Children with blindness and autism – a small, exposed group with specific needs
Preliminary results from a Swedish research project

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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 behaviors, sometimes called "blindisms"

• Does this mean they all have autism?

• 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’s not ”blindisms”?

• Some of these children have more profound difficulties with mutual communication, social interaction, and stereotype behavior – difficulties that cannot be explained by the blindness

• These children may have autism in addition to their blindness
Therefore…

- Correct diagnosis is necessary so the child can receive proper support
- A wait and see-approach is not always beneficial
- But – differential diagnosis is challenging
- Clinical experience of typical and atypical development in blind children is necessary in the diagnostic procedure, along with adapted assessment tools
High prevalence of autism in children with blindness

- Nearly 2/3 of all prematurly born children with blindness (Ek et al, 1998, de Verdier et al, 2016, unpublished data)

High degree of autism in specific etiological sub-groups

- ONH (Ek et al, 2005; Parr et al, 2010, de Verdier et al, 2016, unpublished data)
Why is autism more common in children with blindness?

- Blindness does not cause autism

- But – research suggests that blindness in combination with an abnormal brain function constitutes a substantial risk factor for developmental disorders, such as autism
• Blindness in combination with autism brings complex support needs

• Knowledge is generally insufficient in communities, schools and local habilitation clinics

• Many challenges concerning how to create suitable teaching methods for a child with double processing difficulties

• In Sweden, children with visual impairments generally attend inclusive educational settings – also children with blindness and autism
A qualitative interview study

Aim
• to describe parents’, teachers’ and children’s experiences of the autism diagnosis, of the support offered to families and schools, and of challenges as well as successful strategies in the school setting

Participants
• Strategic selection of six families. All children had blindness and varying degrees of autism, two also had ID. Ages 9 – 15 years, varying types of school placement

Research method
• Qualitative interviews with children (n=5), parents (n=8) and teachers (n=6)

Data analysis
• Transcription of interviews, thematic analysis (currently in process)
Voices from the study
About the autism-diagnosis
About feeling like you never fit in
About support
About inclusive education and other options
Advise to teachers from the children
Advise to teachers…
Summary and conclusions

• Autism is much more common among blind children than among sighted
• Certain etiologies – high risk for autism
• Correct diagnosis is important for proper support
• These children and families face special challenges
• Much more effort must be put into improving the support to these children, and collaboration between different support services is necessary
• Let these children’s voices be heard
Thank you!

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