention on the Rights of Persons with Disabilities*, was established. This convention relates in particular to disabled people's rights to communicate, express their own views and share information. In the convention's article 24, the right to learn braille and have the opportunity to attain optimal academic and social level through studies, is stated. This requires that teachers at all school levels are specially trained to teach braille to students who need this reading medium. UN conventions are legally binding for the states that adopt them (UN, 2006).

The Swedish school system's main regulatory documents, particularly the Education Act (SFS 2010:800) and the curriculum for primary schools (Skolverket, 2011), primarily follows the UN Standard Rules and the Salamanca Declaration.

The concept of inclusion

The concept of inclusion in the educational context has many dimensions, and different definitions are applied both nationally and internationally. In some countries, inclusive education is mainly thought of as an approach to serving students with disabilities within a general education setting. However, it is increasingly viewed more broadly, as a reform that responds to diversity

among all learners (Ainscow, Dyson, & Wiener, 2013). As opposed to the previously used term *integration*, which assumes that a “deviant” student is placed into a “normal” school context, perhaps for a limited time, and has to adapt, the concept of *inclusion* can rather be said to embrace diversity as an asset, and implies that the school context is to be adapted to suit the diversity of all children (Mitchell, 2014). Still, the fact that there is no unanimous definition of what is meant by inclusion, has consequences for the way inclusive education practices are carried out (Ainscow, Farrell, & Tweddle, 2000). Ainscow, Booth and Dyson (2006) proposed that:

Inclusion is concerned with all children and young people in schools; it is focused on presence, participation and achievement; inclusion and exclusion are linked together such that inclusion involves the active combating of exclusion; and inclusion is seen as a never-ending process. Thus an inclusive school is one that is on the move, rather than one that has reached a perfect state (p 25).

Furthermore, they state that:

We want to emphasize the significance of the participation of staff, parents/carers and other community members. It seems to us that we will not get very far in supporting the participation and learning of students if we reject their identities and family backgrounds, or if we choose not to encourage the participation of staff in schools in decisions about teaching and learning activities (p 25).

In a review of the literature on the development of effective ways of including children, and young people with special educational needs in schools, Ainscow, Dyson and Wiener (2013) summarized that:

Schools need to understand clearly what is meant by inclusive education.

Inclusive classroom practices involve overcoming barriers to student participation and learning.

Engaging with various kinds of evidence can encourage teachers to develop more inclusive practices.

Additional support for individual students should be carefully planned; those involved require appropriate training.

Inclusive schools can take many forms, but they all have an organizational culture that views student diversity positively.

Leaders have a central role in working with their colleagues to foster an inclusive culture within their schools (p 2).

Mitchell (2014) also discussed the necessary multiple efforts needed for creating successful inclusion, and described inclusive education as a “multi-com-

ponent strategy” or a “mega-strategy”. In the light of the complexity surrounding the concept of inclusion, this thesis takes its starting point in the assumption that the development of inclusive practices is a multifaceted process, where the diverse needs of diverse students must be named, and addressed by competent teachers. This requires an openness for a variety of pedagogical solutions, out of the aim to promote inclusion in a broader, long term perspective.

1. Introduction

Children with visual impairment and blindness

Prevalence and common causes

The majority of all people living with visual impairment (VI) or blindness, are adults or elderly; globally, 82% of all blind individuals are over the age of 50. Around 19 million children below the age of 15, are estimated to live with VI or blindness. Many of these visual problems are due to refractive errors that could be easily diagnosed and corrected, with available resources. However, these resources are often unavailable, since a majority of these children live in developing countries (WHO, 2017). A small proportion of the total population of children with VI, around 1.4 million, are irreversibly blind (WHO, 2017). Thus, childhood blindness, which is the focus of this thesis, is considered an unusual disability. The majority of children with blindness worldwide, live in the poorest countries of Africa and Asia. In very low-income countries with high under 5-year old mortality rates, the prevalence is estimated to be 1.5 per 1000 children, while in high-income countries with low under 5-year old mortality rates, the prevalence is much lower, around 0.3 per 1000 children (Gilbert, 2007).

There are many different causes of childhood VI and blindness. The most common causes have shifted over the years, creating an increasingly complex image of the population (Ek, 2000). Overall, VI and blindness due to infectious diseases have decreased during the last thirty years, through factors such as overall socioeconomic development, concerted public health actions, such as vaccinations, increased availability of eye care services, and increased awareness about solutions to problems related to VI, such as surgery or refraction devices (WHO, 2017). Globally, fewer children become totally blind today. Instead, low vision in combination with additional neurological impairments has become far more common. One reason behind this is the increased survival of extremely preterm born children, with brain lesions as the underlying cause of the VI (Ek, 2000; Holmström, et al., 2014).

A large American study examining the causes of severe VI and blindness in children, reported that cerebral visual impairment (CVI), Retinopathy of prematurity (ROP) and optic nerve hypoplasia (ONH) were the three most common causes in the United States during recent years (Hatton, Ivy, &

Boyer, 2013). CVI is a term for describing visuo-perceptual deficits, and often other, associated problems, due to various types of cerebral involvement. One common cause of CVI is periventricular leucomalacia (PVL), often leading to cerebral palsy in combination with visual problems (Jacobson, Ygge, Flodmark, & Ek, 2002). Visual acuity in children with CVI may vary from normal to complete blindness. ROP is a perinatally acquired condition in very/extremely preterm born children, which can lead to different severities of VI, or blindness. ONH is a prenatal condition that involves acquired or gene-environmental interaction etiologies. ONH presents with uni- or bilateral involvement and results in VI ranging from low vision to blindness. Bilateral ONH has been reported to be an increasingly frequent cause of blindness in children (Borchert, 2012).

In a Polish study, which reviewed changes in the causes of significant visual loss and blindness in children and young adults born between 1974 and 2004, the most common causes reported were optic nerve atrophy (ONA), ROP, high myopia, congenital cataract and retinal degradations (Seroczyńska, Gralek, & Kanigowska, 2007). A study examining causes of severe VI or blindness among Norwegian Braille users born 1967 – 2007, identified the most frequent causes as ROP, the progressive disease juvenile neuronal ceroid lipofuscinoses (JNCL), Leber congenital amaurosis (LCA) which involves a number of genes encoding functions critical to retinal, developmental and physiologic pathways; ONH, and the retinal disease retinitis pigmentosa (RP), (Augestad, Klingenberg, & Fosse, 2012).

In a recent review, Solebo, Teoh and Rahi (2017) reported that for children in higher income countries, CVI and optic nerve anomalies are now considered to be the most common causes of severe visual impairment and blindness, and ROP and cataract are currently the most common avoidable causes. Due to the advances in neonatal care leading to increased survival rates of extremely preterm born infants, the incidence of ROP has increased during the last decades in developed countries (Ozturk, Er, Yaman, & Berk, 2015; Hellström, Smith, & Dammann, 2013; Zin & Gole, 2013). Solebo et al. (2017) discuss the improvements in maternal and neonatal health care and the development of national ophthalmic care infrastructure, which are important factors for reducing avoidable blindness.

In Sweden, children with VI and blindness have since the 1990's been reported to a national register. According to this register, in 1997 bilateral ONH surpassed ROP as the leading cause of infant blindness in Sweden (Blohmé & Tornqvist, 1997). In a status report from the year 2000, around ten children per year were reported to have complete blindness, or such limited vision that they became braille readers (Blohmé, Bengtsson-Stigmar, & Tornqvist, 2000). During recent years, the coverage of the register has decreased, and reliable statistics about the population and the currently dominating causes of VI and blindness, as well as other clinical characteristics, have become increasingly difficult to find.

Impact of blindness on a child's development

Due to the population of children with blindness being very small, the research about developmental aspects is limited, and study samples are generally small and heterogeneous. This matter makes it difficult to generalize about the population and depict a fully comprehensive background regarding the developmental consequences of blindness. Nevertheless, in the existing research, congenital blindness has long been recognized as being associated with certain developmental impact, and delays have been described in various areas – including motor, cognitive and language domains – as well as in social areas (Dale & Sonksen, 2002; Fraiberg, 1977; Martinsen, 1977/1994; Norris, Spaulding, & Brodie, 1957; Sonksen, Levitt, & Kitsinger, 1984; Webster & Roe, 1998).

Making sense of the surrounding world, understanding concepts and learning to master different skills, is far more complicated when the child cannot see. Learning through senses other than vision takes time, and many things that a sighted child learns automatically through imitation have to be taught deliberately and hands-on, to the child with blindness. Vision is a strong sense that helps us connect different actions or events to a comprehensible whole. The child who cannot see may therefore receive a fragmented understanding of contexts, since they cannot acquire an overview of the whole “puzzle” at once, but instead needs to examine it piece by piece through other senses, and then link the pieces together in their mind – a complicated process (Webster & Roe, 1998).

In addition, while the sighted child with their vision notices interesting things in the environment, which leads them to become curious and start to explore with their body, the child with blindness is often, during the first years, perceived as more passive (Martinsen, 1977/1994; O'Donnell & Livingstone, 1991; Perez-Pereira & Conti-Ramsden, 1999; Tröster, Brambring, & Beelmann, 1991). One hypothesis is that the child may be occupied with listening to sounds in the environment, thus preferring to be still in order to perceive the sounds better. Also, sounds do not seem to be as appealing a reason to move forward as visual stimuli, at least not until the sounds bear meaning for the child (Bigelow, 1986; 1992). Delays in early motor development in children with blindness have been described (Brambring, 1999; Hatton, Bailey, Burchinal, & Ferrell, 1997), and they also differ from sighted children in their development of tactual object recognition (Withagen, 2013).

Regarding language development, there seems to be no significant general delay, compared to sighted children (Brambring, 2007; Pérez-Pereira & Conti-Ramsden, 1999; 2005). However, deficits in certain areas have been reported. While formal language skills seem to develop normally, difficulties have been described regarding pragmatic language, i. e. the ability to use language in social contexts (Tadic, Pring, & Dale, 2010). Children with blindness also tend to ask many questions and exhibit echolalia (James & Stojanovik, 2007; Tadic

et al., 2010; Thorén, 2002), as well as use idiosyncratic expressions (Aasen, Martinsen, Piros, & Rime, 2008) to a higher extent than sighted children.

Social development and interaction is another area where the lack of vision entails challenges. Difficulties and delays regarding communication, early social interaction and play skills have been described (Hobson, 1990; Preisler, 1991; Tröster & Brambring, 1992). The VI restricts access to social information and non-verbal communication, and the child receives no visual feedback on their own behavior. This affects the development of social understanding as well as the social skills needed to take part in play and other interaction (Webster & Roe, 1998). A majority of children with blindness have been reported to show profound delays regarding theory of mind (Green, Pring, & Swettenham, 2004; Peterson, Peterson, & Webb, 2000). Therefore, practicing social communication, joint attention, reciprocity and taking turns, is crucial from an early age, and social behavior, including adequate non-verbal communication, must be taught deliberately (Roe, 2008; Sacks & Wolfe, 2006).

Thus, by limiting the access to information and by the child not being prompted by visual stimuli to be active and spontaneously explore the environment, blindness has significant impact on the child's possibilities to develop in different areas. Therefore, parents, teachers and other people surrounding the child, have a great responsibility to make the environment accessible for the child, and to promote development and learning through senses other than vision – especially hearing and touch (Gense & Gense, 2005). Information through auditory and tactile means is important, as well as providing verbal interpretation of contexts and events. The environment must help the child understand that there are interesting things beyond what is within the immediate touching area (O'Donnell & Livingstone, 1991). Regarding social development, language seems to be a domain that can provide children with blindness with alternative, non-visual strategies for social interaction (Pérez-Pereira & Conti-Ramsden, 1999). A considerable amount of time to explore objects and environments, and the opportunity of repetition, in order to familiarize with new things, is also necessary.

In the light of the above, it is easy to understand that the developmental pattern of a child with blindness differs from sighted children, and that developmental delays, due to the lack of vision, commonly occur. However, while some of the children “catch up” when provided adequate support, others display more profound difficulties, which cannot be explained by the blindness. In the existing research, great variations have been described regarding developmental outcomes in blind children both within and between etiological subgroups, with some children progressing well compared to sighted children, while others exhibit more profound delays or additional disabilities (Dale & Sonksen, 2002; Goodyear et al., 1989; Norris et al., 1957; Preisler, 1991). During recent decades, the awareness has increased about the correlation between additional developmental disorders and etiological subgroups. Such

knowledge can be very important, since it provides an opportunity to monitor certain subgroups of blind children more closely, with the purpose to detect deviant development early.

Coexistence with additional disabilities

The coexistence of VI or blindness with additional developmental disorders overall, as well as in specific etiological groups, has been examined by a number of researchers. In a large American study, Hatton, Ivy and Boyer (2013) reported that 65% of all children with VI or blindness had profound developmental delays or additional disabilities. In Sweden, almost two thirds of the children with VI (including blindness) have been reported to have additional disabilities such as intellectual disability (ID), motor impairment and/or hearing impairment (Blohmé et al., 2000). In these numbers, neurodevelopmental disorders such as autism spectrum disorder (ASD) or attention-deficit/hyperactivity disorder (AD/HD) were not included.

Children born with complete blindness or only light perception, are considered to be at particular risk for developmental disorders (Hatton, Bailey, Burchinal, & Ferrell, 1997). For example, among children with complete blindness (regardless of etiology) more than 30% have been described in earlier studies as meeting the criteria for ASD (Cass, Sonksen, & McConachie, 1994; Hobson, Brown, Minter, & Lee, 1997). In a later review of 12 reports, based on 859 early blind children, the prevalence of ASD was found to be 48% (Jure, Pogonza, & Rapin, 2016).

The relation between blindness and autism was discussed already in the 1950s, when the prevalence of autistic patterns in the blind child population had begun to attract the interest of clinicians in the field (Fraiberg, 1977; Keeler, 1958). Many of the children who displayed a clinical picture that resembled “infantile autism”, were blind due to retrolental fibroplasia, today referred to as ROP (Fraiberg, 1977; Keeler, 1958). Fraiberg discussed the possible causes of these development patterns, which she called “ego-deviations”; whether they could be related to brain damage or had to do with relational problems due to the child’s lack of vision (Fraiberg, 1977). Eventually, a strong correlation between brain dysfunction caused by low gestational age, low birthweight and continuous exposure to high oxygen levels, and ASD in the blind ROP-group was reported by Chase (1972). Since then, several researchers have demonstrated a high comorbidity with ASD in this group.

For example, in a Swedish population-based study of 27 children born 1980 to 1990 with a gestational age of less than 31 weeks – all with total blindness due to ROP – around three quarters displayed major neurological impairments. Nearly two-thirds of the population met the criteria for ASD (Ek, Fernell, Jacobson, & Gillberg, 1998; Jacobson, Fernell, Broberger, Ek, & Gillberg, 1998). In a more recent Swedish population-based study, which included 114 extremely preterm children (i.e. with a gestational age < 28 weeks), 97%

developed ROP. Of the children with ROP, 75% had severe VI or blindness, and 76% of these also had other disabilities, i.e. hearing-, cognitive-, behavioral- and/or motor dysfunction (Jacobson, Hård, Horemuzova, Hammarén, & Hellström, 2009).

Another visual disorder that has been reported as often co-occurring with different developmental disorders, is ONH. Garcia-Filion and Borchert (2013) reported that developmental delays, global as well as specific, were found in 71% of the children with ONH. In a study by Parr, Dale, Shaffer, and Salt (2010), ASD or prominent autistic features occurred in 37% of children with severe or moderate VI due to ONH. In a Swedish study of 13 children with blindness due to bilateral ONH, nine (62%) were found to meet the criteria for ASD, with or without ID (Ek, Fernell, & Jacobson, 2005). In a recent study of children with ONH in Stockholm county, Teär Fahnehjelm and coworkers (2014) found that in children with bilateral ONH, different behavioral problems and autism or autistic features were significantly more frequent than in the general child population (Teär Fahnehjelm, Dahl, Martin, & Ek, 2014). In addition, a subsequent study (Dahl, Wickström, Ek, & Teär Fahnehjelm, 2017) revealed that both ASD and ID was more common in children with bilateral ONH compared to those with unilateral ONH.

In summary, children with VI and blindness constitute a heterogeneous population, where some children display developmental delays, but “catch up” when provided adequate support, but a vast proportion also have difficulties that cannot be explained by the blindness. Research in the field shows that the comorbidity with various additional disabilities, such as ID, ASD, ADHD and/or motor impairment is high, especially in certain etiological subgroups. The existing research suggests that the blindness in itself is not the primary cause of these additional disabilities, but that blindness in combination with lesions or malformations in the central nervous system (CNS), constitutes a substantial risk factor for various developmental disorders, specifically ID and ASD (Ek, 2000).

Developmental and cognitive assessment of children with blindness

Challenges regarding assessment procedures and tools

The purpose of performing a developmental or cognitive assessment of a child is generally to describe the child’s individual strengths, difficulties and needs, in order to provide a foundation for how to properly shape support and interventions. The goal should be to find tools to help the child develop optimally. When the child has a physical disability, like a visual, motor or hearing impairment, such an assessment can be of utmost importance. It can provide an

understanding of how the physical disability may affect the child's general development, identify possible additional disabilities that need to be addressed, and find out what sensory channel/s works best for the child to receive and process information.

Regarding children with blindness, some specific challenges concerning assessment procedures and tools should be pointed out. First, an important issue includes the lack of standardized assessment tools specifically developed for children who cannot use their vision (Brambring & Tröster, 1994; Dial & Dial, 2010; Tobin & Hill, 2011). In the past, for example, the Hayes-Binet Intelligence Scale for the Blind (Hayes, 1942), the Reynell-Zinkin scales (1979) and the Perkins-Binet Tests of Intelligence for the Blind (Davis, 1980) were commonly used. These instruments are now, however, considered somewhat dated, even if they are still in use. Efforts have been made to adopt or develop up-to date instruments suitable for children with blindness, but the lack of sufficient numbers of "typical" children with blindness for norming purposes has affected the progress and utility of these measures (Dial & Dial, 2010; Ek, 2000). Currently, the Cognitive Test for the Blind (CTB), within the Comprehensive Vocational Education System for visually impaired/blind, CVES (Dial, Mezger, Gray, Massey, Chan, & Hull, 1990), and the Intelligence Test for Visually Impaired Children, ITVIC (Dekker, 1989) are most commonly used in many countries. Also, the verbal subscales of the Wechsler Scales, Wechsler Intelligence Scale for Children, WISC (1980; 1999; 2007; 2014) and Wechsler Preschool and Primary Scale of Intelligence, WPPSI (1991; 2005; 2012) are widely applied; scores are then compared to the norms of sighted children.

In Sweden, the majority of the assessments of children with blindness are performed by psychologists and special teachers with expertise in blindness, at Resource Center Vision (RCV) within the Swedish National Agency for Special Needs Education and Schools (SNASNE or SPSM; Swedish abbreviation). At present, the main instruments used for developmental and cognitive assessment of children with blindness at RCV, are the verbal subscales of WPPSI and WISC, ITVIC and sometimes appropriate assignments or scales from Griffiths' Developmental Scales I and II (Alin, Åkerman, & Nordberg, 1980; Griffiths, 1990). In addition, the Tactual Profile (TP) (Withagen & Schellingerhout, 2004; Withagen, Vervloed, Janssen, Knoors, & Verhoeven, 2009) is often used and administered by special teachers, to assess different aspects of tactual functioning. To gather information about development and adaptive behavior from parents and teachers, the Vineland Adaptive Behavior Scales (Sparrow, Cicchetti, & Balla, 2006) and the Adaptive Behavior Assessment System (Harrison & Oakland, 2008) are administered. Items depending on visual ability are omitted or modified by the assessment team. Moreover, observations of the child in the preschool or school environment are carried out, as part of the assessment.

Differentiating between which delays or difficulties can be attributed to the blindness, and what may be caused by other factors such as additional disorders, can be demanding, especially if the assessment is performed by a team that lacks experience concerning children with blindness.

Differentiating between blindness and autism

One topic of certain interest within the area of assessment is the relationship between blindness and autism. There is an ongoing debate regarding how to properly distinguish between typical development and ASD-related development in children with blindness. Many young children with blindness display autistic-like features, sometimes referred to as “blindisms”, like eye-poking, rocking or hand-flapping, as well as delayed social interaction and communication skills (Martinsen, 1977/1994; McHugh & Lieberman, 2003; McHugh & Pyfer, 1999; Tröster et al., 1991), but these symptoms do not necessarily mean that the child has ASD. Instead, some children outgrow or learn to regulate these behaviors, when they mature cognitively, acquire linguistic abilities and learn to understand and handle the environment better (Ek, 2000). However, in some cases the symptoms are more pronounced, and cannot be explained by the blindness, and it may be that the child in fact meets criteria for ASD.

Differentiating between autistic-like features related to the blindness, and “true” autistic features, can be very difficult, and demands clinical experience of children with blindness and their typical development, as well as of ASD. Furthermore, properly adapted assessment tools are required (Matsuba, 2014; Williams, Fink, Zamora, & Borchert, 2014). There are currently no formally standardized assessment tools available for diagnosing ASD in children with blindness. Instead, different “in-house”-adaptations are utilized. In Sweden at RCV, the Autism Diagnostic Interview – Revised, ADI-R (Lord, Rutter, & Le Couteur, 1994; Rutter, Le Couteur, & Lord, 2008) and the Autism Diagnostic Observation Schedule, ADOS, (Lord, Rutter, DiLavore, & Bishop, 2012) are used, modified and adapted by RCV:s clinical psychologists with expertise in blind children. In Ireland, a project is currently being carried out, with the aim to create a more standardized form of the ADOS for children with blindness (Joan Curran, personal communication, november 2016).

