

Early detection of autism and autism-like difficulties in small children who are born blind: a check list



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Vilnius, March 2010
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Theme background

- Children who are born blind and sighted children with autism have some common features. These features may have similarities in appearance, but with a different cause and purpose in the two groups.




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- Being born blind may lead to some of the same types of behaviour and developmental disorders that we can see in sighted children with autism. Even if the behaviour looks similar, the blind-born child does not necessarily have the organic condition autism. Therefore we have decided to use the term **autism and autism-like difficulties** in this project.

Unusual, but functional behaviour

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- The unusual behaviour we can frequently see in blind children may be functional. Delayed development in certain areas and uncommon behaviour may represent the way blind children develop. It may lie within the normal area of behaviour and development for blind children even if it would have been a warning signal of possible autism for a sighted child.

Examples of unusual behaviour

- Higher occurrence of passivity in the child's relation to the social and physical environment.
- Mannerisms, sometimes called "blindisms".
- Engagement in details or unusual parts of objects.
- Delay in the ability to take the perspective of other people.
- Delay in establishing the ability for joint attention.
- Mutual problems of understanding and interpreting information.



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Risk of deviant development

- A substantial part of children who are born blind have autism or develop great difficulties resembling autism.
- A Norwegian study indicates that around 25% of the population of children born blind have problems of this kind. We find similar result in studies from other countries.



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Three categories of “strange” blind children

- Behaviour and development that clearly differs from that of most sighted children, but still within a normal range for blind children.
- Behaviour and development that is highly unusual and a problem for the child, but closely linked to the consequences of congenital blindness in the sense that the child would probably not have had serious problems in the area if it had been sighted.
- Behaviour and development that is truly deviant and within the autism spectre. The child would most likely have had grave problems of this kind even if born sighted.



Focus of attention

- How can we distinguish the unusual behaviour and the development which is normal for blind children from that which may be a warning signal of autism or autism-like development?
- What kinds of development or behaviour in small, blind children may be danger signals of autism or autism-like development?

Project goal

- Develop an assessment tool that could help distinguish the blind children who need special anti-autism efforts or interventions from the ones without such needs.

Method

- First we made a pilot list, based on
 - diagnostic tools for sighted (ICD-10, ADI-R)
 - literature
 - experience of the members of the group.

Quality assurance

- An early version of the check-list was sent to parents of 22 blind children from 4 to 12 years.
- The parents of 14 out of the 22 children answered the query.
- The sample was made up of blind children with and without autism diagnosis.
- The check-list was revised from the incoming responses about each child's behaviour and development from 0 to 4 years, and how the child appeared at the time of response.

The check-list

- The check list consists of 90 questions divided into five different age groups, and covers the three developmental areas that are central in autism (ICD 10 1992):
 - Communication
 - Social interaction
 - Behaviour and interests

Reliability

- This is not a test that is scientifically validated or standardized. It is a check-list developed and based on
 - Theory and knowledge of the members of the project group, supported by information from studies and literature in this field of research.
 - Testing of a pilot list with subsequent statistic analysis to identify questions that indicate warning signals of autism or autism-like development.
 - Our knowledge and experience based on practical work in the field

Purpose of using the list

The list can be used as a support by professionals in the field of visual impairment in evaluating

- number and strength of warning signals of autism-like difficulties or autism spectre disturbances
- how the warning signals are distributed by developmental areas
- how the difficulties have varied according to the child's age

Although the check list has been made for small blind children aged 0 to 4, it can still be used with older children.

Rating of danger signals

Sources:

- The results and statistical analysis of the answers we received from the parents in the pilot part of the project.
- A Swedish research study of "Different but functional behaviour in congenitally blind children 1 – 3 years" (Johansson, 2002) and the results of a Norwegian study based on video analysis of early interaction between small blind children and their parents (Brandsborg, 1999). The results of both studies are integrated into the check list.
- The clinical experience and theoretical knowledge of the five members of the project group.

Items of the list which could be traced to all three sources were given rate 3, the highest level of warning. The others were rated 2 or 1, depending on how strongly they were rooted in our sources..

Experiences

- So far we have used the check list in six assessments of blind children aged two to five years, where worries about autism have been part of the picture. It proved to be very important that the child was compared to other blind children, not primarily to sighted ones.
- The list has also been used as part of an observation of a blind child where there were no worries about the child's development. It was useful as a basis for conversation with the parents about their child.

Who can use the check list?

- The questions in the list have primarily been prepared as support for professionals working in the area of visual impairment. It should be used by, or in close cooperation with, professionals who have substantial knowledge about small blind children and their development.
- The list can be particularly helpful when there is a large amount of uncertainty or worries about a blind child's behaviour. It may contribute to make a suspicion stronger or weaker and to clarify the background and content of the concern.



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Future development of the list

- The project group intends to meet twice a year in the years to come, in order to discuss experiences and suggestions for improvements of the check list. The group will appreciate feedback about the list, particularly of the kind that will help us develop it further.
- We want to present the list and make it available for professionals in the field of visual impairment, in Norway and internationally.
- A future project may be to describe interventions that may be useful related to each of the danger signals.



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