




# One size does not fit all

**Children with blindness: Developmental aspects with special focus on blindness and autism**

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Nordisk Kongress i Synpedagogik 2018



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# Outline

- Background
- A population based study regarding clinical characteristics of Swedish children with blindness
- Blindness and autism spectrum disorder (ASD)
- Glimpses from a qualitative interview study focusing on children with blindness and ASD



# Background

- My encounters with many children, parents and teachers
- Blindness and additional disabilities, such as *ASD*, entails many challenges
- Research is limited, regarding blindness, developmental aspects and implications for the support
- Knowledge about the population and the children's needs is important, when developing the support
- Reliable, up-to-date statistics are difficult to retrieve



# A population based study

## Aim:

- To describe the clinical characteristics of Swedish children with blindness

## Inclusion criteria:

- Birth years 1988 – 2008
- Congenital or early infancy blindness category 4 or 5 (WHO)



# Research group

Kim de Verdier, Lic. psychologist, PhD student, National Agency for Special Needs Education, and Stockholm University

Ulla Ek, PhD, professor of special education, Stockholm University

Elisabeth Fernell, MD, professor of child psychiatry, Gillberg Neuropsychiatry Centre, Gothenburg University

Stefan Löfgren, MD, associate professor, St Erik Eye Hospital, Stockholm





# Data collection

Review of medical, psychological and pedagogical records

- Causes of blindness
- Gestational age, prematurity and birthweight
- Neurodevelopmental disorders/additional disabilities
- Special focus on ASD



# Overview

- N = 150 (M = 7 per year)
- Gender distribution: Boys 47% (n = 70) Girls 53% (n = 80)
- 28% (n = 42) were born preterm (Gestational age, GA <37 weeks)
  - The majority of these were born extremely preterm (GA <28 weeks)
  - GA M = 26 weeks (23 – 35 weeks)
  - Birthweight M = 782 g (522 – 1300 g)
  - The majority in the preterm group had ROP



# Causes of blindness

## When?

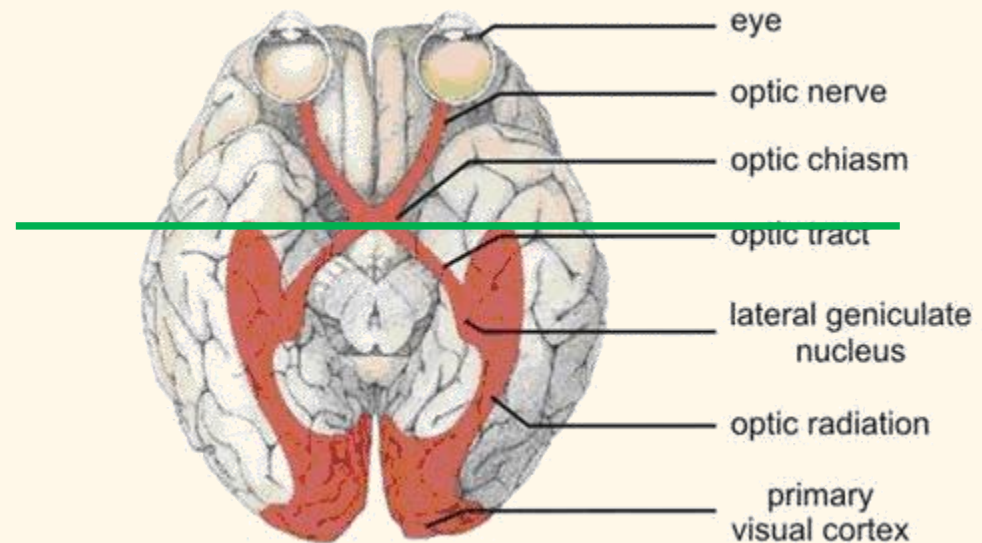
Prenatal

Peri- or postnatal

## Where?

Ante-chiasmal damage

Retro-chiasmal damage







## Causes of blindness represented in the studied cohort

	Girls (n=80)	Boys (n=70)	Total (n=150)
<b>Prenatal antechiasmal causes (n=93)</b>			
Optic nerve hypoplasia (ONH)	9	14	23
Leber congenital amaurosis (LCA)	13	9	22
Optic nerve atrophy (ONA)	8	8	16
Microphthalmia	5	4	9
Anophthalmia	6	1	7
Congenital glaucoma	2	2	4
Retinal dystrophy	2	0	2
Coloboma	1	0	1
Incontinentia pigmenti	1	0	1
Norrie disease	0	1	1
Persistent hyperplastic primary vitreous (PHPV)	0	1	1
Sclerocornea	1	0	1
Unspecified eye malformations	3	2	5
<b>Prenatal retrochiasmal causes (n=10)</b>			
Various cerebral malformations	6	4	10
<b>Peri-/postnatal antechiasmal causes (n=42)</b>			
Retinopathy of prematurity (ROP)	14	22	36
Retinoblastoma	3	0	3
Congenital cataract	1	1	2
Optic glioma	0	1	1
<b>Peri-/postnatal retrochiasmal causes (n=2)</b>			
Cerebral damage due to early trauma or disease	2	0	2
<b>Cause not defined whether pre/peri- or postnatal (n=3)</b>			
Unspecified eye disease (antechiasmal)	2	0	2
Unspecified tumour (retrochiasmal)	1	0	1