Without knowledge about typical and adaptive developmental pathways for a growing child with blindness, it is difficult to distinguish what is atypical or deviant, especially during the early years, when behaviors might change frequently (Dale & Salt, 2008). Consequently, lack of experience concerning blind children’s typical development in the diagnostic procedure, could lead to either giving the child a faulty diagnosis, or overlooking possible co-existing ASD. Either way, the child and their family are at risk of not receiving adequate support.

If the child is blind and also has ASD, it is important to understand and consider how this combination influences the child's learning when shaping the support (Gense & Gense, 2005). If either one of the disabilities is overlooked, the method is likely to fail (Gibbons, 2005). However, very little is reported in the literature about evidence-based practices for children with ASD and blindness (Gense & Gense, 2011). Many of the methods applied for sighted children with ASD build strongly on images or other visual input. Even though the general principle of the method can often be applied, the realization and adaptation of this principle into a pedagogical reality for the child with ASD and blindness is generally left to the individual teacher to figure out. Therefore, more research in this area is needed.

Specific core skills for children with blindness

For a child with blindness, with or without additional disabilities, properly shaped support, adapted material and an accessible environment is crucial for development, learning and participation in different activities. In addition, the lack of vision entails that the child needs to learn how to master a number of specific "core skills" (American Foundation for the Blind, AFB, 2018; Campbell & Mani, 2007; Morris & Sharma, 2011), such as the following:

- Compensatory or functional academic skills: namely the skills needed in order to access all areas of core curriculum.
- Literacy: learn to master the braille code, and learn how to read and write with braille.
- Technology: learn how to use specific computer equipment such as a screen reader, and other assistive technology.
- Orientation and Mobility: learn how to use specific orientation and mobility techniques and tools such as the white cane, to navigate as independently as possible in the school and other environments.
- Social interaction: learn how to understand the many visual components of interaction and communication, and master the necessary skills to take part in interaction.
- Sensory efficiency skills: learning how to use and integrate remaining senses to counter the impact of the lack of vision..
- Independent living skills: learn to master the skills and specialized techniques needed in all the activities of daily living, such as personal hygiene, cooking, eating, and cleaning.
- Career education: have the opportunity to explore career preferences and participate in job experiences, to the same extent as sighted students.

Some of these skills are specifically linked to the lack of vision, such as compensatory academic skills, braille reading, orientation and mobility, sensory efficiency skills and certain technology, while others, particularly regarding the areas of social interaction and daily living, are general skills that are learned automatically through casual observation and imitation by sighted children (Morris & Sharma, 2011). For the children with blindness however, these skills must be actively taught and trained, which sometimes also involves learning how to use assistive tools.

The American Foundation of the Blind (2018) emphasizes that these core skills should be taught by teachers or other staff who are properly trained to teach students with blindness and VI. In some countries these skills are part of an expanded core curriculum (ECC), that is implemented through legislation, and thus has become a natural part of the curriculum for students with VI. For example the United States has for several years applied the Expanded Core Curriculum for Blind and VI Children and Youths (AFB, 2018). AFB states that the ECC, i.e. the necessary skills needed by students with blindness or VI to participate fully in school and daily life, is not an optional part of a student's educational program, but should be considered the most essential part. Without these necessary skills, the student with VI cannot fully access the standard core curriculum, and is also at risk of being excluded from many of the activities that are basic to their well-being (AFB, 2018). There are guidelines available in different states, regarding how to implement the ECC for blind and VI students in the schools' practice. In many other countries, including Sweden, there is currently no adapted or expanded curriculum for students with VI. Instead, many of the core skills must be trained within the framework of the regular school schedule, or outside the school context.

Braille reading and writing

In order to provide a brief insight into the complexity of braille reading and writing, a short introduction of braille as a reading medium is presented in the following. Braille is a tactile code for written language, named after its inventor Louis Braille (1809-1852). A braille character consists of a combination of six dots, which are arranged in two columns with three dots in each column. This unit of six dots is called a braille cell. The individual dots in the braille cell can be combined in 63 different ways. Since all letters, numbers and symbols found in regular print must be represented, it sometimes takes two or more braille characters to represent one unit. For example, numbers are represented by the same characters as the letters a – j, but preceded with a special number character, which indicates that the character is to be interpreted as a number instead of a letter (Myndigheten för Tillgängliga Medier, MTM, 2017). Figure 1 shows the Swedish alphabet a – ö in braille.



Figure 1. The Swedish alphabet a – ö in braille.

The size of the braille cell allows for the fingertip to perceive the entire unit as a whole (Mortensen, 2007). In tactile reading the fingers move over the text, and the reader uses different techniques to decode the letters with their fingertips. It is not possible to decode a whole word at once, but instead the braille reader has to decode the words sequentially, letter by letter. Consequently, braille reading takes time, and the decoding process and reading speed are in fact the parameters that mostly separates print reading and braille reading (Fellenius, 1999). A braille reader reads roughly one third to half of the speed, compared to average sighted readers (Ferrell, Mason, Young, & Cooney, 2006).

Another important difference between braille and print readers is that the sighted child is exposed to letters and text in print, much earlier than the child with blindness becomes acquainted with braille. The sighted child is surrounded by text in the environment, long before they know the meaning of it, which can evoke curiosity and stimulate the child to spontaneously ask about letters and words (Fellenius, 1999). The young child with blindness is at risk of not coming across written text at all, if the environment does not actively arrange these possibilities (Barlow-Brown & Connelly, 2002; Fellenius, 1999). Therefore, parents and preschool staff need to provide braille as much as possible in the child's different environments, by marking up objects, locations and images, and by providing tactile books early and reading together with the child (Dominković, Eriksson, & Fellenius, 2006). It is also important to encourage the child to use their hands and fingers as much as possible, to feel and explore objects and textures, in order to be better prepared for braille decoding (Mortensen, 2007).

Braille is produced with specific tools that have to be provided early, so the child can play-write like the sighted children. The beginner starts with a mechanical braille machine (often called the "Perkins-machine", after the producer), which can be considered to be the child's first "pen". Writing with the mechanical braille machine is not as flexible as writing with a pen on paper. For example, erasing and making changes is more difficult. In parallel with the mechanical machine, the computer is the most common tool for the braille reading student, usually from 1st grade, but sometimes earlier. A regular computer is used, together with a braille display, which presents the written information shown on the screen. In the beginning a computer keyboard, similar to that of the mechanical typewriter, is used for the braille reading student. The equipment is also often connected to an ordinary keyboard, making it possible for the braille reading student to work together with a print reading classmate

on the computer. Eventually, the braille reading student learns to use a regular keyboard with short commands (MTM, 2017). Reading materials can be provided either as braille paper books, in audio or digitally on the computer, according to what suits the student the best.

Education for students with blindness: historical, international and national perspectives

Establishing educational possibilities

The general education of persons with blindness and VI had its' starting point around the turn of the century 1700–1800. Along with the advance of science, the general view of individuals with disabilities slowly began to change towards acknowledging their inherent potential, and understanding that these individuals could develop and contribute to society (Olsson, 2010). However, in the eighteenth century, the popular adult education was still in its' early stages, and had not yet reached the small population of people with blindness (Kretschmer, 1937). Occasional attempts to educate blind students had been made in different European countries, but it was not until the late 1700s, that these pedagogical experiments began to become systematized (Hatlen, 2000).

The French philosopher Diderot played an important role in the founding of the first organized education for the blind, through his “Lettre sur les aveugles” [letter about the blind] in 1749. In this writing, Diderot sketched the philosophical background for the education of students with blindness and VI. From the encounter with two blind adults who had both reached high positions within the areas of mathematics and music, Diderot had become convinced that people with blindness could live productive and successful lives, were they only given the opportunity to receive education (Hatlen, 2000). Inspired by Diderot, the world's first educational institute for the blind, L'institution Nationale des Jeunes Aveugles [the National Institute for Blind Youngsters], was founded 1784 in Paris, by Valentin Haüy (Ek, 1938).

The interest for the French institute grew, when rumors spread about the possibility for people with blindness to learn how to read and write, exercise music and crafts, and learn how to manage daily living skills independently. The institute was initially successful, but then experienced a backlash in connection with the French revolution in 1789. Under Napoleon's command, the formation of the institute was restructured, leading to Haüy leaving Paris. Haüy thereafter travelled all over the world, spreading his mission about education for people with blindness, and contributed to opening schools for the blind in St Petersburg, Berlin and several other locations. In the literature, Haüy is described as a pioneer within the field of systematic education of students with blindness, and the one that opened the path for the establishing of

residential schools for the blind in Europe as well as in the United States, from the 1800s and onward (Kretschmer, 1937).

From special school to inclusive education for students with blindness in Sweden

The first step towards establishing a school for students with blindness in Sweden, was taken by protocol secretary Per Aron Borg, who in 1807 began the private teaching of a young, blind woman. The interaction with his student, convinced Borg that it was possible to improve the future possibilities for people with blindness, and he began his work towards the realization of a Swedish educational facility. In 1808, Borg received royal financial support to begin the establishment of an institute for the blind (Ek, 1938; Gissler, 1964; Kerfstedt, 1889). Borg continued the road that was taken on by Haüy in France, and the first school, which came to include both blind and deaf students, opened up in Stockholm, under the name *Blindes och Döfstummes Institut* [the Institute of the Blind and Deaf-mute] (Ek, 1938; Gissler, 1964; Kerfstedt, 1889).

The operation slowly expanded and the number of students increased, especially among the deaf, who showed great interest in the school and also comprised a much larger population than individuals with blindness. The activities regarding the deaf students continued to develop, eventually at the expense of the students with blindness, who became increasingly invisible in the establishment. During the following years only ten blind students received their education at the institute, and between the years 1817 and 1846, none at all were enrolled. In 1946 the department for students with blindness was revived, and students slowly began to return. However, the crucial moment of development did not come until thirty years later, when a decision was made to separate the deaf students from the students with blindness, and the Royal Institute for the Blind was constituted, through a royal decree in 1878 (Ek, 1938; Gissler, 1964; Kerfstedt, 1889).

Establishing and dismantling Tomtebodas Royal Institute for the Blind

The Tomtebodas Royal Institute for the Blind opened up its gates in 1888 (Kerfstedt, 1889), and since then it stands as the symbol of the education for students with blindness and VI in Sweden. During the first 50 years at the Tomtebodas Institute, a number of important reforms and changes were applied. In 1896 the legislation regarding mandatory education for children with blindness was established, and a pre-school was set up at Tomtebodas. The students attended four years of pre-school, and six years at the Institute, thus a total of ten years. At the Tomtebodas Institute, the students received a theoretical education during their first three school years, and vocational training during the last three (Gissler, 1964). A new educational plan was established

in 1924, and revised in 1933. This plan was on the whole in line with the elementary school's educational plan from 1919 (Gissler, 1964). Children with VI or blindness and additional disabilities were at this point referred to institutions around the country, often with no proper educational possibilities (Gissler, 1964).

Eventually, during the 1950s, the partially sighted students started to disappear from the Tomtebodas Institute. For these students, special "vision classes" or the possibility to receive special education in regular schools around the country, had started to emerge. At Tomteboda, the students with blindness remained. Their education continued to be adapted according to the goals of the public school, but with the maintaining of: "...the peculiar nature stemming from the vision impairments and under continuous attempts to improve the adaptation-education to counteract the barriers, raised by the impairment" (Gissler, 1964, p 19, the author's translation). The provision of vocational training increased, which improved the possibilities for the students to gain access to working life (Gissler, 1964).

In 1965, the Tomteboda Royal Institute for the Blind transformed into the more modern Tomteboda School. From then on, it was decided that the students at the special school should attend a 10-year compulsory school – in contrast to the 9 years in regular schools – and be taught according to an expanded curriculum, which besides the regular school subjects, should also include instruction in the specific core skills and compensatory techniques as well as vocational training (Skolöverstyrelsen [The Swedish National Board of Education], 1970). In the teaching program, The LGR 69, the following was stated:

Visually impaired persons have a slower study pace than sighted. Braille reading and reading audio books is also performed at lower speed than reading ordinary text. Therefore, special schools have an extra primary school year and therefore special schools should also provide students with a specially directed instruction in study skills (Skolöverstyrelsen, 1970, p 12, the author's translation).

During the 1950s and 1960s the discussion about integration and the right for children with VI and blindness to receive their education in local schools, had reached Sweden (Gissler, 1964). Parents began to demand the opportunity for their children to attend school in their home community, just like everyone else, and an increasing number of students left the special school at the senior level and continued their education in schools in their home towns. This led to a relatively fast decline in the number of students at the special school during the following decades. In 1986, only seven students remained at Tomteboda School, and consequently the government decided to close it down (Stenberg, 1997).

In the regular schools, the students with VI and blindness were obliged to follow the ordinary curriculum, like the other students. In order for the students to receive proper educational support, a regional support organization was developed at the Tomtebodas School. This organization consisted of vision-consultants for the preschool children and itinerant teachers for the students. In addition, a resource unit with national responsibility, the Tomtebodas Resource Center (TRC), was established in 1978 to provide additional support to the local schools and the families. TRC expanded during the 1990's, providing expert knowledge, support and training for teachers, parents and students (Stenberg, 1997).

Current educational service delivery models

At present, there are several models applied for delivering educational services to students with blindness or VI around the world (Campbell & Mani, 2007). Traditionally, *the special school model* has been the most common model. In the special school, the staff is specialized in teaching methods for VI students, and all the students are blind or have VI. Although many countries have adopted, or have started moving towards inclusive education, in some countries the special school is still the only option. Other countries adopt a combination of special schools and inclusive settings and provide different solutions, such as the possibility to attend a special school during a restricted period of time for special training, after which the student returns to an inclusive setting in their regular school (Oka & Nakamura, 2005).

The special schools still clearly play an important role in the VI context. Some argue that this is still the best solution for students with blindness or severe VI, especially if they also have additional disabilities (Oka & Nakamura, 2005). In many countries where special schools exist in parallel with inclusive education, the special school teachers are also often involved in the training of the regular teachers, who work with blind or VI students in local schools. By providing their expertise, the special school teachers play an important role in the support provided in the inclusive educational settings; see the *itinerant teacher model*, below (Morris & Sharma, 2011). Moreover, some argue that the special school in a unique way provides important adult role models for the students, since some of the staff often have blindness or VI themselves (Oka & Nakamura, 2005).

Disadvantages with the special schools have also been pointed out. The majority of these schools are still residential, which means that the child has to move away from their family and home. They are also very costly, and far beyond the economic capability of many middle or low income countries (Campbell & Mani, 2007). Furthermore, in the full inclusion-discourse, the special school is often considered excluding and reactionary. From this point of view, students who receive their education in such an excluded environment

are considered to be poorly prepared to function in the regular “sighted society” (Oka & Nakamura, 2005).

Integrated education was during the mid-1900s the first step towards increasing the availability of educational opportunities closer to home for students with blindness or VI. Since then, the concept of *inclusion* has successively come to complement, or replace, *integration*. Today, some countries adopt *the resource model* of integrated or inclusive education for students with blindness or VI. This means that a group of 8 – 10 students with blindness or VI are enrolled in the same school, and often, but not always, placed in the same class. A special teacher, educated in teaching methods for students with VI, works at the school, and provides support and training directly to the students and to their teachers (Campbell & Mani, 2007).

The itinerant model, like the resource model, also means that students with blindness or VI are enrolled in inclusive educational settings. In this model, visiting (itinerant) teachers specialized in the teaching of students with VI, regularly travel to the schools and provide support and training to both students and teachers, and sometimes also parents. The itinerant teachers usually come from special schools or national/regional resource centers for children with VI (Campbell & Mani, 2007). Often, the itinerant teacher is responsible for conducting pedagogical assessments, with the aim to identify the student’s needs in the learning situation. Together with the regular teachers, they help set up goals for the students, and ensure that these goals are achieved, as well as help with adaptations to the curriculum or materials. In many countries, the itinerant teacher serves as a guarantee that the student with blindness or VI receives proper understanding and adequate training in the local school (Morris & Sharma, 2011).

Finally, the *paraeducator* or *paraprofessional model* is widely applied in inclusive settings (Forster & Holbrook, 2005). If students with disabilities are included in general classrooms without receiving appropriate support, they become vulnerable to both academic and social failure (French & Chopra, 1999). A common solution in order to address this concern is to employ a paraeducator or paraprofessional, who works together with the classroom teacher and supports the student. Regarding students with blindness or VI, the paraeducator is often the person who becomes responsible for literacy and braille training – a task that requires specific skills (Forster & Holbrook, 2005). However, a common problem with the paraeducator role, is that there is no consensus concerning the nature of this role or what formal training a paraeducator should have (French & Chopra, 1999; Forster & Holbrook, 2005; MacCuspie, 2002).

In summary, several educational service delivery models are available for students with blindness or VI in different countries. In the Western world, the majority of these students currently attend inclusive educational settings (Foreman, 2011; Tuttle & Tuttle, 2004). Campbell & Mani (2007) argues that each country or community must select the model that suits both needs and

resources the best. However, regardless which model is applied, it should allow every child with blindness or VI to access the same opportunities of appropriate education as any sighted child, including the specific core skills that these students have to master (Campbell & Mani, 2007; Morris & Sharma, 2011).

Present support provision for students with blindness in Sweden

The transition from special schools towards inclusive education for students with different disabilities in Sweden, led to a change in the perception of special education. The main purpose of special education became the teaching of students with special educational needs within their class, rather than separating them from their classmates for individual teaching (Nilholm, 2003). This changed view of special education also entailed an aim to work towards strengthening general teachers' competence regarding different disabilities, in line with the "one school for all" paradigm, where the school is to embrace and meet the diverse needs of all students. However, the Swedish system differs from other countries by still having a separate school form for students with ID ("grundskolan") which entails a special program and adapted curriculum for these students, and also a few special schools for certain defined groups. Furthermore, for students with VI, blindness or other disabilities entailing special support within the inclusive setting, there are no national programs, and the schools' assignment towards these students is not clearly defined. Policy guidelines are vaguely formulated, thereby leaving a large room for interpretation (Westling-Allodi, 2016). Due to the limited number of students with blindness or VI in Sweden, training regarding teaching methods specifically for these students has not been incorporated into the regular teacher training. Instead, the government has been given the responsibility to provide this training in the form of different types of independent teacher courses (further described below).

Today, the majority of students with blindness or VI in Sweden attend inclusive educational settings in elementary schools, or – if the student also has ID – in the school form for students with ID, around the country. There is also one residential special school, Ekeskolan, located in the city of Örebro, for students with VI or blindness and complex additional disabilities, such as motor disabilities, ASD and/or ID (mild to severe), where currently a small number of students are enrolled.

The municipality's responsibility

In Sweden, children attend preschool until the age of six years, when they are enrolled in preschool-class, which serves as a bridge between preschool and school. Elementary school starts at the age of seven, and after nine years, at the age of 15, the student can apply for high school for 2 – 4 years, and then

university. Sweden's decentralized school system implies that the individual municipalities have the responsibility for making sure that a student with blindness or VI receives the same educational possibilities as the sighted students on all educational levels.

Thus, in each local school, the school management along with the classroom teachers are responsible for adapting the teaching to suit the needs of every student. If a student has blindness or severe VI, and is a braille reader, they generally have access to a paraeducator, at least during the lower school years. Some schools apply a two-teacher-model, where two qualified teachers are assigned to the whole class, and either of them can support the student with blindness, when needed. Others apply a model where a paraeducator specifically supports the student with blindness. At the senior level, when the students generally have become more independent in their school work, many have access to a teacher's assistant instead of an extra teacher. It is up to the school management in each school and municipality to decide how to organize the extra support, as well as decide which level of education the staff working with the student should have.

The county's responsibility

The counties' regional low vision clinics are responsible for the habilitation and rehabilitation of individuals with blindness or VI. Among other things, the low vision clinics equip the students with optical devices and assistive technology. The low vision clinics also provide training to the students in order to enable them to use their devices in their school work. However, they do not provide training to teachers. However, the schools can receive help adapting the physical environment according to the student's needs, such as color or tactile marking or adaptation of the school yard. In addition, the low vision clinics provides orientation and mobility-training for the students in the school or other environments, and different kinds of support to parents (Syncentrallerna, 2018).

If the child has additional disabilities besides the VI, support to the families can also be provided by multidisciplinary teams in the county's local habilitation or pediatric clinics.

The governmental responsibility

When the Tomtebodas School closed in 1986, the itinerant teachers who were linked to the special school, were transferred to the County Board of Education. In 1991, they became a part of The National Institute of Disability in Schools (SIH), and their role changed into being regional consultants to schools and families. The resource center, TRC, continued to operate nationally in close collaboration with the regional consultants. In 2001, TRC, along with a number of other government supported facilities for students with disabilities, were merged into a new government agency: the Swedish Institute for Special Needs (SIT). The regional advisory activities were included seven

years later, when the Swedish National Agency for Special Needs Education and Schools (SNASNE or SPSM; Swedish abbreviation) was established in 2008. In this expanded agency, several previously independent authorities were brought together, including the Special Education Authority (SPM), the National Agency for Special Educational Support (SISUS) and SIT (Rönnbäck, de Verdier, Winberg, & Baraldi, 2010).

