

CHILDREN WITH AUTISM GROW UP
Use of the DISCO (Diagnostic Interview for Social and COmmunication disorders)
in population-based cohorts

Akademisk avhandling

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- I. Ellefsen A, Kampmann H, Billstedt E, Gillberg IC, Gillberg C. (2006). Autism in the Faroe Islands. An epidemiological study. *Journal of Autism and Developmental Disorders* (in print).
- II. Billstedt E, Gillberg IC, Gillberg C. (2005). Autism after adolescence: Population-based 13-22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders*, 35:351-60.
- III. Billstedt E, Gillberg I.C, Gillberg C. (2007). Autism in adults: symptom patterns and early childhood predictors. Use of the DISCO in a community sample followed from childhood (submitted).
- IV. Billstedt E., Gillberg, I.C., Gillberg, C. (2007). Adults with autism diagnosed in childhood. Aspects of quality of life in a sample of individuals from the general population (submitted).

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Abstract

Objectives: Examine the prevalence and outcome of autism in child and adult population cohorts using the Diagnostic Interview for Social and Communication disorders (DISCO). **Method:** The Faroe Islands school population aged 7-18 years (n=7689) was screened for autism and cases raising suspicion were examined and tested. Parents were interviewed using the DISCO. Clinical diagnoses were established on the basis of all available information. Prevalence rates for autistic disorder, atypical autism and Asperger syndrome were calculated. The autism outcome was looked at in 3 partly overlapping population cohorts of individuals (n=120) diagnosed in childhood as suffering from autism or atypical autism from the region of Göteborg, Sweden. They were re-examined at ages 17-40 years, 13-22 years after diagnosis. Parents and carers were interviewed using the DISCO. Strict operationalised criteria for outcome were used. Diagnostic stability over time was analysed. Symptom profiles on the basis of the DISCO were reviewed and background factors contributing to outcome in adult age were assessed. Aspects of Quality of Life were examined. **Results:** The prevalence of autism, atypical autism and Asperger syndrome in the Faroe Islands child population was 0.56%. The boy:girl ratio was 4.8:1. The DISCO was very useful in eliciting the information needed for a correct clinical diagnosis. The overall outcome of autism in the Göteborg population was psychosocially poor with few adults leading independent lives. Mortality was high (5%) and seemed to be associated with medical disorders including epilepsy. All but one of the individuals included in the follow-up study (n=108) still met criteria for autism or atypical autism. A small subgroup showed better psychosocial outcomes. They had all had some spoken language at age 3 years. Those with a childhood diagnosis of atypical autism tended to be diagnosed with autism at follow-up. The correspondence between clinical diagnoses and DISCO algorithm diagnoses was very good. The level of intellectual functioning showed a significant shift downwards. A subgroup deteriorated in adolescence. According to DISCO results, social, communication, and sensory impairment problems typical of the childhood period were still present at very high rates in late adolescence and adult life. Quality of Life seemed to be relatively good in some cases in spite of the poor overall psychosocial outcome. Early communication skills and IQ predicted aspects of outcome. **Discussion:** The DISCO is a useful instrument for diagnosis and follow-up of individuals with autism spectrum conditions. Combined with clinical examination of the individuals themselves, the DISCO yields important diagnostic and symptom information needed for appropriate diagnosis in childhood and for clinical review of diagnosis and symptom load in adolescence and adult life. The prevalence of autism in the Faroe Islands was very similar to that reported for autism in other parts of the world. The outcome of autism in the Göteborg cohort was psychosocially very poor, but life quality did not generally appear to be at a correspondingly low level. However, an important minority had very poor quality of life. The Faroe Islands cohort included relatively much higher functioning individuals than did the Göteborg group, which included cases diagnosed 15-30 years ago. The Faroe Islands cohort may have a very different prognosis, and the outcome findings from the Göteborg study can only be generalized, if at all, to other populations with autism diagnosed before the 1990s, when diagnostic concepts and criteria were more narrow than they are today. **Conclusions:** Autism is not a very rare disorder. Outcome in severe cases with intellectual impairment is psychosocially poor (with little or no independence in adult life), but life quality can be good even in such cases. The DISCO is a very helpful instrument for diagnosis in childhood and in adult life and can be used for follow-up of symptom profiles and problem assessment before and after adolescence.

Key words: DISCO, autism, Asperger syndrome, diagnosis, prevalence, outcome, quality of life

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