## Dominating causes

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# Dominating causes of blindness

- ROP 24% (n=36)
  - ONH (incl SOD) 15% (n=23)
  - LCA 15% (n=22)
  - Micro-/Anophthalmia 11% (n=16)
  - ONA 11% (n=16)
- 
- Prenatal causes 70%
  - Ante-chiasmal causes 90%



# Additional disabilities

- 22 % (n=33) only blindness
- 72 % (n=108) at least one additional disability
  - Intellectual disability (ID)
  - Autism spectrum disorder (ASD)
  - Motor disability
  - Attention deficit/hyperactivity disorder (ADHD)
  - Hearing impairment
- 54 % of these (n=81) had more than one additional disability
- 6 % (n=9) uncertain information



# A closer look at ASD in our study

- 31 % (n=46) met full criteria for autism/Asperger syndrome
- 38 % (n=57) if prominent autistic features were included
- 63 % (36/57) also had ID
- Dominating etiologies in the ASD-group:
  - ROP 37 % (21/57)
  - ONH/SOD 28 % (16/57)
  - LCA 14 % (8/57)
  - Micro-/anophthalmia 12% (7/57)



# ASD in etiological subgroups

- 70% of all children with ONH or SOD (100% in the SOD-group!)
- 58% of all children with ROP
- 44% of all children with Micro-/anophthalmia
- 36% of all children with LCA



# Previous research about blindness and ASD

- At least 1/3 of all blind children regardless of etiology (Cass et al, 1994; Hobson et al, 1997, Jure et al., 2016)

## ASD in etiological sub-groups

- ONH (Ek et al, 2005; Parr et al, 2010)
- ROP (Ek et al, 1998, Jacobson et al., 1998; 2009)
- Anophthalmia (Blyth & Baralle, 2011; Pushker et al., 2013)
- LCA??? (Rogers et al., 1989; Fazzi et al., 2007)



# Some main points from this study

- Only blindness is unusual in children
- High comorbidity with ID and ASD
- The prevalence of ASD is extremely high compared to the sighted population





# Blindness and ASD – what is known?

- Congenital blindness has great impact on a child's development, and developmental delay is common
- Many younger, blind children show autistic-like features, sometimes called "blindisms"
- Does this mean they all have ASD?
- No – some of these children outgrow or learn to regulate these behaviors, when they mature cognitively and develop skills to handle the environment



# But what if it is not "blindisms"?

- Some of the children have more profound difficulties with mutual communication, social interaction, and stereotype behavior – difficulties that cannot be explained by the blindness
- These children may meet criteria for ASD



# What does this mean?

- Correct diagnosis is necessary so the child can receive properly adapted support
- A "wait and see"-approach is not always beneficial
- But – differential diagnostics can be challenging
- Clinical experience of blind children is necessary in the diagnostic procedure, along with adapted assessment tools



# Why is ASD more common in children with blindness?

- Blindness in itself does not cause ASD!
- Blindness in combination with an abnormal brain function constitutes a substantial risk factor for developmental disorders, such as ASD
- Comorbidity with ID is common



# 1 + 1 > 2

- Blindness in combination with ASD brings complex support needs
- Knowledge is insufficient in communities, schools and local habilitation clinics
- Challenges concerning how to create suitable teaching methods for a child with double processing difficulties
- Optimal school placement?



# A qualitative interview study

## Aim

- To describe parents', teachers' and children's experiences of the support and of challenges as well as successful strategies in school

## Participants

- Children (n=6) with blindness and ASD, parents (n=8), teachers (n=6)

## Procedure

- Semi-structured interviews with parents, teachers and children

## Data analysis

- Thematic analysis (Braun & Clarke, 2006)



## Parents', teachers' and students' voices...





# Take home message

- Isolated blindness is unusual in children; the rate of multi-disability is high
- ASD is much more common among blind children than among sighted
- Certain etiologies – high risk for ASD (and ID)
- Early identification of atypical development is necessary for proper support
- Lacking support – risk for underachievement
- One size does not fit all
- Collaboration between different support services is necessary





# Publications

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.

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.



**Thank you!**

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