Currently, SPSM covers the government's support in special educational needs to staff in the public school system and private schools subject to government supervision. The support is organized into five geographical regions. Each region has counsellors in special education, with expertise in one or more disability areas. SPSM also allocates grants to various education coordinators, and produces teaching materials for students with disabilities. Furthermore, SPSM includes eight special schools (primarily for students with deafness, but also for students with severe speech and language disorder and VI and multi-disability; Ekeskolan), as well as four national resource centers. The resource centers have specialized competence regarding the following disability-areas:

- severe speech and language disorder
- deafness or hearing impairment in combination with ID
- congenital deaf-blindness
- blindness and VI, with or without additional disabilities

The Resource Center Vision (RCV), which is directed towards blindness and VI with or without additional disabilities, is a re-organisation of the resource center originally built up at the Tomtebodas School. RCV is today located in the two cities of Stockholm and Örebro, and serves the whole country. RCV provides support to children, their parents and teachers. The support includes pedagogical counselling, basic courses for teachers regarding braille and teaching methods, courses for parents and students, and multidisciplinary assessments of children (Specialpedagogiska skolmyndigheten, 2018). RCV has a special governmental assignment regarding braille reading students, and all schools where a braille reading student is enrolled, have contact with a special needs advisor at RCV. Teachers in the local schools can seek their advice regarding pedagogical inquiries, but the advisors do not have the same assignment as the itinerant teachers in other countries, in the sense that they do not work pro-actively or travel to the schools and provide training to the students and teachers on a regular basis.

In addition, the Stockholm University has a commission from the government, to provide higher education regarding the teaching of students with blindness and VI. Currently, this education is provided within the frame of the special teacher's program.

Theoretical framework

There are several possible theoretical perspectives that could be suitable for framing the empirical studies in this research. However, systems theory became the natural choice, since this perspective emphasizes the interplay between the individual and the environmental context, as crucial for development and learning. This approach applies to children in general, but while typically developing children learn many skills automatically, children with different disabilities are in many ways more dependent on the environment to actively support their development. Therefore, theories that emphasize a multifactorial influence on a child's development, and point to the importance of the child's individual prerequisites as well as aspects of the social context as necessary for learning, can be considered especially useful when discussing children who are born with specific developmental challenges.

In addition, the children and youth version of WHO's framework for health and disability, the International Classification of Functioning, Disability and Health, ICF-CY, (WHO, 2007) could serve as a complementary and helpful tool for practitioners, in the implementation of the results. The ICF-CY will therefore be commented upon briefly, in relation to the bio-ecological theory.

Modern neuro-cognitive science could provide an additional perspective, but the decision was made not to include research from this extensive field, in order to delimit the focus of this thesis.

A bio-ecological perspective on development in blind children

In traditional, general systems theory, the study of the interactions between different parts of a system leads to an understanding about how the whole system works. Each system consists of several parts, or subsystems, that together make up an entirety. Through the synergetic effects between the subsystems, the entirety of the system is always greater than the sum of its different parts (von Bertalanffy, 1968).

The American developmental psychologist Urie Bronfenbrenner (1979), took his starting point in traditional systems theory, when he created his ecological systems model, which emphasizes the interaction between a child's development and crucial environmental factors. Bronfenbrenner's model puts the child, with their natural characteristics and prerequisites in the center, and then describes interacting systems on different levels. Closest to the center are the different *micro-systems* of which the child is part, namely relational systems such as family, friends, preschool and school. For a child with blindness, additional micro-systems may be the low vision clinic and the habilitation center. The pathways between the different micro systems, such as the dialogue between parents, teachers and other professionals, is labelled the *meso-system*. How the interaction and communication between the different micro-systems work, in turn affects the individual micro-systems. The *exo-system*

consists of the surrounding local community, which comprises all the different micro-systems. Farthest in the model is the *macro-system*, which includes the society with its culture and attitudes, policies, legislation and economy (Bronfenbrenner, 1979). Later in Bronfenbrenner's career, he developed his model further, by including the biological dimension, thus the model is often referred to as the bio-ecological systems theory model (Bronfenbrenner, 2005). One reason behind the revision of his model, was that Bronfenbrenner considered the focus on the environment in much research as being too one-sided. He argued that the child's biological prerequisites were equally important as the environmental components, and focus should be directed at the interaction between individual and social factors. Bronfenbrenner in his revised model also added a time-factor, which he called the *chrono-system*. The time-factor according to him, has significance for the child's development, as well as for the continuous development of the cultural and social context in which the child lives (Bronfenbrenner, 2005).

Thus, the interaction between a child and the social context takes place in the proximal environment of the micro systems, and is defined by both individual and environmental factors. Children born with disabilities entailing certain particular characteristics and developmental challenges, add a particular dimension into these processes, since the situation poses specific demands on the physical as well as the social environment. The unique regions in the environment that differently influence children with particular personal characteristics are called niches, and the constancy and changes in a child's development occurs through the proximal processes in these niches (Bronfenbrenner, 1999; Sontag, 1996).

Proximal processes can be many things; interplay between the child and a caregiver or other adult, interaction with another child or taking part in group activities with adults or other children. These different relations and interaction processes in a variety of situations and activities, provide the child with experiences that are stored within the child's memory and successively builds new knowledge and skills, thus leading to developmental progress (Bronfenbrenner, 1999). Bronfenbrenner highlights three areas of activity, roles and social relations as particularly important for the development. With activity, he refers to the child's participation in different activities in interplay with others. In these activities the child meets, and has the possibility to try different roles, a matter which constitutes an important part of the development process (Bronfenbrenner, 1979).

Andersen, Boyle, and Deppeler (2014) discussed the bio-ecological systems theory in relation to learners in inclusive education, and concluded that it offers an invaluable framework for organizing different environmental factors and understanding how they influence the inclusion, through placing the learner in the centre of the model. The individual characteristics of both the learner and their environment, as well as the relationships between these, are

pointed out as key determinants in the learning process, and the social components of the inclusive educational setting are highlighted (Anderson et al., 2014).

McLinden and co-workers (2016) take their starting point in the reasoning of Anderson et al., when they apply the ecological systems theory model on inclusive education and curriculum access specifically for students with VI or blindness. For the supporting adult to be able to create activities that provide optimal developmental opportunities for a child with VI or blindness, knowledge is required about how the lack of vision affects the child's understanding of the surrounding world. Such knowledge enables the adult to adjust the demands just enough to challenge the child to move forward in their development. Moreover, it is necessary that the child is offered many possibilities to take part in various contexts and activities with other (sighted) children, and thereby is given the opportunity to be inspired to master and practice new skills. McLinden et al introduce the role of the specialist teacher, with competence about teaching methods for students with VI, as a crucial actor in these processes, within the school's micro-system (McLinden, Douglas, Cobb, Hewitt, & Ravenscroft, 2016).

A key barrier to learning for students with VI in inclusive education, is the reduced access to information in the educational context, caused by the lack of vision. Therefore, an important task for the educator is to reduce potential barriers to access information in different situations, by providing the student with appropriate strategies. According to McLinden and Douglas (2014), the specialist teacher should be a natural part of the proximal processes close to the child with VI, and ensure that the child is able to access the curriculum with support, as well as equip the child with both confidence and competences to independently access different curriculum areas, thus creating possibilities for the child to learn together with the sighted peers.

In summary, the micro-systems closest to the child, where the direct interactions between the child and its' caregivers, teachers or other professionals occur, have a direct influence on the child's development. The surrounding systems impose more indirect effects on the child, through for example legislation and policies regarding education and support provision. The time-factor inevitably and continuously entails shifts and changes on every level. Thus, in order to gain an understanding of a child's situation in school, systems on all levels must be analyzed (Nilholm, 2017).

The ICF-CY in relation to the bio-ecological perspective

The ICF-CY is designed to record individual characteristics of the developing child, as well as the influence of different aspects of the environment. The aim of ICF-CY is to focus on the everyday functioning of children, with a holistic perspective. It can be used by actors on all levels in the system, who are con-

cerned with children's health, education, and well-being, by providing a common and universal language to facilitate the documentation and measurement of health and disability. The classification builds on the ICF conceptual framework and uses a common terminology for recording problems involving body functions and structures, activity limitations and participation restrictions, and relevant environmental factors (WHO 2007). In WHO's international classifications, health conditions, such as diseases or disorders, are classified primarily in the International Classification of Disease, ICD-10 (WHO, 1990), which provides an etiological framework, while functioning and disability are classified in the ICF-CY. The term *functioning* in the ICF-CY refers to all body functions, activities and participation, while *disability* is used as an umbrella term for activity limitations and participation restrictions. ICF-CY also lists different environmental factors that interact with all these components (WHO 2007). The ICD-10 and the ICF-CY should be used complementary.

Thus, the ICF-CY can be useful for providing individual functional descriptions, and point to environmental barriers as well as facilitators for activity and participation. The ethos of the ICF-CY corresponds well to the underlying assumptions of the bio-ecological systems theory, through their common emphasis on the interplay between the child and its' social context. For a child with a disability such as blindness, who is subject to different kinds of special educational and other support and interventions, the effect of competence, decisions and changes on all levels in the system, is supposedly very tangible for the developmental outcome. Moreover, the communication and interaction between the different microsystems – family, school and different support facilities – is crucial, concerning for example the transfer of information about the child's (and family's) needs, collaboration regarding support and interventions, and making transitions between different environments smooth and effective. In the communication between different actors about the shaping of interventions and adaptations, the ICF-CY can provide a helpful tool for creating a mutual terminology to describe important individual and environmental aspects, for practitioners working with the child.

Important factors for the inclusion of students with blindness or visual impairment in the regular classroom – a review

Even though different models of inclusive education for students with blindness or VI are widely adopted, research regarding the outcome of inclusive education for these students is still very limited. Studies in this area that specifically focus on students with complete blindness, or blindness and additional disabilities, are practically non-existent. Thus, in the handful of studies that were identified as relevant for the purpose of this thesis, the samples include students with both low vision and blindness. No studies are longitudinal, samples are often small, and teachers' perspectives dominate, while students'

or parents' experiences are not reported. Nevertheless, in four reviewed studies, a number of factors that seem to be of importance for the inclusion of students with VI have been pointed out.

Simón et al. (2010) examined barriers and beneficial factors for the inclusion of students with VI in Spain, from an organizational perspective. A questionnaire was distributed to educational experts (n=56) from the National Organization of Blind People in Spain (ONCE), which supports regular teachers working with students with VI in local schools. The findings pointed to deficits in the schools regarding access to study material and assistive technology, as well as teachers' often having limited knowledge about the students' learning needs. Important factors for a positive outcome that were reported by the informants were high awareness and understanding of the VI students' individual needs, the providing of relevant education and support to teachers, active encouragement of collaboration between school and home, increased economic resources to the schools, and a high degree of staffing around the students (Simón, Echeita, Sandoval, & Lopez, 2010).

A study from Northern Ireland explored Special Educational Needs Coordinator's (SENCO:s) experiences from including students with VI in regular schools (Gray, 2009). A total of 270 SENCO:s were invited to answer a questionnaire regarding their work with supporting the local schools. The response rate was low, only 42 %. Of the SENCO:s that responded to the questionnaire, a strategic sample of six individuals, participated in follow-up interviews. The results from questionnaires and interviews, showed that accessibility was a crucial factor for the students' inclusion. Difficulty making certain school subjects accessible for the students with VI could lead to the teachers discouraging them from studying these subjects. Furthermore, limited knowledge in teaching methods for VI students led to difficulties in the teaching situation, in one third of the cases. Thus, the need for increased knowledge was emphasized. Moreover, the importance of positive relations between teachers and students, and actively working with the social climate in the class, was highlighted as crucial for the social inclusion.

Bardin & Lewis (2008) in their American study, aimed to examine VI students' engagement in school work in relation to their inclusion and participation in school activities. By using a questionnaire for teachers working with the targeted students (n=79), the authors found that a majority of the students were rated as poorly engaged in their school work, and having a low degree of participation in the school activities, compared to their sighted classmates. The authors argue that working actively with increasing the students' engagement should lead to increased participation, and thus a higher grade of social inclusion.

A British case study, including 23 students with VI in 17 regular schools, had the aim to increase the knowledge about how to improve the teaching methods for these students in Great Britain, and to identify possible barriers for the students' inclusion (Davis & Hopwood, 2002). All staff involved in the

teaching of the students were interviewed, resulting in more than 80 interviews. Classroom observations were also performed. The authors highlighted a number of factors that were identified as important for the outcome of the students' inclusion: the importance of promoting the student's independence, working with non-visual teaching methods for the whole class, using teaching methods that promoted all students' participation, strengthening the VI student's social skills, providing properly adapted materials, and having the VI student spend considerable time inside the classroom instead of being taught separated from the other students. Furthermore, flexibility between teachers in the classroom, proper education to teachers and time for planning, as well as possibilities to exchange experiences with other teachers, were also pointed out as crucial aspects for successful inclusion.

The findings from the reviewed studies can be summarized as follows:

- It is important to increase the awareness about the students' specific needs both for classroom-teachers, and on an overarching, organizational level;
- Teachers must receive adequate education about teaching methods for students with VI, have time for planning and have the possibility to exchange experiences with other teachers in the field;
- Collaboration between actors in external professional networks is necessary;
- Good communication between school and home is vital;
- The students must have access to properly adapted school material and adequate supportive technology;
- Teaching methods and practices should promote participation and independence for all students in the class;
- Important to work with the social climate in the class, as well as with the social skills of the student with VI;
- The student should to a considerable extent take part in classroom activities, instead of having individual teaching;
- It is important to increase the student's engagement in activities.

The notion that the student should to a considerable extent take part in classroom activities instead of having individual teaching, presents a delicate dilemma regarding how to provide individual support when needed, without excluding the student. Larsen (2003) discussed such common dilemmas, and argued that inclusive practices involve the balancing of a number of prerequisites and goals, for example: the need to admit the occurrence of limitations yet focus on possibilities; to find a balance between the students' resistance against being treated differently and their right to compensatory strategies; their wish to be independent as well as their wish to master tasks with support; their wish to be alike and their right to be different; and prioritizing learning

goals, versus prioritizing social goals (Larsen, 2003). These dilemmas illustrate the complexity surrounding the student in the school context.

The reviewed studies do not explicitly take their start in a systems theory framework; nevertheless, this perspective is highly applicable to fit their findings into a theoretical context. Consequently, the emphasis in these findings lies on organizational factors and needs for improvements within the schools, as well as the need for communication between the different micro-systems and actors on higher levels in the exo-system. The importance of taking the starting point in the center, through addressing and understanding the individual needs of the child, is also pointed out as crucial.

2. Aims

Overall aim

The overall aim of this thesis is to deepen the knowledge about developmental aspects, comorbidity and implications for education and support provision, regarding children with blindness. Special focus in part of the research is directed towards children with blindness in combination with ASD, with and without ID, since there are specific challenges concerning differential diagnostics as well as the shaping of support and teaching methods for this particular group. Also, research regarding children with this unusual dual disability is particularly limited. Moreover, the existing research concerning inclusive education and special educational support regarding children with VI and blindness often focuses on pedagogical perspectives through information and data from teachers or other school staff. Children's voices from this field are rarely heard, even though their perspective is important in order to reach a deeper understanding of the situation (Westling Allodi, 2002; Whitburn, 2014). In addition, parents' opinions and experiences are also generally missing in the existing studies. The research projects constituting this thesis includes children, as well as parents and teachers, with the aim to elucidate experiences of support needs and support provision from their different perspectives.

Aims of the research projects

This research involved three projects, each with specific aims, relating to the overall aim of the thesis.

Project A

Knowledge about the clinical characteristics, developmental outcomes and developmental risk factors present in the population of children with blindness is an important starting point for ensuring valid diagnostic procedures and shaping the support. However, reliable and up to date statistics about the Swedish population of children with blindness have become increasingly difficult to find. Project A involved a population-based study (study I) aiming to describe the clinical characteristics of children with blindness in Sweden during

two recent decades, regarding common causes of blindness, the prevalence of different associated developmental disorders/disabilities – specifically the prevalence of ASD in etiological subgroups – and what this means for the provision of support.

Project B

Students' school outcome in terms of learning and academic achievement, is closely linked to mental health and psycho-social aspects (Gustavsson, Westling Allodi, Alin Åkerman, Eriksson, Eriksson, Fischbein, et al., 2010). In Sweden, no systematic research has been performed before, regarding the academic and psycho-social outcome, for braille readers in inclusive education. Project B aimed to describe academic outcome, as well as the psycho-social aspects and experiences of support and accessibility, for an age cohort of braille reading students in inclusive educational settings. One part of the project (study II) focused on the students' reading development and general academic achievement, as well as students', teachers' and parents' experiences concerning accessibility and pedagogical support, while another part (study III) explored the students' psychological well-being and students', teachers' and parents' experiences of the social inclusion in school.

Project C

Children with blindness and ASD constitute a group with very complex learning needs, and creating an optimal learning environment for these children is often extremely difficult. The existing research that focuses on pedagogical aspects and support provision in relation to blindness and ASD is very limited. The aim of project C, was to describe the characteristics and needs of children with blindness and ASD, pedagogical challenges and strategies, and experiences of pedagogical, as well as family oriented support. One part of the project (study IV) explored students', teachers' and parents' experiences of the school situation and challenges as well as successful strategies in the school-work. The other part (study V) focused specifically on parents' experiences of their children's dual disability and the support needed and provided to the families.

3. Procedure

Methodological overview

This research included three projects: project A, B and C. Each project involved empirical studies, which adopted different research designs and included the collection of qualitative as well as quantitative data. Note that while project A comprised the total population of children with blindness over two decades, there was no overlap between the participants in projects B and C. These two projects had different inclusion criteria, and thus included entirely different samples of children, parents and teachers.

Table 2 shows an overview of the methodological approaches applied (Table 2).

Table 2. Objectives, target groups and study design in projects A – C.

Project	<u>Project A</u> "Blindness and clinical characteristics"	<u>Project B</u> "School outcome for braille readers in inclusive education"	<u>Project C</u> "Support to children with blindness and ASD"
Studies/papers	Study I	Studies II and III	Studies IV and V
Object of study	Clinical characteristics of the population of Swedish children with blindness	<i>Study II:</i> Reading development, academic achievement and pedagogical support for braille readers in inclusive education <i>Study III:</i> Psycho-social aspects regarding braille readers in inclusive education	<i>Study IV:</i> Blindness in combination with ASD, pedagogical challenges and strategies <i>Study V:</i> Blindness in combination with ASD, parents' perspectives on diagnosis and support
Target group	Swedish children with blindness born 1988 – 2008 (n=150)	Braille reading students born the same year (n=6), parents (n=6), teachers (n=18)	Sample of children with blindness and ASD (n=6), parents (n=8), teachers (n=7)
Study design	Population-based, retrospective record-based study	Longitudinal design Collection of qualitative as well as quantitative data	Mainly qualitative approach
Data collection and measures	Review of medical files, psychological assessments, pedagogical records	Semi-structured interviews LS-test Reading observations School grades SDQ Review of assessments	Semi-structured interviews School grades Review of pedagogical documentation Review of assessments

Note: ASD: Autism spectrum disorder. LS-test: Klassdiagnoser i Läsnings och Skrivning för högstadiet och gymnasiet [Diagnostic test of reading and writing skills in secondary and high school] (Johansson, 2004), SDQ: The Strengths and Difficulties Questionnaire (Goodman & Goodman, 2009).

Recruitment of participants

The participants in all three research projects could be identified and recruited through files and records provided at RCV, since the resource center usually establishes contact early with children who will become braille readers (blind or partially sighted). Two of the projects (A and B) were population-based: i.e. all children with congenital or early acquired blindness, born between 1988 and 2008 (project A), and all braille reading students (blind or partially sighted), who started grade 1 in an inclusive educational setting a specific year (project B). Project C included a strategically selected sample of children with blindness and ASD, with or without ID. There was no participant overlap between projects B and C. In projects B and C the participants were invited by letter. Project A was record based, thus individual contact with participants was not necessary.

Methods for data collection and measures

The qualitative interview

In projects B and C, individual, qualitative interviews (Kvale & Brinkmann, 2014; Trost, 2010) were used to collect information about the participants' (students, parents and teachers) subjective experiences of different phenomena. Semi-structured interview guides were used to structure the interviews around certain major areas of interest, yet provide freedom to follow the informants' narratives, go deeper and formulate additional questions when needed (Trost, 2010). The interview guides, including the areas of interest, were sent out to the participants prior to the interviews. The interview-procedures will be described in more detail below, in relation to each project. All interviews were audio-recorded, with permission from the informants.

Reading skills and academic achievement

The LS-test

Klassdiagnoser i Läsning och Skrivning för högstadiet och gymnasiet (the LS-test [Diagnostic test of reading and writing skills in secondary and high school], Johansson, 2004) is a Swedish standardized test, widely used by teachers. Norms for grades 7 – 9 are based on a large Swedish standardization sample from 1989 and 2003 (Johansson, 2004). Two subtests from LS were used in project B to measure the students' decoding skills. One subtest included lists of regular words, the second one included lists of nonsense words; both were to be read aloud, while the time and correct words and mistakes were noted. Both subtests had been adapted to braille. The LS-test was chosen

out of the aim to obtain a brief measure of the decoding skills and reading speed for braille reading students, compared to Swedish print readers of the same age.

Reading observations

At RCV, reading observations with braille reading students are performed regularly when the students visit the center to attend student courses. The text-materials that are utilized in these observations are not part of a formally standardized test, but have been used in-house at RCV for many years to collect measures of braille reading students' reading skills. The students in project B took part in reading observations yearly during grades 1 – 7. During the observations the students read texts out loud, and words per minute (wpm) and correct words as well as mistakes, were noted. Comprehension was measured through questions about the contents. For the purpose of project B, individual results from the reading observations performed in grades 1 – 7 were collected retrospectively in grade 9.

School grades

At the time of this research project, all Swedish students received their first school grades in the 8th grade. Grades in each subject were set using a national scale of six levels: A, B, C, D, and E (different levels of passing, A being the highest grade), and F (fail). Individual school grades from grades 8 and 9 were collected for the students in project B. In project C, school grades were collected for those two students who attended inclusive education at senior level.

Pedagogical documentation

Pedagogical documentation regarding the students' achievements and progress in school, such as individual evaluation plans (IEPs) and the documentation of individual goal fulfillment, were collected for the students in project C.

Psycho-social aspects

The SDQ

The Strengths and Difficulties Questionnaire, SDQ (Goodman, 1997; Goodman, Meltzer, & Bailey, 1998), provides a brief measure of psycho-social strengths and difficulties as well as psychological well-being, in children and youths. The SDQ builds on the Child Behavior Checklist (CBCL) and the Rutter questionnaire, which are both well-established instruments, and widely used internationally (Goodman, 1997). The SDQ consists of 25 items that are divided into five subscales, measuring the following areas: emotional symp-

toms, conduct problems, hyperactivity, peer problems and pro-social behaviors. A total difficulties-score is obtained by adding the items from the four first subscales.

The SDQ has been modified and translated into Swedish. The Swedish version includes questionnaires for parent- and teacher ratings regarding children and youth between 3 – 16 years, as well as self-rating questionnaires for youths between 11 – 16 years (Smedje, Broman, Hetta, & von Knorring, 1999). The SDQ was in project B administered verbally to all students, parents and teachers, as part of the interviews. The Swedish norming sample only includes parent-ratings for ages 6 – 10 years. Therefore, British norms for 15-year-olds, were used in this study (see below, under project B).

Data from medical and psychological files and records

The study within project A was based on data from medical, psychological and pedagogical records, which were retrieved from the targeted children's files at RCV. The files contained records retrieved from low vision clinics, pediatric clinics, as well as psychological assessments performed at RCV.

In projects B and C, we received access to assessments of the targeted children, which had been performed previously at RCV, that is, outside the frame of this research. In project B, all the children had been assessed by a psychologist at RCV before school start – a common practice at RCV at that time, in order to provide the families and schools with information about the children's cognitive strengths and difficulties, as well as pedagogical recommendations. The cognitive assessments included the verbal scales from WPPSI-III (2005) or WISC-IV (2007), tactile subtests from ITVIC (Dekker, 1989), preschool observations, and interviews with parents and school staff. Concerning the two partially sighted children in this study, the assessments also included pedagogical visual assessments and recommendations regarding what reading medium was most suitable for the child.

In project C, all six children had gone through neuropsychological assessments at RCV in their late preschool years or their early school years, because they had displayed different cognitive and/or behavioral difficulties. All had received an ASD-diagnosis and two had received an ID-diagnosis. The assessments included the verbal scales from WPPSI-III (2005) or WISC-IV (2007), tactile subtests from ITVIC (Dekker, 1989), preschool or school observations, parts of the ADOS (Lord et al., 2008; 2012), ADI-R-interviews (Rutter et al., 2008) and ABAS-II-questionnaires (Harrison & Oakland, 2008) with parents, and interviews and ABAS-II-questionnaires (Harrison & Oakland, 2008) with teachers. Items depending on eye-sight in the tests and questionnaires had been omitted or adapted by the assessment team.

All assessments were reviewed by KDV, with the view to validate other information given about the children's cognitive levels and in certain cases, about additional disabilities/diagnoses.

Methods for data analysis

Thematic analysis of interviews

The qualitative interviews performed in projects B and C, were analyzed through inductive thematic analysis (Braun & Clarke, 2006). Thematic analysis is a qualitative, descriptive approach, within the same tradition as descriptive phenomenology or content analysis (Vaismoradi, Turunen, & Bondas, 2013). Methods following this tradition employ a lower level of interpretation than, for example, grounded theory or hermeneutic phenomenology. In descriptive methods such as thematic analysis, coding categories are derived directly from the text data, instead of taking its starting point in a specific theoretical assumption. Methods like these are considered to be suitable when the aim is to describe subjective phenomenon, and when the existing research literature or theory regarding the studied area is limited (Hsieh & Shannon, 2005). The value of qualitative description lies, among other things, in the increased knowledge about subjective experiences and phenomenon that can originate from the individual narratives of the respondents (Vaismoradi et al., 2013).

Thematic analysis has many similarities with conventional content analysis. However, while content analysis focuses more on the frequency of occurrence of categories and themes, by using a descriptive approach in both the coding and its interpretation of quantitative counts of the codes, thematic analysis instead focuses on providing a more detailed and nuanced account of the data, involving the identification of central themes, but without quantification (Braun & Clarke, 2006; Vaismoradi et al., 2013). In thematic analysis the relevance of a theme does not necessarily depend on quantifiable measures, but rather on whether the theme seems to capture something important in relation to the area of research (Braun & Clarke, 2006). Thus, individual variation as well as similar experiences, can be made visible through such analysis.

This approach was used in both projects B and C. The study samples in these two projects were comprised out of different inclusion criteria; in project B the target group consisted of an age cohort of braille readers in inclusive education (n=6), three of whom had additional disabilities (AS, ID, ADHD), while project C included a strategic sample of children with blindness and ASD, with or without ID, in different school settings (n=6). Thus, both target groups were small, and both were heterogeneous. We decided that the same method could be applied in both projects, since it was judged to be suitable for both groups. Overall, we considered thematic analysis to fit the purpose of both studies well: namely to describe subjective experiences of small and unusual study groups. The different steps in the analyzing processes are presented in more detail below, in relation to each project.

Compilation and analysis of quantitative data

No inferential statistical analysis was performed of quantitative data in any of the studies, due to the small numbers in the target groups. Data from records in project A were compiled in an excel-file and simple, descriptive statistics were calculated and compiled in tables and graphs. Individual, quantitative results from the LS-test and the SDQ used in project B were scored and analyzed according to the available test manuals and instructions (further described below). In project B, individual mean grade-levels from grades 8 and 9 were calculated for each student, and individual results regarding reading speed and comprehension from the reading observations in grades 1 – 7 were summarized. In project C, grade levels and pedagogical documentation were summarized for each student. In projects B and C, previously performed psychological assessments were reviewed and served as background information.

Project A

Design

The study in project A had a population-based, retrospective design. All data were retrieved from medical, psychological and pedagogical files and records.

Participants

The study included all Swedish children who were known at RCV and met the following criteria:

- pre/perinatal or early infancy blindness, defined as total blindness or light perception at the most (WHO-categories 4 and 5)
- birth-year 1988 – 2008
- the child was born in Sweden or had immigrated to Sweden during infancy or early childhood.

As far as we know, the study comprised all children with blindness in Sweden within the studied time-period. Possible omission may concern children who, for unknown reasons, had not been identified at RCV.

Data collection

Files of all children who have been assessed and/or have received support from RCV are kept at either of the two RCV-units, in the cities of Stockholm

and Örebro. The files contain medical records retrieved from low vision clinics and pediatric clinics, as well as records of psychological assessments performed at RCV (or occasionally at another clinic) and pedagogical information. When an individual reaches 20 years of age, all files are sent to central archives for storage.

For the birth years 1994 – 2008, files could be retrieved from the RCV-units in Stockholm and Örebro. For the birth years 1988 – 1993, files were retrieved from Arkivsupport 100%, a central archive located in Falkenberg. In the first search phase, the files of all children with VI, born between 1988 and 2008, were examined briefly in order to identify the children who matched the study's inclusion criteria. In the second phase, the files of the targeted children were searched more deeply, and information about each child's year of birth, gender, cause of blindness, gestational age, associated developmental disorders/disabilities, cognitive level and type of school placement was noted. In some cases the files and records did not include complete information about all the variables. All data collection was performed by one researcher (KDV).

Data analysis

The collected data was compiled in an excel-file, where each individual was represented by a code, thus the identification of specific individuals was not possible. The excel-file was studied and analyzed by a multi-disciplinary research group (KDV, UE, EF, SL), with expertise in ophthalmology, child neurology, and developmental psychology specifically regarding children with blindness. All data was analyzed by hand and compiled in descriptive statistics. No inferential statistical analysis was performed, since we considered the study population and its subgroups too small and heterogeneous for such an analysis to be valid.

Project B

Design

This project had a longitudinal design and combined qualitative interviews with quantitative data. A sample of braille reading students (n=6) born the same year were followed during their entire compulsory school years (grades 1 – 9), with data collection points in grades 1, 2, 3 and 9. The project included students', parents' and teachers' perspectives. The first phase of the project (grades 1 – 3) was part of a larger development project at SPSM, conducted by a research group (KDV, AR, AW). Findings from the first phase was presented in a SPSM-report (Rönnbäck et al., 2010).

Participants

The first phase of the project (grades 1 – 3) included all Swedish children who were known at RCV and met the following criteria:

- birth-year 19XX (year not stated, to protect participant-integrity);
- blindness or severe VI;
- assessed at RCV before school start, and had been recommended braille as their only, or primary, reading medium;
- no identified ID or other diagnosed additional disability when the project was initiated;
- about to start school in an inclusive educational setting, in the year 20XX (year not stated, to protect participant-integrity).

A total of seven children from different parts of Sweden were identified as meeting the inclusion criteria. Invitation letters were sent to the families when their child was about to enter 1st grade, and informed consent was received from all seven. In the next step invitation letters were sent to the schools, all of whom consented to participating. Thus, the participants in grades 1 – 3 were seven students (n=7), one parent per child (n=7) and their classroom teachers and paraeducators (n=14).

When the students entered 9th grade, the last year of Swedish compulsory school, all the families were invited to participate in the project's concluding phase. At this point, one student declined participation, thus informed consent was received from six families. Thereafter, the students' current schools were invited; all six consented to participate. Accordingly, the concluding phase comprised six students (n=6), as well as one parent per student (n=6), and one teacher per student (n=6).

Note that the student who chose not to participate in the project's concluding phase has been treated as an omission. Available data from this student in grades 1 – 3 have not been included in the analysis. Thus, the total number of participants in the complete project spanning from grade 1 – 9 was as follows: students (n=6), parents (n=6) and paraeducators/teachers (n=18).

Data collection

Qualitative interviews

Grades 1 – 3: Each of the students was randomly assigned to one of the three researchers in the research group. Each student was then followed by the same researcher during the entire three year period, and individual, semi-structured interviews were conducted twice a year with the student, classroom teacher and paraeducator by this researcher. At the end of grade 3 the parents were

also interviewed. All interviews were conducted in the students' schools. During these three years, a total of 133 interviews were conducted (114 when removing the interviews from the student that did not participate in the concluding part of the project). All interviews were audio-recorded. The average duration for the student-interviews were approximately 30 minutes and the interviews with teachers, paraeducators and parents varied between 60 and 90 minutes.

The interview guides were structured around certain areas of interest, with a set of questions within each area combined with the possibility to pose additional questions and follow up the narratives of the respondents. The students' interviews during grades 1 – 3 covered the following areas: their view of different activities and school subjects, school work and support, and social activities and peer relations. The teachers', paraeducators' and parents' interviews covered the following areas: organization, resources and support, accessibility and teaching methods, psycho-social aspects and peer relations.

Classroom observations were conducted in conjunction with the interviews. On each visit the researcher began by observing a lesson, which then primarily served as a starting point for the interviews with the children.

Grade 9: Individual, semi-structured interviews were conducted with all students, parents and teachers, on one occasion each. The interviews took place either at the students' school or in their home, according to their own choice. This time, all interviews were conducted by one researcher (KDV). A total of 18 interviews were conducted at this point. All interviews were audio-recorded. The average duration of the student interviews were approximately 30 – 40 minutes and the interviews with teachers and parents varied between 60 and 80 minutes. The interview-guides for each informant group covered the same areas as during grades 1 – 3, but in addition, the informants (students as well as teachers and parents) were this time also asked to reflect in retrospect on the school situation during different periods of the compulsory school years. Through this procedure, experiences of the pedagogical support needed and offered, and different psycho-social aspects of the school situation were explored. Furthermore, the teachers and parents were asked to describe the students' academic progression during compulsory school, with regard to goal achievement and general academic performance.

Quantitative data

In grade 9 school grades in each subject from grades 8 and 9 were collected for all the students. In addition, individual results from reading observations conducted once a year at RCV during grades 1 – 7, and individual results from two subtests (decoding of regular and nonsense words) from the LS-test (Johansson, 2004), which had been adapted to braille by KDV were also gathered. The SDQ (Goodman, 1997; Goodman et al., 1999), was distributed verbally to the students, parents and teachers as part of the interviews.

In addition, cognitive assessments of the children, which had been performed at RCV before the children's school start, were reviewed by KDV. The cognitive assessments included the verbal scales from WPPSI-III (2005) or WISC-IV (2007), tactile subtests from ITVIC (Dekker, 1989), observations and interviews with parents and school staff. Three of the students had been assessed again during middle school, because they had displayed different kinds of learning difficulties. These later assessments had resulted in the students' being diagnosed with ADHD, ID and Asperger syndrome, respectively. Additional tests and methods in these assessments were ABAS-II (Harrison & Oakland, 2008), ADI-R (Rutter et al., 2008) and ADOS (Lord et al., 2008) in one case, and Browns ADD-scales (Brown, 2001) in another. These later assessments were also reviewed by KDV.

Data analysis

Qualitative interviews

The interviews were transcribed and analyzed through thematic analysis (Braun & Clarke, 2006). The interviews from grades 1 – 3 and grade 9, were analyzed in two phases. First, the analysis of grades 1 – 3 was performed, directly after completing the data collection in grade 3. This analysis was performed by the research group responsible for the first part of the project (KDV, AR, AW). The three researchers first read and coded all data individually, after which we went back to the group, to discuss and combine codes into potential themes. Each identified theme was built up by narratives from all informant-subgroups taken together. The themes were then reviewed again, resulting in some of them being combined. In the last step the final themes were re-analyzed, defined and named, and the analysis was agreed upon by the group.

The analysis of the grade 9-interviews, was performed by the responsible researcher (KDV) and the principal research supervisor (UE) after completing the data collection in grade 9. The process followed the same steps as described above. As a final step, the thematic maps from grades 1 – 3 and from grade 9, were studied and compared. For the purpose of study II, which focused on reading development, academic achievement, accessibility and support, the interviews from grades 1 – 3 were used to reflect the retrospective narratives about school achievement and pedagogical support in grade 9. For the purpose of study III, themes regarding psycho-social aspects from grades 1 – 3 and grade 9, were pooled together into four overarching themes in order to obtain a longitudinal view of the students' psycho-social situation.

The classroom observations performed in grades 1 – 3 were not analyzed, but were merely used to support the information collected in the interviews.

Quantitative data

Mean grade levels in grades 8 and 9 were calculated for each student. The results of the reading observations in grades 1 – 7 (wpm for each grade, and special teacher's evaluation of comprehension; i.e. good/average/poor) were compiled for each student. The LS subtests were scored according to the test manual, and results regarding correct words, time and reading quotient (number of correct words divided by time) were transformed into Stanine-scores (scale 1 – 9, M=5, Sd=2) for each student. The results were compared to norms of Swedish sighted 9th-graders (Johansson, 2004) in order to obtain a brief measure of the VI students' decoding skills and speed, compared to print-readers of the same age.

The SDQ-questionnaires of students, parents and teachers, were scored and analyzed by hand according to the instructions provided by YouthInMind on the SDQ-info-website (YouthInMind, 2012). Since available norms from Sweden and the Nordic countries Denmark and Finland, provided by YouthInMind, only include younger age groups, British norms for 15-year old boys and girls, were used respectively (YouthInMind, 2012). The students received individual measures of no/minor, some, or extensive difficulties within each examined area, according to parents, teachers and self-rating.

A review of the assessments that had been previously performed of the students at RCV, served as background information to support other information about the students' cognitive levels and, in three cases, additional disabilities.

Project C

Design

This project adopted a mainly qualitative design, with an emphasis on interviews. In addition, pedagogical data was collected. The project included students', parents' and teachers' perspectives.

Participants

The project comprised a sample of children who were known at RCV and met the following criteria:

- pre/perinatal or early infancy blindness, defined as total blindness or light perception at the most (WHO-categories 4 and 5)
- the child had been assessed at RCV and received a diagnosis of autism or Asperger syndrome, according to DSM-IV (APA, 1994)
- aged between 6 and 16 years (i.e. compulsory school age) at the time the study was initiated

A total of 22 children matching these criteria, were identified through the medical and psychological files available from project A (presented above). Out of these 22 children, eight were selected out of the aim to include children of different ages, of different genders, with and without ID, with different types of school placement, and from both urban and rural backgrounds. One of the eight invited families did not respond, and one declined participation. Thus, informed consent was received from six families. Thereafter invitation letters were sent to the schools. All invited teachers consented to participate.

The final participants were three girls and three boys between 9 and 15 years (n=6). Three had a diagnosis of autism and three had a diagnosis of Asperger syndrome or high functioning autism. Three had average intellectual functioning (AIF), two had ID and one had borderline intellectual functioning (BIF; IQ level between 70 and 85). At the time of the study, two children attended inclusive education and four attended special schools or groups. In addition, parents (n=8) and teachers (n=7) participated.

Data collection

Qualitative interviews

Individual, semi-structured interviews were conducted with parents, teachers, and five out of the six students (one student did not have sufficient cognitive and linguistic skills to participate in interview) on one occasion each. All teachers were interviewed at the schools; the students were interviewed at their school or in their home, and the parents were interviewed at the school, in their home, at SPSM, or, in one case, over the telephone, according to their own choice. The interview guides were structured around certain areas of interest with a set of questions within each area, combined with the possibility to pose additional questions and follow the narratives of the respondents. The interviews with parents and teachers included the following areas: their experience of the child's diagnosis and functional strengths and difficulties, the organization of the school situation, schoolwork, and support to teachers and families. The student-interviews focused on their experiences of school, schoolwork and support from the teachers. A total of 17 interviews were conducted. All interviews were audio recorded. The average duration for the student-interviews were 30 minutes, for teachers 69 minutes and parents 76 minutes. All interviews were performed by one researcher (KDV). Before the interviews with the students, KDV participated in their classes to see the environment and to provide an opportunity for the student to become acquainted.

Quantitative data

Teachers' pedagogical documentation, such as individual evaluation plans (IEP:s) were collected for each student, as well as school grades for those attending senior level. The assessments of the children that had been performed

previously at RCV, and had resulted in an ASD-diagnosis and in two cases an ID-diagnosis, were reviewed and served as background information to support other data. The assessments included the verbal scales from WPPSI-III (2005) or WISC-IV (2007), tactile subtests from ITVIC (Dekker, 1989), observations, parts of the ADOS (Lord et al., 2008), ADI-R-interviews (Rutter et al., 2008) and Vineland (Sparrow et al., 2006) or ABAS-II-questionnaires (Harrison & Oakland, 2008) with parents, as well as interviews and ABAS-II-questionnaires (Harrison & Oakland, 2008) with teachers. Items depending on eyesight had been omitted or adapted by the assessment team.

Data analysis

Interviews

All interviews were transcribed and analyzed through thematic analysis (Braun & Clarke, 2006). The analyzing process included several steps. First, KDV together with the research supervisors (UE and EF) read through the material in order to become familiar with the contents. This was followed by the generation of an initial coding of statements across the entire data set (all three informant-subgroups). In the next step codes were combined into potential themes, which were visualized in thematic maps for each informant subgroup separately, with the aim to capture variation as well as similar thoughts and experiences between individuals and informant sub-groups. The themes for each informant-group were then reviewed all over again, resulting in some of them being combined. In the last step the final themes were re-analyzed, defined and named. Finally, a thematic summary was developed, in which the themes for each informant-group were organized.

Quantitative data

Pedagogical documentation and school grades were summarized for each student in the attempt to acquire an overview of the students' achievement levels. The review of previously performed psychological assessments served as background information to support other data about the children's cognitive and behavioural strengths and difficulties.

Ethical approval

The empirical studies included in this research were conducted according to the Declaration of Helsinki, and have been approved by the Regional Ethical Review Board in Stockholm (2012/665-31/5).

Ethical considerations

Recommendations and guidelines from the Swedish Research Council (Vetenskapsrådet, 2011) have been considered and followed, and certain ethical issues and dilemmas need to be highlighted and commented on.

Informed consent was obtained from all participants in projects B and C. Written information was sent to all parents and teachers and followed up by contact via telephone and e-mail, where they had the opportunity to ask questions. They were also informed about the possibility to refrain from further participation at any time. The participating children received simplified letters in braille about what was going to happen, and were invited to contact me if they had any questions. Research involving children, especially children with disabilities that might influence their level of understanding, like ASD and ID, must be conducted with sensitivity, taking into account their cognitive abilities. Therefore, I met with the children in both projects, prior to the interviews, to let them become acquainted with me, in the hope of helping them relax and feel more secure in the interview situation. During the interviews the interview guides were used, but I mostly tried to follow the children's narratives and talk about what seemed most important to them. I also informed parents and children before the interviews that if any kind of worrying information arose during the children's interviews, this information would have to be shared with the parents.

Furthermore, research involving small samples, always entails risks regarding the possible identification of the participants' identities. This issue was therefore brought up with the invited families in projects B and C. Despite the risk of identification, however, they all wanted to participate, since they considered the area of research important, and had a wish to contribute. Thus, in order to protect the anonymity of the participants as far as possible, details such as the families' home-towns, the children's birth-years, individual gender, the existence of siblings, as well as other specific details, have been omitted in the documentation of the studies. Also, when quotes from interviews are presented in the papers, these are not linked to specific individuals. In project A, all data was collected from files and records. The findings from this study are reported on a group level only, thus identification of individuals is not possible.

Finally, the dilemma concerning my insight into the studied area through my work at RCV for many years, as well as my combined role as researcher and practitioner in the field, needs to be commented on. Previous understanding may involve a risk of bias or fixed preconceptions, which must be carefully considered. However, one can also view previous knowledge of the studied area as a strength, since this offers a sensitivity for the subject and the possibility to pose relevant questions in the interviews, thereby hopefully reaching a deeper level of understanding (Kvale & Brinkmann, 2014).

Regarding my combined role as a researcher and practitioner within the same field, this inevitably led me to have had some prior contact with some of the participants – children, parents and teachers. Before initiating this research, I had taken part in performing the assessments of some of the participating children (see projects B and C for further information about these assessments), and I had met some of the parents and teachers during courses at RCV. When conducting research in a field where you are also working, and which includes a limited number of potential participants, this situation is difficult to avoid. Risks involving individuals feeling forced to participate due to feelings of dependence or gratitude, must be considered, as well as possible limitations regarding what was possible to discuss during the interviews, for example feelings about the assessment procedure, in the cases where I had been part of the assessment team. However, by bringing this subject up with the participants in the initial stage of the studies, we could talk about this dilemma and hopefully eliminate some of the potential impact on the interviews.

Validity and reliability

The research design in projects B and C, were chosen out of the purpose to elucidate the aims and research questions through different types of data, qualitative as well as quantitative (Biesta, 2010). Certain efforts were also made in the research process to strengthen the validity and reliability.

Interview guides were sent out in advance to the participants in projects B and C to provide them with the possibility to look through and think about the included areas and get back to me regarding any queries or uncertainties. After completing the interviews, all participants were invited to contact me at any time afterwards, to add or revise any given information. Project B had a longitudinal scope with data collection on several occasions, in the aim of strengthening the findings. In the interviews of both projects B and C, information was obtained from multiple sources, in the attempt to strengthen the trustworthiness and understanding of the examined areas (Bogdan & Biklen, 2006).

Regarding specific measurements, the SDQ, which was used in project B, is considered a reliable and valid measure of psycho-social strengths and difficulties and psychological well-being, and is frequently used in research. Its psychometric qualities have been examined in international as well as Swedish studies (Goodman, 1997; Goodman et al., 1999; Smedje et al., 1999). In addition, the fact that the SDQ builds upon already established methods (the Rutter-questionnaire and CBCL, Goodman, 1997), is considered to strengthen the validity. Also, both British and Swedish norms include large samples. However, the Swedish norms only include parent ratings of children 6 – 10 years, and could therefore not be used. In the British version, the norms include parents' ratings as well as teachers' and children's self-ratings and all

age groups, separated by gender. Even though using norms from other countries is not ideal, we judged that the British norms were applicable to our study.

The LS-test, used in project B, is considered a valid and reliable test of reading skills for grades 7 – 9, and the Swedish norms are based on a large and representative national sample (Johansson, 2004). It should be noted, though, that only two subtests were used, and on only one occasion. Reading skills were otherwise measured through the reading observations conducted at RCV during school years 1 – 7. However, even though the text materials used in the reading observations have been developed and used in-house at RCV for many years in the assessment of braille readers, they are not part of a formally standardized test.

In projects B and C, the review of the previously performed assessments of the children, served to validate other information provided, regarding the children's cognitive levels and eventual additional diagnoses.

Regarding project A, where the study was based on available medical, psychological and pedagogical records, we have to assume that the information provided in these records is correct. In an attempt to further validate the information, all data was scrutinized by a multidisciplinary research group, with expertise in the field of ophthalmology, child neurology and developmental psychology regarding children with blindness.

The research supervisors had access to raw data in all the studies, to enable transparency in the analyzing processes. Acknowledged analyzing methods were applied, and in all three projects the analyzing processes were performed by groups of researchers who agreed on the final analysis. The purpose of this procedure was to increase the trustworthiness of the findings, and thus strengthen the internal validity of the studies.

The external validity in project A is considered to be strong, since this study included if not all, at least the vast majority of all blind children in Sweden over the period of two decades. Therefore the study population should be representative regarding the etiologies and prevalence of additional disorders and disabilities during recent decades. In projects B and C however, due to the small and heterogeneous target groups, the external validity may be considered low, since the results from the included samples should not be directly generalized to other children with blindness. On the other hand, since the total population of children with blindness is in fact very small and heterogeneous, the findings from the studies, even though subjective, is supposedly also relevant for others in this population.



4. Results

Results from project A

Project A examined the clinical characteristics of the population of children with blindness in Sweden during recent decades and was reported in study I. The main findings can be summarized as follows:

- A total of 150 children were identified within the birth-years 1988 – 2008. This corresponded to a prevalence of 7/100 000 children.
- Five causes of blindness dominated in the studied population: ROP, ONH, LCA, ONA and micro-/anophthalmia, in decreasing order.
- A total of 72% of the children had been born at term, while 28% had been preterm born. Of these preterm children, the majority were born extremely preterm (GA <28 weeks), with a mean birthweight of 782g. Among the preterm children 90% had ROP as their primary cause of blindness, and in this group the rate of cerebral involvement and multi-disability was high.
- Overall, there was a high rate of multi-disability in the total studied population. Only 22% of the children had only blindness, while at least 72% had one or more reported additional disability. The most common co-existing disabilities were ID, ASD and motor disability, in decreasing order. In 6% of the cases data on comorbidity were uncertain or unavailable.
- Of the total population, 38% had clearly described ASD-symptoms, 31% had been diagnosed with ASD. The majority of the children with ASD also had ID. The most common etiologies in the ASD-group were ROP, ONH, micro-/anophthalmia and LCA, in decreasing order.
- The rate of ASD was high in certain etiological subgroups: 70% of all children with ONH (including SOD), 58% of all children with ROP, 44% of all children with micro-/anophthalmia, and 36% of all children with LCA. When looking at the children with SOD separately, we found that 100% of them had ASD-diagnoses.

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- While 50% of the children (all with multi-disabilities) attended different special schools, 39% attended inclusive settings. Among the children in inclusive settings, the majority had only blindness, but there were also a number of children with additional disabilities, mainly ASD. In 11% of the cases, information about school placement was unavailable.

Results from project B

Findings from project B were reported in two papers: Study II reported results concerning reading development, academic achievement, and experiences regarding accessibility and support. Study III reported findings concerning psycho-social aspects. The major findings from both study II and III are summarized as follows:

- The six students all started out as braille readers, but their reading development then took different directions. Two blind students developed good skills, while another two had great problems with reading. The two partially sighted students both stopped using braille, seemingly due to identity-related issues – they compared themselves with their sighted peers, wanted to be like everyone else and read “normally”.
- Several teachers expressed a lack of sufficient competence regarding braille and teaching methods for students with VI, thus making it difficult to fully support the students in their reading development and learning. In addition, not all those working as teachers or paraeducators had sufficient – or any – pedagogical education. Overall the teachers expressed a need for additional support and education.
- All students received grades on at least the lowest passing level, and a couple received very high grades. However, several teachers expressed insecurity regarding evaluation, a matter that entailed the risk that the obtained grades did not fully reflect the students’ true capacity in all cases.
- Difficulties regarding how to make certain school subjects accessible at the senior level led some teachers to discourage the students from studying these subjects. Thus, these students were excluded from certain learning areas out of reasons unrelated to their own choice or ability. Apparently it was easier to make school subjects accessible during the lower school years, than it was at the senior level.
- Only two out of six families were satisfied with the educational support throughout school. These two emphasized the positive attitude from school management and teachers as crucial. Also, both these students

were regarded as cognitively gifted and independent in their schoolwork, and their individual prerequisites had clearly contributed to the positive outcome.

- Three students had during middle school been diagnosed with additional disabilities (ID, AS and ADHD), and were in need of extensive support. However, these families were very unsatisfied with the support provided during the vast part of their children's schooling. One student, with ID, eventually transferred to a special school, due to the dissatisfaction with the support in the local schools. In the special school, both student and parents were satisfied with the pedagogical as well as the social situation.
- Challenges regarding the social inclusion and gaining access to the peer group in school, were identified in a majority of the cases. Structured classroom activities seemed to work better in this respect, while break time was more difficult. In the lower school years it was easier to apply suitable interventions to increase the social inclusion, than it was at the senior level. All the students described experiences of loneliness in periods, and some of them primarily had friends outside school, among VI peers.
- There was no major difference in the SDQ-ratings between the students with VI (parents' teachers' and self-ratings) and the sighted norms. However, in the interviews the students revealed feelings of stress and psychosomatic symptoms such as headaches or stomach aches. These symptoms seemed to be linked to consequences of their VI, and worries about not being able to manage their school work at the same pace as their sighted peers.
- The five students who attended inclusive education during their entire schooling, all stated that they would not have wanted to go to a special school. Even though some of them had experienced a difficult time, they thought this was the best option in order to be prepared for life in "the sighted society". The parents' opinions differed regarding this issue. When reflecting on their child's schooling, some questioned inclusive education strongly, since they perceived that their children had not received enough pedagogical support and had also suffered socially. For others, inclusive education was considered the only plausible option, since they regarded special schools or groups as being excluding and restrictive.

Results from project C

Findings from project C were reported in two papers. Study IV reported results concerning challenges and successful strategies in the schoolwork for students with blindness and ASD. Study V reported findings regarding parents' experiences of having a child with blindness and ASD, and experiences of support needs as well as support provision to the families. The major findings from both study IV and V are summarized as follows:

- All children in the study received their ASD-diagnoses rather late, just before school start or during the lower school years ($M=7$ years). Several parents experienced that their worries about the child's development had not been taken seriously by professionals in local pediatric or low vision clinics. Instead, due to lack of experience of blind children, they had attributed the child's difficulties to the blindness, thus delaying the assessment. All parents emphasized the importance of eventually receiving the children's ASD-diagnosis from professionals with expertise in blind children.
- The children displayed a number of unique strengths as well as difficulties: All were talented in music and had a great auditory memory, some had excellent linguistic skills. They also all displayed multiple information-processing problems and executive functioning deficits, as well as a pronounced sensitivity for loud noise, to which they could react strongly.
- Five out of six children started their education in inclusive settings. However, at the time of the study, only two remained in regular classes, while the other three had changed schools one or more times due to dissatisfaction with the support, and currently attended specialized settings. In one case, the child had gone through several school transitions in the search for the right placement.
- Several challenges in the school work were identified in each informant subgroup (students, teachers and parents) and included: situations leading to confusion, and difficulty handling the surrounding stimuli (students); how to broaden the student's horizons, how to balance the need for individual support with group activities, motivation and study technique, and evaluation (teachers); the risk for underestimation of the child's capacity, and what could be the right choice of school placement (parents).
- Successful strategies in the schoolwork were also identified in each informant subgroup (students, teachers and parents) and involved: the importance of peace and quiet, and the ability to understand and be understood (students); small context and flexible working forms, planning,

structure and control, and the importance of building on strengths and interests (teachers); the attitude from teachers, and the need to address individual needs and differences (parents).

- The teachers, regardless of which school form they were working in, pointed out the need for formal education and additional hands on-support regarding specific teaching methods addressing the combination of blindness and ASD.
- The parents were all occupied with the question of what was the most suitable school placement. Regardless of their child's current placement, a majority reported feelings of worry and stress related to whether they had made the right decision for their child.
- The parents described many feelings of being lonely and "odd", and constantly being subjected to professionals who lacked experience and competence about the unusual combination of blindness and ASD. A strong need for a more coordinated and continuous support to the families was expressed, together with the possibility to meet other families who had children with the same dual disability.



5. Discussion

The overall aim of this research was to deepen the knowledge about developmental aspects, comorbidity and implications for support and education regarding children with blindness, and thereby fill an existing research gap. Special focus was directed towards children with blindness in combination with ASD and their families. Two of the research projects included children's, parents' and teachers' voices in order to elucidate experiences from their different perspectives. Since children and parents are rarely heard in the existing research within the field of blindness, this was considered especially important. Moreover, a multi-disciplinary approach has framed the implementation of the research projects, in order to capture the complexity surrounding children with blindness and questions regarding education and support.

The findings from the research projects have highlighted the individual as well as the environmental complexity surrounding blind children's situation in and out of school. The results, viewed out of a bio-ecological perspective, suggest that the children's individual characteristics together with different environmental factors, are of significant importance for the proximal processes in the micro-systems. Also, the relations and communication within and between different levels in the total system, are crucial for the child's development.

On the micro-level, the development is directly influenced by interaction between the child and adults or other children, within the family, in school, at the low vision clinic or the habilitation center. Within every one of these micro-systems, the child needs to be met with understanding of their individual prerequisites, and knowledge about what the lack of vision means for development and learning. The meso-level includes the communication between the different micro-systems; parents, children, teachers and professionals in the local supporting facilities. It is clear that the communication, knowledge-exchange and collaboration between the different actors in the micro-systems is necessary, to find common ground for support and intervention. The exo-level involves the municipality and support provided by actors further from the center of the system, such as SPSM/RCV, as well as the general teacher training programs. The results from our studies show that decisions made, and competence provided on this level, have a very tangible effect on the conditions for the child with blindness in the local school. On the macro-level, specific resources and options regarding educational possibilities in relation to the blind children's individual needs must be discussed: for example aspects

regarding governance, planning, expanded time and curriculum, and the need for guideleines to ensure a more equal support and education.

The following discussion will focus on the heterogeneity of the population of children with blindness and the necessity of considering the children's individual needs, as well as issues regarding competence, support and inclusion, and aspects regarding the need for improvements in the service delivery model to families and schools. These aspects will be discussed out of a bio-ecological frame of thought.

A small group with complex needs

In the bio-ecological model, the child with their individual characteristics and needs is placed in the center, thereby highlighting the importance of the biological component and the individual complexity in the interactive model. Bronfenbrenner pointed out that the biological dimension was incorporated into the model since he found that much research focused too much on only environmental factors. According to Bronfenbrenner, focus should instead be on the interaction between the unique individual and the social context (Bronfenbrenner, 2005). In line with this reasoning, it is important to emphasize the fact that children with blindness constitute a very small and heterogeneous group; a matter that makes it necessary to carefully consider the individual variation in the context of education and support provision.

The awareness of the high rate of multi-disability in the blind population has increased, and an image of a population with complex needs has emerged. In Sweden, previous research has been conducted regarding the developmental outcome in specific etiological subgroups (ROP and ONH) of blind children, but detailed information about the clinical characteristics of the total population of children with blindness, has not been presented before. Thus, the findings from our research project A add important information to the field.

Our results show that, on average, seven children per year have been born with blindness category 4 or 5 (total blindness or only light perception) in Sweden during recent decades. Thus, these children are very rare in the general population. Five causes of blindness dominated during this period: ROP, ONH, LCA, ONA and micro-/anophthalmia, and the rate of multi-disability was high in all these etiological groups. Our findings strengthen the assumption that children with isolated blindness are unusual; the majority had at least one reported additional disability. ID and ASD were especially common, and specifically, the prevalence of ASD largely exceeds the prevalence of around 1 – 2 % in the population of sighted children (Sandin, Lichtenstein, Kuja-Halkola, Larsson, Hultman, & Reichenberg, 2014). ASD also seemed to be more strongly associated with certain etiological subgroups.

ROP and ONH have been previously pointed out as frequently associated with both ASD and ID (Ek et al., 1998; Jacobson et al., 1998; Borchert et al., 2008; Jacobson et al., 2009; Parr et al., 2010; Teär Fahnehjelm et al., 2014; Dahl et al., 2017), and this was also confirmed in our present study. Interestingly, two additional etiologies also stood out as being commonly occurring with ASD in our study; namely micro-/anophthalmia and LCA. Micro-/anophthalmia has previously been described to co-exist with additional developmental disorders in genetic malformation syndromes (Blyth & Baralle, 2011; Pushker, Tinwala, Khurana, & Sen, 2013). The association between LCA and ASD is more debated. While for example Rogers and Newhart-Larson (1989) reported a high degree of ASD in blind children with LCA, while others have questioned these findings (Fazzi, Rossi, Signorini, Rossi, Bianchi, & Lanzi, 2007). Considering the complex genetic background of LCA, which entails that the disease exists in various forms, one hypothesis that could explain the contradictory results regarding ASD, is that the studies may have involved different subgroups of the disease. Further research about the possible relationship between LCA and ASD is therefore needed. Nevertheless, there seems to be a group of etiologies that involves a substantial risk for atypical development. Awareness of this matter is important to enable early screening for deviant development in specific “risk-groups”.

In the light of the above, when encountering young children with blindness, pediatric ophthalmologists and pediatricians need to be aware of the common coexistence between blindness – with different etiologies – and additional neurodevelopmental disorders. A helpful outset in this context is the concept of ESSENCE – Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations (Gillberg, 2010), which highlights that developmental disorders commonly coexist, and that the existence of only one isolated disorder is unusual. The ESSENCE-perspective implies that a holistic approach is necessary, even when there is one “marker symptom”, such as blindness. In line with a bio-ecological frame of thought, an ESSENCE-approach in regularly performed clinical examinations and assessment procedures, could contribute to broadening the image of the child’s individual characteristics and possible additional disabilities – so that interventions can be implemented and adjusted accordingly.

Ensuring a valid assessment procedure

The establishing of a mutual view of the child’s strengths, difficulties and needs, through communication between the different micro systems (parents, preschool/school, professionals from low vision and habilitation clinics), is an important starting point for the shaping of support and interventions. In this process, the assessment can provide necessary information and become the basis for the continued care. Knowledge of the developmental risk factors pre-

sent in the population of children with blindness, is important when performing assessments, providing functional descriptions and establishing diagnoses. The ICD-10 (1990) and ICF-CY (2007) should preferably be used together as complementary frameworks in this procedure.

Importantly, previous research has pointed out that differentiating between delays or difficulties related to the blindness, and difficulties related to additional developmental disorders is demanding, thus, the assessment team needs to have experience of blind children's typical development (Dale & Salt, 2008; Ek, 2000). Otherwise, there is a risk that additional disabilities are either overlooked, or that the child may receive a faulty diagnosis.

The parents of children with ASD in research project C, confirmed that professionals in local clinics who had rarely, or never, encountered a child with blindness, tended to adopt a "wait-and-see"-approach, when the parents expressed worries about their child's development. Instead of taking the parents worries seriously, the child's delays or difficulties were often attributed to the lack of vision. Already twenty years ago, Ek (2000) observed this phenomenon in relation to Swedish children with blindness due to ROP, and referred to the approach as in line with Warren's "developmental lag theory", meaning that the child will catch up, if only given time (Warren, 1994). Ek pointed to the risk with such an approach towards children with blindness, since it might prevent and delay necessary measures needed to promote development (Ek, 2000).

In line with this reasoning, the "wait and see"-approach described in the present research project sometimes meant that the family received no help in understanding the child's way of functioning, and they were left to "trial and error" when trying to support their child. When they finally had the assessment performed, which resulted in the ASD-diagnosis as a new framework for understanding their child, this was perceived as liberating, but also frustrating, since some of them experienced that this information should have come much earlier. The fear of having lost important time, where the support could have been shaped differently to better suit the child's needs, was expressed. In summary, a functional description of the child's unique strengths and difficulties, as well as the identification of possible additional disabilities, is considered crucial for the provision of optimal support.

Regarding the challenges surrounding the assessment of children with blindness, some argue that the time has come to design a modern intelligence test (and other measures), standardized specifically for children with blindness (Tobin & Hill, 2011). The main problem, however, still concerns the gathering of large enough and representative samples, for norming purposes (Dial & Dial, 2010). Out of the aim to collect larger samples, there are ongoing discussions about possible international collaboration, with the purpose of developing such tests and other assessment tools for children with blindness. Important as this may be, I would like to argue that the assessment team's clinical

expertise in children with blindness, and their typical and deviant developmental patterns, is still the most important factor for ensuring a valid assessment procedure.

Support and competence in relation to needs

The complex developmental characteristics of the population of children with blindness place great demands on the shaping of the support to the children, their families and schools. Granlund and Roll-Pettersson (2001) in their study of perceived needs of parents and teachers of children with ID, pointed out that individuals with the same diagnostic labels, may show significant variations regarding their individual profiles (Granlund & Roll-Pettersson, 2001). This entails the need to carefully consider individual child differences in for example temperament, communications skills and cognition, in the shaping of support. As was demonstrated in our studies, the same assumption applies to children with blindness, and this matter entails that the different actors in the exo-system, such as teachers and professionals in low vision clinics and habilitation centers, need to consider that the diverse needs of the children means that interventions and support that suits one child, may not necessarily suit another. Thus, individualized support, based on adequate knowledge, is crucial.

Moreover, besides the regular school curriculum, children with blindness also need to master all the specific core skills; braille literacy, orientation and mobility techniques, social and daily living skills as well as assistive technology. The previous special school for students with blindness in Sweden had a duration of ten years, instead of the nine years in regular school, and it implemented an expanded core curriculum (ECC). The purpose was to provide sufficient time for the students to study the regular school subjects, as well as learn the specific core skills, with support from teachers with expertise in teaching methods for students with blindness. In today's Swedish inclusive school system, the students are expected to follow the regular curriculum at the same pace as the sighted students, despite the fact that many tasks take much longer to perform without vision, and braille is a much slower reading medium than print (Ferrell et al., 2006). In addition, the core skills are to be trained partly during the ordinary school day, by the regular teachers, and partly outside school. This situation is highly demanding for everyone involved, and lack of time is a constant problem.

McLinden, Douglas, Cobb, Hewett, and Ravenscroft (2016) emphasize that there is a strong link between students' access to the ECC and their future independence. They argue that without a thoughtful implementation of an ECC and adequate training of the core skills in school, many students with VI in fact leave inclusive settings without having developed necessary skills (McLinden et al., 2016). According to their reasoning, this may lead to the

students being less independent when they leave school, thus being poorly equipped to handle future studies, work or daily living skills, compared to sighted students. Consequently, failure to address certain aspects of curricula which are important to specific groups, such as students with VI or blindness, is not only unfair, but may also be also excluding in a wider perspective (Douglas, McLinden, Robertson, Travers, & Smith, 2016).

Some of the parents in our studies expressed concerns that, due to unrealistic demands and insufficient support, their children were at risk of not being provided enough opportunity to move forward in their development. Teachers confirmed that they sometimes saw more capacity within their student, but that they lacked sufficient knowledge, tools and time to bring this to the surface – a problem that must be considered serious. Several teachers also expressed uncertainty concerning how to properly evaluate the students' achievements, a matter which possibly affected how well the obtained grades matched their true capacity. Regarding the children with both blindness and ASD in project C, their many strengths and talents were described by the parents. However, in school these talents were at risk of being overshadowed by various challenging behaviors, if the learning environment was not adapted to the students' complex needs. Without the right guidance and support, the child may be forced into a role of someone who is less competent and maybe also destructive, instead of being given the opportunity to show their strengths.

The results of both research projects B and C, imply that much of the current support provided, corresponded neither to the complex needs of the students, nor to the general demands in the inclusive setting. Instead, the support seemed to vary a great deal between the schools, due to various factors on different levels in the system, such as students' individual characteristics, teachers' competence, organization of the support, attitudes from school management and the communication and collaboration between the different micro systems, i.e. home, school and other professionals. The results paint an image of a support system that is fragile, and does not guarantee equal educational opportunities for these students. Even though there are positive examples, many of the inclusive school settings described in this research showed deficits, mainly due to lack of competence in the school staff. The teachers clearly have good intentions and do their best, but they face a difficult task. Creating an optimal learning environment for a student with blindness is demanding, even more so if the child also has additional disabilities, when the school is shaped for students who are sighted and is very much based on visual information. Thus, the teachers in all school forms in the studies, strongly pointed out the need for additional support and education regarding suitable teaching methods.

The overall findings from these studies are strengthened by extensive clinical experience from RCV, where we have witnessed many teachers struggle with their task over the years. The municipal autonomy entails that it is up to the local school management to organize the support around the student.

While most schools do send their staff to courses at RCV, some, in fact, do not. Our research, as well as clinical experience also shows that fewer teachers working at the senior level attend the courses, than those working in the earlier school years. This is despite the fact that many school subjects at the senior level, such as mathematics, physics, technology and home economics, are difficult to make accessible for the blind student, without proper knowledge. Consequently, it happens that, due to problems making subjects accessible, teachers advise the students not to study these subjects, and instead provides a reduced curriculum (as for two of the students in project B), a scenario that was also described by Gray (2009) in her study of inclusion of students with VI in Ireland. By doing this, the students are excluded from important learning opportunities with their sighted peers, instead of the schools addressing the problem with providing the teachers with proper competence.

Furthermore, the results from our studies, as well as clinical experience, show that sometimes the staff – teachers or paraeducators – working closest to the student with blindness, have no formal pedagogical education. Still, they are often responsible for much of the individual support and training, not least braille and reading instruction. Forster and Holbrook (2005) discussed the role of the paraeducators in relation to students with VI, and pointed to the fact that their role is becoming increasingly complicated, with much responsibility, despite the fact that they often lack formal training. Mc Linden et al. (2016) emphasized the role of the specialist teacher with competence about VI, as a crucial actor in the schools micro system, to ensure proper support and access to different curriculum areas. In Sweden however, such a model with specialist teachers educated about VI, is not applied.

The right to braille and qualified instruction

The macro level in the bio-ecological model, deals with, among other things, policies and legislation that effect the different levels of the system, the support provision and in turn the development of the individual child. For children with blindness, the particular aspect regarding literacy and the right to braille as reading medium, needs to be addressed in this context. In the UN convention on the rights of persons with disabilities from 2006, the right to learn braille is established. In article 24 it is also said that this demands that teachers on all educational levels receive special training to be able to teach braille (UN, 2006). Despite the fact that Sweden has ratified the convention, nothing is mentioned about students' right to braille, in the school law. The current school law (SFS 2010:800) establishes that education within the Swedish school system shall be equal and highlights the right to special educational support. Specific disability groups are mentioned, and for example the right to sign language is established (Skolverket, 2011). However, there is no mention of braille. Consequently, it is up to the individual schools to see to that the teachers receive adequate training, but there is no legislation to invoke, in

order to ensure that this is actually done, and courses and training provided by SPSM/RCV are not mandatory. Furthermore, as pointed out above, it is not to be taken for granted that the staff responsible for the students' reading acquisition have adequate pedagogical education.

As a comparison, Norway, whose school system is very similar to Sweden's, has a different application of the UN convention. Like in Sweden, Norwegian students with blindness and severe VI attend inclusive education. Reading acquisition is in Norway a high priority, since good reading skills are considered necessary to be able to benefit from inclusive education (Utdanningsdirektoratet, 2013). In the Norwegian school law (Opplæringsloven §§ 2-14, 3-10) the right to adaptations of the school environment, as well as the right to receive teaching of and in braille, is established for students with blindness or VI. This legislation has led to the education of teachers in braille being more formalized, and the responsible teacher is obliged to have braille-competence. Moreover, the legislation postulates the possibility of extra time for the students, in order to incorporate braille instruction and the training of core skills in the curriculum (Utdanningsdirektoratet, 2013).

Holbrook (2008) argues that reading and braille instruction for students with blindness or VI, should ideally be provided by staff with the following characteristics:

- Creativity, flexibility, and other personal characteristics of a good teacher.
- Ability to teach. The person teaching reading should have experience, at least at the level of student teaching or field experience, and have received feedback about his or her teaching from a qualified person. This person should have a proven track record of success in formal, organized teaching. He or she should be skilled in examining student performance and planning, adjusting, or realigning instruction to meet student needs.
- Understanding and knowledge about the development of language and literacy in young children.
- Competence in the code or codes or media that are used by the child. By competence, I mean a deep comfort with the code, not mere familiarity.
- Understanding and knowledge about the impact of visual impairment on the acquisition of literacy. This includes concept development, tactile skills, hand movement requirements, use of tactile graphics and diagrams, and other related skills (p 204).

Holbrook argues, that these characteristics are not expected be found in one single person, but instead, staff with proper pedagogical training must be further educated in braille and teaching methods for students with blindness and VI. Also, the teacher responsible for the planning of the reading activities and lessons should be the same person who carries it out, it should not be done by someone else – for example a less skilled paraeducator (Holbrook, 2008). In

addition, studies have shown that braille reading students in inclusive education, seem to do best when the literacy instruction is part of a well-organized plan, and when the classroom teachers have the opportunity for close collaboration with teachers with expertise in VI (Wall Emerson, Sitar, Erin, Wormsley, & Leigh Herlich, 2009).

The results of our research (project B), along with the experience from RCV, points to specific lack of competence in the area of braille instruction, within the Swedish schools. With the current organization of support and training, the teachers or paraeducators generally learn braille in parallel with teaching it to the student. The same scenario would be absurd to transfer to a sighted student – no one would accept that a teacher learn the alphabet and how to read, at the same time as they teach it to the student. Yet, this is the reality for many braille readers.

Furthermore, sometimes the braille instruction is carried out by paraprofessionals with no formal pedagogical training. Knowledge of the braille code, but no pedagogical education, is clearly insufficient for teaching braille (McCuspie, 2002; Topor, Holbrook, & König, 2000). In the longer perspective, Amato (2000) pointed out that without high quality braille instruction, children with blindness may be at great risk for literacy problems, which may lead to difficulties regarding their general achievement, educational career and, later, their employment potential (Amato, 2000).

The inclusive school setting in relation to blindness

When reflecting on the inclusive school setting specifically in relation to children with blindness, with and without additional disabilities, it is necessary to consider the interplay between all levels of the system, from micro- to macro-level. In our research projects, the complexity surrounding the inclusion of blind children in regular classes, has become evident. All six students in research project B, and five out of six in project C, started school in regular classes. When the research projects were completed, out of the twelve students, five had transferred to specialized schools or groups, due to dissatisfaction with the support in the inclusive settings. Some had undergone several school transitions in the struggle to find the right support. These transitions are likely to have affected the students negatively by them having to adapt to new environments, as well as to new teachers and peers. Such adaptations take time for a student with blindness, time which could instead have been used for learning. For students with blindness and ASD, who are often especially sensitive to changes and transitions, such situations are supposedly particularly problematic.

The teachers in the studies reflected on the subject of inclusion for their students, and pointed out advantages as well as disadvantages. While some pointed to the importance of their students being part of a regular context with

sighted peers, others described their students' strong need for a small, structured context and individual training. In these cases, the large, regular class clearly entailed many challenges. Some of the teachers who were currently working in special schools or groups, were themselves ambivalent towards these settings. On one hand, they considered the special settings necessary and "life-saving" for certain students, through providing an adapted environment with expertise in special education. However, on the other hand they could see the risks involved with the special school being too protective and limiting. Teachers working in the special school for students with VI and multi-disability, made the reflection that many of their students came from inclusive educational settings or schools for students with ID, where they had experienced massive failure. Thus, the special school was sometimes a "last resort" for these students, and the school's mission became in many ways to provide a "safe haven" and increase the students joy and motivation that had been lost on the way. One of the teachers argued that the fact that the special school still attracted students, could be considered the "receipt" of the fact that the Swedish inclusive school system had not yet succeeded very well with its assignment.

In contrast, the students in project B, who remained in inclusive education their entire schooling, stated that even though it sometimes had been difficult, they still considered inclusive education the best option, in order to be prepared for inclusion in the "sighted society". However, it was clear that they had struggled hard and invested considerable time and effort to keep up with the sighted peers in their schoolwork, often at the expense of other things, such as having time for leisure activities. They had also experienced many social challenges, which will be further discussed in the following section. The students with blindness and ASD in project C, who had chosen to transfer from inclusive education to special schools or groups, were all more negative towards the inclusive setting. They specifically pointed out the lack of peace and quiet, and activities and communication being too fast and difficult to comprehend, as the main problems with inclusion in a large, regular class.

Among the parents participating in both projects B and C, the opinion about inclusive education differed as well. Some were convinced that inclusion was the natural option even though it entailed several challenges, while others were critical and described a lack of competence and qualitative support, and their children as having a difficult time in the inclusive setting. Some had experienced negative attitudes from the school management, resulting in them feeling that their child was a resource-consuming "problem". The parent of a child with ASD and severe ID, who from the beginning attended a special school, was the one most content with the school situation. This parent felt that the teachers in the special school had a sincere engagement in children with complex needs, which helped the family relax and feel that the child's needs were met. In summary, all the parents were occupied with the question of school placement for their children, whether they had made the right choice, and

whether in reality there was a choice – let alone any “best” choice. Attitudes and competence stood out as key components for the outcome. Thus, the findings elucidate the complexity regarding inclusive education in general, as well as for students with blindness specifically.

The European Agency (2009) considers it necessary, that national legislations state inclusion as a goal, and Mitchell (2014) argues that developing practices for successful inclusion for students with diverse needs must be viewed as a continuous process. The realization of successful inclusive education both pedagogically and socially, for children with, as well as without disabilities, requires resources and various actions, such as the adaptation of curriculum and teaching methods, and the modification of evaluation procedures and accessibility (Mitchell, 2014). The general classroom teachers need to have skills and competence, the opportunity to receive professional training and support, and, importantly, a positive attitude towards inclusion (European Agency, 2009).

Moreover, inclusion requires general educationalists to effectively teach groups of children that can be very diverse, and the inclusive teaching practices enables the teachers to educate large numbers of students with different disabilities (Morris & Sharma, 2011). Therefore, inclusive education as a general idea, places great demands on the teachers’ competence, in order for them to meet the needs of a wide spectrum of students. In the Swedish educational context, research has shown that there is a tendency to overlook the heterogeneity and varying needs of the children in regular classes, a matter which may influence the allocation of resources (Allodi & Fischbein, 2000), thus supposedly impose challenges for the teachers to give all their students equal educational opportunities.

Bearing this in mind, regarding students with blindness, the inclusion places specific demands on the schools since most teaching practices are designed for children who are sighted. Students without the ability to use their vision, have unique learning needs that requires alternative forms of media and equipment, as well as additional areas of instruction. Preparing general educators to meet the needs of students with blindness or VI in inclusive educational settings is therefore challenging, and the ordinary classroom teachers and paraeducators are generally not trained to deliver the type of support needed by these students (Correa-Torres & Howell, 2004; Olmstead, 2005). In Sweden, this is true in the inclusive classrooms in regular compulsory school, as well as in the schools with programs for students with ID. In the latter, the competence about special education in general may be more pronounced, but experience of blindness is still lacking. Consequently, the organization of the support provision around the schools is crucial (Morris & Sharma, 2011; Campbell & Mani, 2007).

In summary, in our studies, factors that were emphasized as particularly important for the outcome of the students schooling in inclusive education,

were quite consistent with the previous research about the inclusion of VI students (Simón et al., 2010; Gray, 2009; Bardin & Lewis, 2008; Davis & Hopwood, 2002), namely: a positive attitude from teachers and school management, creative teachers, good communication between school and home, teachers with understanding and knowledge about the learning consequences of the students' disability/ies, and close collaboration and coordination between professionals. Teachers in our studies specifically emphasized the need for more education about braille and teaching methods for students with blindness, with or without additional disabilities, as well as support from the school management and more time for planning. The emphasis in the findings, both in our studies and in the previous research, lies on organizational factors and improvements that can be done within the individual schools, and through collaboration between school and other actors. However, focus is also directed towards higher levels in the system, when highlighting the importance of raising the awareness of the individual needs of these students, to serve as a starting point for the allocation of resources.

Psycho-social aspects of the inclusion

The psycho-social aspects of inclusive education for students with blindness, should also be addressed. While children both with and without disabilities have been reported to show positive developmental outcomes in inclusive educational settings, on a group level, children with disabilities are not as socially included as their non-disabled peers (Odom, Collet-Klingenberg, Rogers, & Hatton, 2004). Students with blindness face specific challenges regarding the social inclusion (Roe, 2008). For example, they cannot perceive the non-verbal communication which is a large part of all social interaction, and they may encounter practical difficulties, such as difficulties locating their friends in the schoolyard, participating in visually based games and activities, or difficulty with finishing tasks in time, and thus being left behind (McCuspie, 1992; Roe, 2008). In addition, they need specific support to develop and practice their social skills (Sacks et al., 2006; Roe, 2008).

In research project B, the findings revealed that the students were more socially included in earlier school years, while the social inclusion became increasingly difficult at senior level. The students with additional disabilities struggled the most, in this sense, but the students who were considered very independent and well-functioning, also encountered social challenges and expressed feelings of loneliness in periods. These findings are in accordance with previous research about students with blindness or VI, which points out the necessity of working deliberately with the social climate in the class (Roe, 2008; Gray, 2009). In our study, clearly the students who experienced the most positive social outcomes, attended schools where working both on an individual level and a group level with social skills, social exercises and attitudes,

had been a high priority. Nevertheless, the group dynamics seemed easier to influence in the early school years, than at the senior level.

In this context, it is also noteworthy that a majority of the students in project B, in the interviews and the SDQ-ratings, displayed feelings of stress and psycho-somatic symptoms related to the VI, such as headaches and stomach aches, of which the environment was not always aware. Some of these symptoms were clearly related to stress and worry about schoolwork, stemming from the awareness that they had to struggle very hard to keep up with the pace of the sighted peers. The experiences of poor support and having to ask for adapted material, added to the stress for some students, as did the fact that the braille reading sometimes was considered too slow and impractical. These matters presumably affected several areas in school, including the social area, since the students sometimes had to prioritize school work at the expense of taking part in social activities. Spending time with friends, both in and out of school, is important for the social inclusion in the peer group. However, several of the students in our studies seldom took part in activities with their classmates in their spare time.

Furthermore, the partially sighted students in the study seemed to have an increased vulnerability regarding their identity as visually impaired. For example, they compared themselves with their sighted peers to a larger extent than the totally blind students, since they felt that they should be able to do the same things as their fully sighted peers. They were more reluctant to use assistive devices such as the white cane – even though they needed it – and strived hard to blend in. Both these students also stopped using braille in school, mainly because of identity-related issues. They wanted to read “normally” like the others, even though reading became much more demanding and tiresome when trying to manage reading print.

Consequently, it is necessary to consider that the school context has great impact on students’ mental health, and vice versa. In an extensive literature review provided by a review group within the Royal Swedish Academy of Science, the Health Committee (2010), the relationship between school, learning and mental health was examined. Clearly, having positive experiences of school is important for the sense of well-being, and the pedagogical support provided is a crucial factor, as is the obtaining of good reading skills. While poor school achievement leads to low well-being, also the opposite applies – low well being can lead to poor achievement (Gustafsson et al., 2010). Furthermore, the Health Committee report found that some of the protective factors related to school are participation, competence and supportive relations with teachers and peers. According to this report, some of the risk factors in school are test situations, stress and achievement anxiety, negative evaluation, unsatisfying relations with teachers, school difficulties, exclusion and harassment. Among the risk factors on an individual level, disability is mentioned (Gustafsson et al., 2010).

In the light of the above, since students with blindness or VI may face specific challenges in the school context, both learning wise and socially, the environment needs to be observant of psychological symptoms that may need to be addressed in this group, through interventions on an individual as well as a structural level.

Individual solutions, collaboration and a lifelong perspective

Finally, what can be said about the available options regarding support and pedagogical solutions for children with blindness, with or without additional disabilities? What options are there in reality, and what needs for improvement on higher levels in the system can be identified? Bearing in mind the existing advantages of inclusive education, regarding students with blindness one should also be aware that something important may have been lost on the way. The extra time, the expanded core curriculum, and the vocational training provided in the special school, have been removed without really being replaced with anything similar. Thus, a relevant question is how well the current Swedish educational and service delivery model prepares these children for the future?

Professor Cay Holbrook, from the University of British Columbia, in a lecture about service delivery for students with VI and blindness in North America (2017), talked about the underlying belief that guided the shaping of the pedagogical solutions and support for these students. She stated that: “We believe in the value and importance of direct, ongoing, consistent instruction by a qualified teacher of students with visual impairments. We believe this can happen through a variety of service delivery options, or combinations of options” (Cay Holbrook, personal communication, april 2017).

In line with Holbrook’s statement, the present research suggests that there is not one single, optimal pedagogical solution for children with blindness. To succeed with the inclusion of a student with blindness, great demands are placed on everyone involved. The inclusive educational setting, given that the support is well organized and of high quality, may suit some of these students well. For others, the inclusive setting in a regular, large class is difficult to handle, both learningwise and socially, and these students may require a more specialized solution. For these students, a specialized solution in a small group or special school may be necessary for the child’s well-being and possibility to engage in learning as well as social activities. Such a solution may be required, for the child to develop the skills and independence, which makes future inclusion in a broader perspective, possible. Students with blindness and ASD are especially vulnerable in this sense. Since 2011 (Skolverket, 2011) there is no given school placement for children with ASD, but without ID, in

Sweden. They are expected to follow the regular curriculum in an ordinary class, like every other student, despite the fact that their complex learning needs often make it very difficult to meet the expected school requirements, even though the child may in fact have good cognitive skills – a matter that can only be considered as deeply unfair.

In summary, different options, which take the individual needs of each child into consideration, would be required. The implementation of carefully individualized educational programs of high quality, carried out by teachers with adequate training, has been shown to significantly reduce the impact of the lack of vision on the child's development and help them develop necessary life skills (Ferrell, 2000; Ferrell, Shaw & Deitz, 1998). Furthermore, expanded teacher training in braille and teaching methods for students with blindness and VI is needed for teachers in all school forms, and the courses provided must reflect the heterogeneity of the population. Currently, the majority of the existing courses are mainly directed towards blindness only, despite the fact that in reality, very few of the students are only blind. The complexity of the population entails the need for additional courses regarding braille and teaching methods, applicable also for students with additional disabilities.

Specifically, our research points to the need for additional teacher education regarding suitable teaching methods for students with a combination of blindness and ASD, since the consequences of these two disabilities, and the available methods for blind students and students with ASD, sometimes collide (Gense & Gense, 2011). Gense and Gense (2011) emphasized that students with blindness and ASD need access to evidence-based methods for children with ASD, but these must be properly adapted according to the students' lack of vision. In this area, many teachers are currently left to try and combine the two perspectives, and “invent” teaching methods. Even though successful strategies and ideas may come up out of this situation, as described in project C, there is a strong need for formal education in this area, provided by professionals with expertise in blindness and ASD. Further development of adapted teaching methods is also needed.

Finally, some reflections on the support to families. The parents of children with additional disabilities in our studies described several unmet support needs. Specifically, the parents of children with blindness and ASD, with or without ID, described feelings of loneliness in their situation, being “bounced around” between authorities, and a strong wish to meet other families with whom they could share experiences and find strength. The parents valued the support provided about blindness from RCV and the low vision clinics, but pointed out that it is often too one-sided, and that too little support was offered regarding complex combinations of disabilities from these facilities. On the other hand, in the habilitation clinics, with their expertise in ASD, ID and motor disabilities, the knowledge of blindness was often non-existent.

Roll-Pettersson (2003) reported a study about perceptions of parents of children with disabilities, receiving special educational support in specialized

settings as well as regular classes in Sweden. Roll-Pettersson emphasized that regardless of school setting, the parents expressed a strong need for information about their childrens specific needs, suitable ways to teach the child and information about future support in a longer perspective (Roll-Pettersson, 2003). The general impression from our studies, is that the support provided to the families with blindness and additional disabilities, is often perceived as fragmented, divided into compartments with expertise in different areas, separated by closed walls, and with limited collaboration. Information about the consequences of combined disabilities is often lacking, and too often, the parents become responsible for bringing different professionals together, a matter that can be tiresome and frustrating.

Moreover, a long term perspective seem to be missing in much of the general support provided. To strengthen the families, thereby giving them increased tools to further support their children and prepare them for the future, increased communication and coordination of the support within, and between, different levels of the system is needed, as well as a lifelong perspective in the support provision. The goal must be to provide the children with opportunities to develop their full potential and master the necessary skills needed for a meaningful future.

Limitations and strengths

The studies included in this research have certain limitations that need to be considered. Children with blindness constitute a small, heterogeneous and geographically spread population. This entailed several methodological challenges during the research process. Regarding the recruitment of participants, it was not possible to include large samples in the different studies, simply because there were very few individuals in each target-group who matched the different studies' inclusion criteria. The explanation for this is that blindness is an unusual disability, entailing that larger national samples are impossible to obtain. For example, project B originally included an entire age cohort of braille reading students in Sweden who started 1st grade one specific year, yet they were only a handful.

In project C, the sample was strategically selected to reflect the target population. Randomization might have been a more desirable sampling method, but the decision was made that in relation to the aims of the study, it was more suitable to select participants that guaranteed a variation regarding certain variables. Out of all blind children identified in the study of medical records in project A, only 22 children matched the inclusion criteria of project C. Of these 22, a number were excluded as possible participants for different reasons, for example the family having an active, ongoing contact with KDV in my role as psychologist at RCV. Of the remaining possible participants – since

we wanted to let the children's voices be heard – we prioritized including children who had cognitive and linguistic abilities that enabled them to take part in the interview. Eight families were finally invited; four of the invited children had ID and four had AIF or BIF. One family declined participation and one did not respond; both of these families had children with ID. Thus, only two children with ID remained in the final sample. It should therefore be noted that the sample is not entirely representative regarding the children's cognitive levels, since only two out of the six participating children had ID. In reality, the proportion should be reversed.

Regarding data collection in project B, additional data regarding the students' academic achievement levels, for example individual results from tests in central school subjects, would have provided a deeper understanding of the students' academic progression. Also, additional questionnaires or other measures could have been used to obtain a more thorough assessment of the students' psychological well-being, since the SDQ only provides a very brief measure. Another option could have been to use a typically developed, matched control group with which to compare the VI students results, thereby increasing the specificity in the interpretation of the SDQ-results and what factors may be linked to the VI. However, such a procedure was not possible due to time-limitations and other practical conditions. Furthermore, the retrospective element in the interviews in grade 9 involves a risk, since retrospective questions may produce answers about how the informants currently view something that happened earlier, instead of about what actually happened (Trost, 2010).

The fact that the participants in project B and C were spread geographically all over the country, brought additional challenges, since the data collection procedure entailed a significant amount of travelling. This led to the decision that the participants in project C were only interviewed on one occasion each. It would have been desirable to return to the schools to take further part in the schools' activities and follow up the interviews – especially with the children – but more than one visit to each school was constrained by practical conditions. Following up the interviews with the children over the telephone was considered unsuitable.

Project A involved a record-based study. In this study, to our knowledge, the vast majority of children with blindness in Sweden were included. However, possible omission may concern occasional children who were not known at RCV for unknown reasons. Also, certain variables, such as ethnicity, could not be included, due to incomplete or uncertain information in the records. However, regarding the examined variables, the studied population should be representative for children with blindness during recent decades, and we find the information drawn from the collected data a valuable contribution to the statistics regarding children with blindness in Sweden.

The main methodological approach in this research was qualitative. The reason behind this decision was that quantitative methods were not considered

suitable, bearing in mind the small numbers in the target groups, specifically in projects B and C. However, in order to obtain as much valid information as possible, the three studies adopted different designs, where a combination of qualitative and quantitative data were collected. Also, triangulation was used in data collection as well as analyses. In projects B and C, information was collected from multiple sources; students, teachers and parents, in order to obtain a broader and deeper understanding of the examined phenomena, in spite of the target groups being small. The aim of this procedure was to try to capture subjective experiences from the informants' different perspectives, and capture individual variation as well as possible common experiences. In project A, all collected data were reviewed by a team of researchers with expertise in ophthalmology, child neurology and developmental psychology regarding blind children, in order to validate the reviewed assessments and information in medical records. Data analyses were in all studies performed by teams of researchers, who took part in the analyzing processes and agreed on the final analyses, out of the purpose to strengthen the trustworthiness of findings.

Conclusions

In relation to the overall aim of this research, namely to deepen the knowledge about developmental aspects, comorbidity and implications for support and education, the following major conclusions can be drawn:

First, children with blindness constitute a very small and heterogeneous population with diverse needs. It is a fact that many of the children are at risk for developmental challenges, and that certain etiologies are often associated with additional disabilities. Therefore, these children and their families, must be picked up and cared for early through a multi-disciplinary approach. The children's development should be closely monitored and screening for deviant development should be performed continuously by professionals with expertise in blind children. Such an approach would enable early intervention, prevent difficulties and promote optimal development.

Second, the current Swedish support model provided to children with blindness, their parents, and the teachers responsible for the children's education, clearly does not correspond to the complex needs of the population. The support is perceived as too fragmented and short term, with a lack of collaboration between support facilities on different levels. Parents of children with blindness and additional disabilities, such as ASD, especially express a strong need for more continuous and coordinated support, in a lifelong perspective. Teachers ask for continuous, hands-on support regarding braille and teaching methods for children with blindness, with and without additional disabilities, such as ID and ASD.

Third, in the Swedish inclusive educational setting, students with blindness are expected to follow the regular curriculum at the same pace as the sighted students. This is in spite of the fact, that many tasks take longer without vision, braille is a much slower reading medium than print and the students, in addition, need to learn many specific core skills. This equation is not easy to solve, and it places great demands on everyone involved – not least on the students themselves. The teachers may have the best intentions, but they often lack sufficient competence, and thus they face a very difficult task. Consequently, there is a risk that children with blindness do not receive opportunities to develop their full potential, and may also experience stress and low psychological well-being related to their school situation.

Finally, the support provision and the general school outcome for children with blindness in inclusive education differ to a large extent, and cannot be considered equal. One explanation for this is that too much responsibility is laid on the individual municipalities, to organize the learning environment, the teaching and the support, without having previous experience and knowledge about the specific learning needs of students with blindness. Bearing in mind that these children are so unusual, it is unreasonable to expect each school to shoulder this responsibility, without a more extended national support.

Implications for practice

To address the issues raised by this research, the following actions on different levels of the system are suggested:

A review of all levels of the support system should be performed, including current policies and legislations regarding the rights of children with blindness. Following the example of Norway, the school law should incorporate the right to learn braille and receive training concerning the specific core skills, provided by teachers with adequate competence. Also, there is strong a need for the establishing of national guidelines out of a holistic approach, that would enable continuity and collaboration between authorities regarding the support to children with blindness, with and without additional disabilities. A national support program building on clear routines, continuity and collaboration between RCV, low vision clinics and habilitation centers should be produced, with the purpose to guarantee equal support to all children with blindness, regardless of where they live. In this context, the ICF-CY framework may be of help to assist policy-makers, clinicians, educators, as well as parents, to document the children's characteristics that are of importance for promoting optimal growth and development.

For unusual and complex disability groups, such as children with blindness, experience and knowledge needs to be gathered and developed nationally, in order to secure sustainable competence. Therefore, RCV, with its' national assignment and multidisciplinary expertise in children with blindness, should

be given increased capacity to be involved at an early stage, and continuously. Preferably, a routine should be developed for RCV to take part in regular developmental screenings in collaboration with the low vision clinics, during the children's preschool years. This would enable the provision of a more adapted support from early age, out of the aim to promote development and prevent difficulties.

In addition, RCV's support to both teachers and parents should be further developed. The child's development and well-being is dependent on the support provided within the family system as well as in school. However, since the experience of children with very unusual disabilities, such as blindness in combination with ASD or other additional disabilities, is practically non-existent in local support facilities, these families are at risk to be left completely outside the support-system. The national responsibility should therefore be increased for these specific, unusual groups, and additional parent courses and counselling, focusing on complex dual disabilities, should be incorporated in RCV's assignment. Regarding support for teachers, it should involve a more pro-active, continuous, systematic and hands on-support, in the form of additional courses, counselling and training, within the areas of braille and teaching methods for children with blindness, with and without additional disabilities, and specifically for blindness in combination with ASD and/or ID. Preferably, RCV's teacher courses should be mandatory for the responsible teachers, when a school enrolls a blind student.

Finally, for those children, whose needs are not met within the frame of a regular inclusive educational setting, flexible pedagogical solutions building in the child's individual needs must be available. The voices of the children and parents need to be listened to, and the child's well-being should always be given highest priority.

Sammanfattning

Introduktion

Blindhet har en genomgripande inverkan på ett barns utveckling, och det är vanligt med försenad utveckling inom ett flertal områden (Dale & Sonksen, 2002; Fraiberg, 1977; Martinsen, 1977/1994; Norris, Spaulding, & Brodie, 1957; Sonksen, Levitt, & Kitsinger, 1984; Webster & Roe, 1998). Såväl språkliga, som motoriska och sociala färdigheter, tar längre tid att lära sig när barnet inte har den visuella informationen till hjälp. Omgivningen har därför ett stort ansvar för att stödja barnet och erbjuda optimala utvecklingsmöjligheter. För att kunna utforma stödet på ett bra sätt behöver omgivningen ha kunskap om vad det innebär att lära sig att förstå omvärlden och bemästra olika färdigheter utan synens hjälp.

En stor andel av alla barn med blindhet har dessutom andra funktionsnedsättningar, vilket innebär ytterligare utmaningar. En grupp med särskilt komplexa behov är barn med blindhet i kombination med autismspektrumtillstånd (AST), med eller utan intellektuell funktionsnedsättning (IF). Dessa barn har ofta omfattande svårigheter med att bearbeta information, förstå sammanhang och generalisera kunskap mellan olika situationer (Gense & Gense, 2005). Undervisningsmetoder anpassade för barn med blindhet, och metoder som tillämpas för seende barn med AST, är dessutom inte alltid kompatibla. Därför behövs särskild kunskap för att kunna anpassa metoder och förhållningssätt så att de fungerar för barn med blindhet i kombination med AST.

Många färdigheter som ett seende barn lär sig automatiskt, måste medvetet läras in och tränas när barnet inte ser. Utöver allmänna färdigheter och skollämen, behöver barn med blindhet även lära sig ett antal specifika färdigheter, så kallade "core skills". Dessa färdigheter innefattar bland annat att lära sig läsa och skriva punktskrift, att bemästra tekniska hjälpmedel, tekniker för orientering och förflyttning, sociala färdigheter, att lära sig använda övriga sinnen för att kompensera för synbortfallet, samt tekniker för att bli självständig i vardagsaktiviteter (American Foundation for the blind, AFB, 2018; Campbell & Mani, 2007; Morris & Sharma, 2011). Att lära sig att bemästra alla dessa områden tar tid, och ställer höga krav på både barnet och omgivningen.

Sedan mer än trettio år tillbaka finns i Sverige ingen specialskola för elever med synnedsättning och blindhet. I stället går majoriteten av dessa barn inkluderade i vanlig grundskola, eller om barnet också har IF, i grundsärskola. I

Örebro finns en statlig specialskola, Ekeskolan, för barn med synnedsättning eller blindhet i kombination med komplexa ytterligare funktionsnedsättningar. För närvarande går ett mindre antal elever i denna skola, majoriteten av dessa har IF och/eller rörelsehinder och AST. Barn med blindhet och AST med normalbegåvning, placeras i regel i vanliga klasser och förväntas följa grundskolans kursplan, trots att de ofta har en annorlunda inlärningsgång och kan ha mycket svårt att nå de förväntade målen, trots goda begåvningsresurser.

Eftersom blindhet hos barn är mycket ovanligt, är barnet oftast den enda med denna funktionsnedsättning i skolan, eller i hela kommunen. Sveriges decentraliserade skolsystem innebär att varje enskild kommun och skola ansvarar för att erbjuda likvärdiga utbildningsmöjligheter för alla elever, inklusive elever med blindhet. Dock är det i regel omöjligt för enskilda kommuner att bygga upp hållbar erfarenhet och kunskap om de pedagogiska konsekvenserna av blindhet, eftersom ett barn med denna funktionsnedsättning kanske föds i kommunen bara en enstaka gång under en period på många år. Därför är det oftast en helt ny erfarenhet att undervisa ett barn med ingen, eller mycket begränsad synförmåga, för den lärare som blir ansvarig för barnets utbildning. Har barnet ytterligare funktionsnedsättningar blir förstas utmaningen ännu större. Skolorna och familjerna kan få stöd från Specialpedagogiska skolmyndigheten (SPSM) och dess nationella enhet Resurscenter syn, samt från landstingets syncentraler och – om barnet har flera funktionsnedsättningar – landstingets habiliteringscenter. Ansvaret för den dagliga undervisningen i skolan vilar dock på den enskilda läraren.

I vissa länder, till exempel USA, tillämpas en lagstadgad utökad studieplan för elever med synnedsättning och blindhet – the Expanded Core Curriculum, ECC (AFB, 2018). Denna utökade studieplan innebär att eleven får extra tid och kvalificerat stöd för att lära sig de nödvändiga färdigheter som krävs för att kunna tillägna sig den ordinarie undervisningen och bli självständig. Enligt AFB (2018) är detta en förutsättning för att elever med blindhet ska klara skolan, och i förlängningen, vuxenlivet. I många andra länder, inklusive Sverige, har vi idag ingen utökad studieplan för elever med synnedsättning och blindhet. I stället förväntas eleven tillägna sig den allmänna kursplanen samt de ytterligare, specifika färdigheterna inom ramen för den ordinarie skoldagen, alternativt utanför skoltid. Detta ställer höga krav på alla inblandade, inte minst på eleverna själva. Lärare i de lokala skolorna har således en mycket utmanande uppgift, när det gäller att anpassa lärmiljö och undervisning, samt lära ut punktskrift och stödja elevens utveckling inom många specifika områden.

Teoretiskt ramverk

Forskningsresultaten ramas in av bio-ekologisk systemteori (Bronfenbrenner, 1979; 2005). Utgångspunkten är att ett barns utveckling påverkas av samspelet

mellan individen, med dess unika biologiska förutsättningar, och den omgivande sociala miljön. Det bio-ekologiska perspektivet placerar individen i centrum, och beskriver sedan interagerande system på flera nivåer, från mikro- till makro-nivå, där de proximala processerna i mikro-systemet har en direkt påverkan på barnets utveckling, medan system längre ifrån centrum utgör en mer indirekt påverkan, genom till exempel attityder, lagstiftning och ekonomi (Bronfenbrenner, 1979, 2005). Detta perspektiv utgör ett användbart ramverk för att beskriva viktiga faktorer på olika nivåer och förstå ett barns situation och utvecklingsmöjligheter i och utanför skolan. För barn som föds med en funktionsnedsättning som innebär särskilda utmaningar, utgör ett teoretiskt perspektiv som betonar multi-faktoriell påverkan på utvecklingen en särskilt lämplig utgångspunkt i tolkningen av forskningsresultaten.

Vidare kan WHO's International Classification of Functioning, Disability and Health, barn- och ungdomsversionen, ICF-CY (WHO, 2007) utgöra ett användbart verktyg för att beskriva såväl individ- som omgivningsfaktorer och identifiera gynnsamma och hindrande faktorer för barnets delaktighet och aktivitet i olika situationer. ICF-CY har många beröringspunkter med det bio-ekologiska perspektivet i sin betoning av samspelet mellan individ och miljö, och kan med fördel användas för att skapa ett gemensamt språk kring barnets förutsättningar och behov, och anpassningar som behövs i miljön för att gynna barnets utveckling.

Syfte

Avhandlingens övergripande syfte är att fördjupa kunskapen om barn med blindhet, utvecklingsaspekter och konsekvenser för utformningen av utbildning och stöd till målgruppen. Forskning som rör barn med blindhet i en utbildningskontext är mycket begränsad, såväl nationellt som internationellt. Förhoppningen är därför att denna avhandling skall bidra med kunskap som kan komma till nytta i diskussioner kring vidareutvecklingen av stödet till barn med blindhet, deras familjer och lärare. Särskilt fokus riktas mot barn med blindhet i kombination med AST, med och utan IF, eftersom det finns särskilda utmaningar gällande såväl differentialdiagnostik, som utformandet av stöd och pedagogiska metoder för denna specifika grupp. Forskningen gällande barn med denna ovanliga kombination av funktionsnedsättningar är också särskilt begränsad.

För att få en fördjupad förståelse för elevers skolsituation, är det viktigt att låta barnen själva komma till tals (Westling Allodi, 2002; Whitburn, 2014). I den forskning som finns avseende barn med blindhet, inkludering och specialpedagogik, ligger dock fokus ofta på pedagogiska perspektiv utifrån information som inhämtats från pedagoger, medan barn och föräldrar sällan kommer till tals. De forskningsprojekt som ingår i föreliggande avhandling, inkluderar

såväl barn, som föräldrar och lärare, i syfte att belysa upplevelser av stödets utformning, utifrån deras olika perspektiv.

Avhandlingen bygger på tre forskningsprojekt, projekt A, B och C, vart och ett med specifika syften som relaterar till det övergripande syftet. De tre projekten redovisas i fem artiklar; studie I – V.

Projekt A

Kunskap om kliniska egenskaper, utvecklingsmässiga riskfaktorer och förekomst av ytterligare funktionsnedsättningar i populationen barn med blindhet, är en viktig utgångspunkt för utformningen av stödet till målgruppen. Dock har tillförlitlig och aktuell statistik om gruppen på senare tid varit svårt att få fram. Projekt A innefattade en populationsbaserad studie (studie I) som syftade till att beskriva kliniska data som orsaker till blindhet och associerade utvecklingsrelaterade funktionsnedsättningar (med särskilt fokus på AST i specifika etiologiska subgrupper) hos barn med blindhet i Sverige under två decennier.

Projekt B

Lärande och skolprestationer har ett nära samband med elevers psykisk hälsa och andra psykosociala aspekter (Gustavsson, Westling Allodi, Alin Åkerman, Eriksson, Eriksson, Fischbein, et al., 2010). Vad gäller elever med synnedsättning och blindhet i inkluderande undervisning i Sverige, har forskning avseende utfallet av deras skolgång gällande såväl kunskapsutveckling som psykosociala faktorer hittills saknats. Projekt B syftade till att beskriva skolresultat, psykosociala aspekter och upplevelser av tillgänglighet och stöd för en årskull punktskriftläsande elever i inkluderande undervisning, ur ett longitudinellt perspektiv. En del av projektet (studie II) fokuserade på elevernas läsutveckling, skolresultat samt elevers, föräldrars och lärares upplevelser av tillgänglighet och stöd. Projektets andra del (studie III) undersökte elevernas psykologiska välbefinnande och upplevelser av den sociala inkluderingen i skolan.

Projekt C

Barn med blindhet i kombination med AST är en grupp med mycket komplexa behov, och det är ofta svårt att skapa en optimal lärandemiljö för dessa barn. Forskning som fokuserar på pedagogiska aspekter i relation till blindhet och AST är i det närmaste obefintlig. Syftet med projekt C var att beskriva egenskaper och behov hos barn med blindhet och AST i olika skolformer, utmaningar och framgångsrika strategier i skolarbetet samt upplevelser av såväl pedagogiskt som familjeorienterat stöd. En del av projektet (studie IV) under-

sökte elevers, lärares och föräldrars upplevelser av skolsituationen, samt utmaningar och framgångsrika strategier i skolarbetet. Projektets andra del (studie V) fokuserade på föräldrars upplevelser av barnens kombination av funktionsnedsättningar, diagnostiska utmaningar samt deras behov av stöd och erfarenheter av stödet till familjerna.

Genomförande

De empiriska studier som ingick i de tre forskningsprojekten, tillämpade olika typer av forskningsdesign och involverade insamling av såväl kvalitativa som kvantitativa data. Tabell 3 visar en översikt över de tre projekten (Tabell 3).

Tabell 3. Översikt över fokus, deltagare och design i projekt A – C.

Projekt	<u>Projekt A</u> Kartläggning av populationen barn med blindhet	<u>Projekt B</u> Punktskriftsläsare i inkluderande undervisning	<u>Projekt C</u> Blindhet och AST i olika skolformer
Artiklar	Studie I	Studie II och III	Studie IV och V
Vad undersöktes?	Kliniska data för populationen barn med blindhet i Sverige, t ex orsaker till blindhet, ytterligare funktionsnedsättningar	<i>Studie II:</i> Läsutveckling, skolresultat, upplevelser av tillgänglighet och stöd i skolan <i>Studie III:</i> Psykosociala aspekter i skolsituationen	<i>Studie IV:</i> Utmaningar och framgångsrika strategier i skolarbetet <i>Studie V:</i> Föräldraperspektiv på diagnostiska utmaningar och stöd
Deltagare	Svenska barn med blindhet kategori 4 och 5, födda 1988 – 2008 (n=150)	Punktskriftsläsande elever födda ett specifikt år (n=6), föräldrar n=6, lärare (n=18)	Urval av barn med blindhet och AST, med och utan IF (n=6), föräldrar (n=8), lärare (n=7)
Forskningsdesign	Populationsbaserad retrospektiv journalstudie	Longitudinell design (åk 1 – 9) kvalitativa och kvantitativa data	Huvudsakligen kvalitativ design
Datainsamling	Granskning av medicinska, psykologiska och pedagogiska journaler och handlingar	Semistrukturerade intervjuer med barn, föräldrar, lärare LS-test Läsobservationer Betyg SDQ Granskning av tidigare utredningar	Semistrukturerade intervjuer med barn, föräldrar, lärare Betyg Granskning av pedagogisk dokumentation Granskning av tidigare utredningar

AST:Autismspektrumtillstånd, IF:Intellektuell funktionsnedsättning, LS-test:Klassdiagnoser i Läsning och Skrivning för högstadiet och gymnasiet (Johansson, 2004), SDQ: The Strengths and Difficulties Questionnaire (Goodman & Goodman, 2009).

Deltagarna i samtliga tre projekt identifierades och rekryterades genom deras tidigare kontakter med SPSM/Resurscenter syn. I projekt A ingick samtliga barn födda 1988 – 2008, med medfödd eller mycket tidigt förvärvat blindhet kategori 4 och 5 (Socialstyrelsen, 2017). Datainsamling skedde i detta projekt enbart genom granskning av journalmaterial.

I projekt B ingick en årskull punktskriftsläsande elever med blindhet eller viss synförmåga, som började åk 1 ett visst år, samt deras föräldrar och lärare. Projektet hade en longitudinell design med datainsamlingspunkter i åk 1, 2, 3 och 9. Resultat från läsobservationer i åk 1 – 7 samlades in, liksom resultat från två deluppgifter ur LS-testet (Johansson, 2004) samt SDQ-skattningar av psykosociala styrkor och svårigheter (Goodman, 1997; Goodman et al., 1999) med elever, föräldrar och lärare i åk 9.

I projekt C ingick ett strategiskt urval av barn med blindhet och AST, med och utan IF, i olika skolformer, samt deras föräldrar och lärare. Datainsamling skedde i detta projekt vid ett tillfälle per deltagare.

I både projekt B och C genomfördes semistrukturerade intervjuer (Kvale & Brinkmann, 2014; Trost, 2010) med barn, föräldrar och lärare. Skolbetyg samlades även in i båda projekten. Observera att projekt B och C inkluderade helt olika undersökningsgrupper.

I projekt A analyserades och sammanställdes resultaten med deskriptiv statistik. Tematiska analyser (Braun & Clarke, 2006) av allt intervjumaterial genomfördes i projekt B och C. Testresultat i projekt B bearbetades enligt tillgängliga testmanualer.

Etik

Forskningsprojekten har prövats och godkänts av den regionala etikprövningsnämnden i Stockholm (2012/665-31/5). I genomförandet har Vetenskapsrådets forskningsetiska rekommendationer följts.

Resultat

Huvudresultaten från de tre forskningsprojekten sammanfattas i följande avsnitt.

Projekt A

- Mellan födelseåren 1988 och 2008 identifierades totalt 150 barn med blindhet kategori 4 och 5, vilket motsvarar en prevalens på 7/100 000 barn.
- Fem orsaker till blindhet dominerade i den studerade populationen: ROP, ONH, LCA, ONA och Mikro-/anoftalmi, i fallande ordning.

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- Totalt 72% av barnen var födda fullgångna, medan 28% var prematurfödda. Av de prematurfödda barnen var majoriteten extremt prematurfödda (GÅ <28 veckor), med en genomsnittlig födelsevikt på 782 g. Bland de prematurfödda barnen hade 90% ROP som huvudsaklig orsak till sin blindhet, och i denna grupp var andelen med hjärnskador och flerfunktionsnedsättning mycket hög.
 - I den totala gruppen (n=150) var andelen med flera funktionsnedsättningar hög. Bara 22% av barnen hade enbart blindhet, medan minst 72% hade en eller flera ytterligare funktionsnedsättningar utöver blindheten. De vanligaste ytterligare funktionsnedsättningarna i gruppen var IF, AST och rörelsehinder, i fallande ordning. I 6% var informationen om ytterligare funktionsnedsättningar otillförlitlig.
 - I den totala gruppen hade 38% tydligt beskrivna autistiska symtom, 31% uppfyllde kriterierna för diagnoserna autism/Aspergers syndrom. Majoriteten av barnen med autism hade även IF. De vanligaste orsakerna till blindhet i AST-gruppen var ROP, ONH, mikro-/anoftalmi och LCA, i fallande ordning.
 - Andelen barn med AST var särskilt hög i vissa etiologiska grupper: 70% av alla barn med ONH (inklusive SOD), 58% av alla barn med ROP, 44% av alla barn med mikro-/anoftalmi och 36% av alla barn med LCA hade AST-diagnoser. När vi studerade gruppen med SOD separat, visade det sig att samtliga av dessa barn hade diagnosticerad autism.
 - 50% av alla barn i studiegruppen gick i grundsärskola eller specialskola, alla dessa hade IF och/eller ytterligare funktionsnedsättningar. 39% av barnen gick inkluderade i vanliga grundskoleklasser. Bland dessa barn hade majoriteten enbart blindhet, men där fanns också barn med ytterligare funktionsnedsättningar, huvudsakligen AST. I 11% av fallen saknades information om skolplacering.

Projekt B

Resultaten från projekt B redovisas i två artiklar; studie II och III. Nedan sammanfattas huvudresultaten från båda dessa artiklar:

- Alla sex eleverna började inför skolstarten läsa punktskrift, men deras läsutveckling tog därefter olika riktning. Två blinda elever utvecklade goda läsfärdigheter, två blinda elever hade stora svårigheter med läsningen och de två elever som hade viss synförmåga slutade båda att använda punktskrift i skolan, huvudsakligen på grund av faktorer som hade att göra med

känslomässiga faktorer – de ville vara som sina fullt seende klasskamrater och läsa ”normalt”.

- Lärarna upplevde ofta att de saknade tillräcklig kompetens i punktskrift och pedagogiska metoder för elever med synnedsättning, vilket gjorde det svårt för dem att stödja eleverna läs- och kunskapsutveckling på ett optimalt sätt. Dessutom saknade en del av de lärare och resurspedagoger som arbetade med eleverna grundläggande pedagogisk utbildning. Sammantaget efterfrågade många lärare mer kompetensutveckling om punktskrift och lämpliga undervisningsmetoder.
- Alla elever i studien som följde grundskolans kursplan, fick betyg på åtminstone godkänd-nivå; ett par elever var högpresterande. Ett flertal lärare uttryckte dock en osäkerhet gällande hur elevernas kunskapsutveckling skulle bedömas, vilket medförde en risk att elevernas betyg i vissa fall inte speglade deras faktiska kapacitet.
- Svårigheter att tillgängliggöra vissa skolämnen ledde i vissa fall till att elever på högstadiet avråddes från att läsa dessa ämnen, och i stället fick en anpassad studiegång. Generellt framstod det som lättare att tillgängliggöra skolämnen under lägre stadier, än på högstadiet.
- Bara två av sex familjer var nöjda med det pedagogiska stödet under grundskoletiden. Dessa familjer betonade att den positiva attityden från skolledning och lärare hade varit avgörande för utfallet. Det faktum att de två eleverna ansågs vara teoretiskt begåvade och självständiga, bidrog också till det positiva utfallet då de strävade efter att klara så mycket som möjligt på egen hand i skolarbetet.
- Tre elever diagnosticerades under mellanstadieåren med ytterligare funktionsnedsättningar (IF, Aspergers syndrom och ADHD), och var i behov av mycket extra stöd. Dessa familjer var mycket missnöjda med det stöd deras barn hade fått under stora delar av grundskoletiden. En elev, med IF, valde på högstadiet att flytta till en specialskola för elever med synnedsättning och ytterligare funktionsnedsättning, till följd av bristande stöd i de lokala skolor hen hade gått i; såväl grundskola som grundskola.
- Utmaningar kring den sociala inkluderingen framkom i en majoritet av fallen. Inkluderingen i strukturerade klassrumsaktiviteter tycktes fungera bättre, medan raster och andra ”fria” situationer var svårare. Under lägre skolår upplevdes det från lärarhåll som lättare att arbeta metodiskt för att öka den sociala inkluderingen, än på högstadiet, då det upplevdes som svårt att påverka gruppdynamiken.

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- Det framkom inga tydliga skillnader i SDQ-skattningarna för eleverna med synnedsättning, jämfört med normer för seende ungdomar i samma åldersgrupp. Emellertid framkom i elev-intervjuerna att eleverna upplevde stress och psykosomatiska symtom, som magont och huvudvärk. Dessa symtom tycktes i hög grad hänga samman med konsekvenser av synnedsättningen, och oro för att inte hinna med skolarbetet i samma takt som de seende klasskamraterna.
 - De fem elever som gick inkluderade i vanliga klasser under hela grundskolan, hävdade alla att de inte skulle ha velat gå i specialskola. Även om några av dem hade haft det svårt och fått kämpa hårt i skolan, så ansåg de att inkludering var en nödvändig förberedelse för att kunna delta i det ”seende samhället”. Föräldrarnas uppfattningar skiljde sig åt i denna fråga. När de reflekterade kring sina barns grundskoletid, ifrågasatte några av dem kraftigt inkluderingen, eftersom de upplevde att barnet hade fått bristfälligt pedagogiskt stöd och även hade haft det svårt socialt. För andra var inkluderande undervisning det enda tänkbara alternativet, eftersom de ansåg att specialskolor och särskilda undervisningsgrupper var exkluderande och begränsande.

Projekt C

Resultaten från projekt C redovisas i två artiklar, studie IV och V. Nedan sammanfattas huvudresultaten från båda dessa artiklar:

- Samtliga barn i undersökningsgruppen fick sina autism-diagnoser relativt sent, inför skolstarten eller i de lägre skolåren ($M = 7$ år). Åtskilliga föräldrar upplevde att deras oro för barnets utveckling inte hade tagits på allvar av professionella vid syncentraler eller barnkliniker. Till följd av bristande kunskap och erfarenhet av barn med blindhet, hade barnets svårigheter hänförts till blindheten, vilket ibland bidrog till att utredning fördröjdes. Föräldrarna betonade alla hur viktigt det var att autism-diagnosen till sist fastställdes av team med expertis om blinda barns utveckling.
- Barnen uppvisade en mängd unika styrkor och svårigheter. Alla sex hade musikalisk talang på en nivå klart över sin generella funktionsnivå, och de hade allihop ett mycket gott hörselminne. Några hade också påfallande god språklig begåvning. Bland de svårigheter som beskrevs fanns problem med exekutiva funktioner och att bearbeta information, samt uttalad känslighet för bland annat höga ljud.
- Fem av de sex barnen påbörjade sin skolgång inkluderade i vanliga grundskoleklasser. Vid tidpunkten för studiens genomförande gick dock endast två av barnen kvar i inkluderande undervisning. Övriga hade bytt skola en

eller flera gånger till följd av bristande stöd, och gick nu i specialskola eller särskild undervisningsgrupp.

- Teman rörande utmaningar i skolarbetet identifierades i varje informantgrupp (elever, lärare, föräldrar). Utmaningar som beskrevs av eleverna var situationer som skapar förvirring, samt svårigheter att hantera stimuli i miljön; av lärarna lyftes följande utmaningar fram: att utvidga elevens upplevelsehorisont, att balansera elevens behov av individuellt stöd med gruppaktiviteter, att förbättra motivation och studieteknik, samt svårigheter att bedöma elevens kunskapsutveckling. Föräldrarna lyfte fram utmaningar som handlade om risken att underskatta elevernas förmågor, samt vad som är det rätta valet av skolplacering.
- Teman rörande framgångsrika strategier i skolarbetet identifierades i varje informantgrupp (elever, lärare, föräldrar). Bland eleverna betonades vikten av lugn och ro samt att ha möjlighet att förstå och göra sig förstådd. Lärarna lyfte fram fördelarna med en mindre grupp och flexibla arbetsformer, planering, struktur och kontroll och att bygga på elevens styrkor. Föräldrarna beskrev betydelsen av lärarnas attityder och nödvändigheten att ta hänsyn till elevernas individuella behov.
- Lärare i samtliga skolformer beskrev ett stort behov av formell utbildning och konkret stöd gällande specifika pedagogiska metoder anpassade för barn med blindhet och AST.
- Föräldrarna var alla uppfyllda av frågan om vilken som egentligen var den optimala skolplaceringen för deras barn. Barnen gick vid studiens genomförande i olika typer av skolor, men föräldrarnas funderingar kring skolplaceringsfrågan var likartade oavsett om barnet var placerat i vanlig grundskoleklass, eller i specialskola/särskild undervisningsgrupp. I stort sett alla föräldrar beskrev återkommande känslor av oro och stress kring huruvida de hade gjort ”rätt” val för sitt barn.
- Föräldrarna beskrev känslor av ensamhet och att vara udda, genom att det ofta saknades erfarenhet och kunskap om barnets kombination av funktionsnedsättningar hos de professionella som familjen kom i kontakt med inom sjukvård och habilitering. Ett stort behov av bättre samordning, kontinuitet och långsiktighet i stödet till familjerna framkom bland föräldrarna, liksom behovet att få träffa andra familjer med barn som också hade blindhet och AST.

Diskussion och slutsatser

Resultaten från de empiriska studierna visar på komplexiteten som omger barn med blindhet och deras situation i och utanför skolan, både vad gäller individuella faktorer och omgivningsfaktorer. Ur ett bio-ekologiskt perspektiv pekar resultaten på att barnets utveckling är beroende av såväl proximala processer som relationer och kommunikation mellan aktörer på olika nivåer i systemet. På mikro-nivån påverkas barnets utveckling direkt av samspelet mellan barnet och vuxna eller andra barn, i familjen, i skolan, på syncentralen eller habiliteringscentret. Inom vart och ett av dessa mikro-system, är det nödvändigt att barnet möts av förståelse för sina individuella förutsättningar, och kunskap om vad avsaknaden av syn innebär för utveckling och lärande. Meso-nivån innefattar kommunikationen mellan de olika mikro-systemen, alltså föräldrar, barn, lärare och övriga professionella aktörer. Dialog, kunskapsutbyte och samverkan mellan de olika parterna i mikro-systemen framstår som avgörande för att hitta en gemensam utgångspunkt för utformningen av stöd och interventioner.

Exo-nivån involverar det omgivande samhället med de stödjande aktörer som finns längre ifrån systemets mittpunkt, såsom SPSM och Resurscenter syn, och lärarutbildningarna. Resultaten från våra studier visar att beslut som fattas, samt kompetensutveckling som erbjuds, på denna nivå får stor effekt på villkoren för det enskilda barnet i skolan. På makro-nivån handlar det om vilka specifika resurser som krävs för undervisningen och stödet till barn med blindhet, samt vilka pedagogiska alternativ som står till buds, i relation till barnens individuella förutsättningar och behov; till exempel faktorer som styrning, planering, utökad tid och kursplan samt behovet av nationella riktlinjer för att säkerställa ett mer likvärdigt stöd.

Utifrån de resultat som framkommit i forskningsprojekten och hur de förhåller sig till de olika nivåerna i det totala systemet, kan följande slutsatser dras: Barn med blindhet utgör en mycket liten och heterogen grupp, med skilda förutsättningar. Det är nödvändigt att identifiera och beakta varje barns individuella behov i utformandet av stöd och interventioner, och för att göra detta behövs adekvat kunskap. Det är därför avgörande att barnen och deras familjer fångas upp tidigt, utifrån en multidisciplinär och holistisk ansats. Barnens utveckling behöver följas och utvecklingsscreening bör genomföras regelbundet av personer med kunskap om blinda barn, för att identifiera utvecklingsavvikelser, möjliggöra tidiga insatser, förebygga svårigheter och främja optimal utveckling.

Den stöd-modell som för närvarande erbjuds i Sverige till barn med blindhet, deras familjer och lärare, svarar inte upp mot gruppens varierade och komplexa behov. Stödet som erbjuds upplevs som alltför fragmenterat och kortsiktigt. Föräldrar till barn med blindhet och ytterligare funktionsnedsättningar, som AST, uttrycker ett stort behov av ett mer kontinuerligt och samordnat stöd. Lärare efterfrågar också mer kontinuerligt och konkret stöd gällande

punktskrift och undervisningsmetoder för elever med blindhet, med och utan ytterligare funktionsnedsättningar.

I det svenska skolsystemet förväntas elever med blindhet i inkluderade undervisning följa samma kursplan som de seende eleverna, och nå förväntade mål i samma takt. Detta trots att många uppgifter tar betydligt längre tid att förstå och utföra när man inte ser och punktskrift är ett mycket långsammare läsmedium än tryckt text. Dessutom måste eleverna lära sig ett flertal synspecifika ämnesområden, som orientering och förflyttningsteknik, olika hjälpmedel, vardagsfärdigheter och sociala färdigheter. Detta är en ekvation som inte är enkel att lösa, och som ställer höga krav på alla inblandade – inte minst på eleverna själva. Lärarna må ha de bästa intentioner, men ofta saknas tillräcklig kompetens vilket gör att deras uppgift är svår. Följaktligen finns en risk att barn med blindhet inte får möjlighet att utveckla sin fulla potential, och dessutom riskerar att uppleva stress och psykisk ohälsa kopplat till skolsituationen.

Både tillhandahållandet av stöd i skolan och elevernas skolprestationer varierar alltför mycket, och stödet till målgruppen kan därför inte anses vara likvärdigt. En förklaring till detta är att alltför stort ansvar ligger på enskilda kommuner och skolor att organisera lärmiljö, undervisning och särskilt stöd, utan att de har någon tidigare erfarenhet och kunskap om de pedagogiska behoven hos en elev som inte ser. Med tanke på att dessa barn är så ovanliga, är det helt orimligt att förvänta sig att enskilda skolor ska kunna axla detta ansvar utan ett mer utbyggt nationellt stöd.

Praktiska implikationer

Med utgångspunkt i ovanstående slutsatser föreslås följande åtgärder:

En organisatorisk översyn över systemets samtliga nivåer vad gäller stödet till barn med blindhet bör genomföras. Denna översyn bör även inkludera aktuell lagstiftning avseende rättigheter för målgruppen. I likhet med till exempel Norge, vars skolsystem liknar Sveriges, skulle skollagen behöva tydliggöra rättigheten till punktskrift och träning av synspecifika färdigheter, av lärare med adekvat kompetens. Idag finns i Sverige inga sådana lagstadgade rättigheter för barn med blindhet, vilket bidrar till att utfallet blir mycket varierat.

Vidare finns ett behov av att utifrån en holistisk approach, ta fram nationella riktlinjer som skulle möjliggöra ökad kontinuitet och samverkan mellan myndigheter och andra stödjande aktörer, kring stödet till barn med blindhet, med och utan ytterligare funktionsnedsättningar. Ett nationellt program bör formuleras, med tydliga rutiner för hur och av vem stödet ska tillhandahållas i olika skeden, i syfte att garantera större likvärdighet i stödet till dessa barn oavsett var i landet de bor. I framtagandet av individuellt utformade insatser kan ICF-CY med fördel användas som redskap för funktionell beskrivning av förutsättningar och behov.

När det gäller mycket ovanliga och komplexa funktionshindergrupper, som barn med blindhet, är det nödvändigt att kunskap och erfarenhet byggs upp nationellt, för att säkerställa långsiktigt hållbar kompetens inom området. Resurscenter syns med dess nationella uppdrag och multi-disciplinära expertis om blindhet, bör ges ökat mandat att involveras tidigare och mer kontinuerligt, samt arbeta mer pro-aktivt. Exempelvis skulle en rutin behöva tas fram, där Resurscenter syns deltar i årliga utvecklings-screenings i samverkan med de lokala syncentralerna, under barnets föreskoleår. Genom en sådan rutin skulle avvikande utveckling kunna upptäckas tidigare, och stödet skulle kunna individanpassas i högre grad från tidig ålder, i syfte att främja positiv utveckling och förebygga svårigheter.

Dessutom bör resurscentrets stöd till såväl familjer som lärare, utökas. Till följd av att erfarenheten av barn med ovanliga funktionsnedsättningar, som blindhet, i synnerhet i kombination med ytterligare funktionsnedsättningar som AST, är i stort sett obefintlig vid lokala kliniker, riskerar dessa familjer att hela falla mellan stolarna i stöd-systemet. Konsekvensen blir att familjer som skulle behöva omfattande stöd, i realiteten ofta får mindre än många andra. Därför behövs ett utökat nationellt ansvar för dessa små, specifika grupper, och utökad föräldrautbildning och rådgivning bör inkluderas in Resurscenter syns uppdrag, eftersom det endast är där den samlade kompetensen kring dessa ovanliga kombinationer finns.

Vad gäller stödet till lärare, bör detta inkludera ett mer pro-aktivt, kontinuerligt, systematiskt och handfast stöd. Ytterligare kurser, rådgivning och praktisk träning, gällande punktskrift och undervisningsmetoder för barn med blindhet, med och utan ytterligare funktionsnedsättningar – i synnerhet AST – bör utvecklas. SPSMs och Resurscenter syns lärarkurser bör dessutom vara obligatoriska när en skola tar emot en blind elev.

Slutligen, för de elever vars behov inte kan tillgodoses på ett optimalt sätt inom ramen för ordinarie, inkluderande undervisningsformer, måste det finnas möjlighet att skapa flexibla, pedagogiska lösningar som utgår ifrån barnets individuella förutsättningar, behov och önskamål. Det är nödvändigt att lyssna på familjernas och barnens åsikter i dessa frågor, och barnets välbefinnande och utveckling bör vara högsta prioritet i utformandet av lärmiljön.

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