

ASPERGER SYNDROME IN MALES OVER TWO DECADES

AKADEMISK AVHANDLING

som för avläggande av medicine doktorexamen vid Sahlgrenska akademien, Göteborgs universitet, kommer att offentligens försvaras i Academicum, Hörsal Arvid Carlsson, Medicinaregatan 3, fredagen den 3 juni 2016 kl. 13:00

av

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Fakultetsopponent: Dr Bonnie Ayeung,
University of Edinburgh

Avhandlingen baseras på följande arbeten:

I.

Helles, A, Gillberg, I C, Gillberg, C & Billstedt, E. Asperger syndrome in males over two decades: stability and predictors of diagnosis. *Journal of Child Psychology and Psychiatry* 2015; 56(6): 711-8.

II.

Gillberg, I C, Helles, A, Billstedt, E & Gillberg, C. Boys with Asperger Syndrome Grow Up: Psychiatric and Neurodevelopmental Disorders 20 Years After Initial Diagnosis. *Journal of Autism and Developmental Disorders* 2016; 46(1): 74-82.

III.

Helles, A, Gillberg I C, Gillberg, C & Billstedt E. Asperger syndrome in males over two decades: Quality of life in relation to diagnostic stability and psychiatric comorbidity. *Autism*.
Accepterad.

IV.

Helles, A, Wallinius, M, Gillberg I C, Gillberg, C & Billstedt E. Asperger syndrome in childhood – personality dimensions in adult life: Temperament, character and outcome trajectories. *Submitterad*.

Handledare: Docent Eva Billstedt
Biträdande handledare: Professor Christopher Gillberg



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ABSTRACT

● **BACKGROUND:** Not much is known about the long-term outcome of Asperger syndrome (AS). The first set of diagnostic criteria was published in the late 1980's. Research on other normal range IQ Autism Spectrum Disorders (ASD) has shown great variability in terms of outcome. ● **AIMS:** The purpose of the present study was to study the naturalistic course of AS into adulthood in a clinical cohort of 100 males with AS diagnosed in childhood and to examine (1) stability of the diagnosis, (2) psychiatric comorbidity, (3) objective and subjective quality of life (QoL) and (4) examine Temperament and Character Inventory (TCI) traits in relation to aforementioned factors. ● **METHODS:** A cohort of 100 males diagnosed with AS at a mean age of 11 years has been followed from diagnosis (T0) over a period of 19 years in two follow-up studies. In the first follow-up (T1) at a mean age of 20 years, 76 of the 100 males participated and at the second follow-up (T2) at a mean age of 30 years, 50 individuals took part. A number of relevant and psychometrically established instruments were used at both time points. ● **RESULTS:** At T2, 78% still fulfilled criteria for an ASD diagnosis, compared to T1 when 90% still fulfilled an ASD. Almost all participants (94%) had at least one comorbid psychiatric or neurodevelopmental disorder during their lifetime and 54% had at least one current comorbid disorder. The 22 % (n=11) who no longer met criteria for ASD after nineteen years, had better objective QoL and average to high subjective QoL. Forty-four percent (n=22) of the men had a stable ASD and at least one current comorbid psychiatric disorder ("ASD Plus") and this group had extremely varied objective QoL (with many having low independence) and low subjective QoL. Lastly, there was a group of individuals (34% of those who participated) with a stable ASD diagnosis but no current comorbidity (n=15, "ASD Only") who also had extremely varied objective QoL (with many having low independence) and reporting average range subjective QoL. The three outcome groups (No-longer-ASD, ASD Plus and ASD Only) had significantly different profiles on the TCI. Background factors associated with negative outcome were ASD symptom load at T1 (but not T0) and degree of lifetime comorbidity. ● **CONCLUSION:** AS in males, when considered as an ASD was a relatively stable diagnosis over almost two decades. A majority met criteria of at least one other current comorbid disorder. No longer meeting criteria for an ASD was associated with better objective QoL, while having comorbidity was associated with lower subjective QoL. Personality traits were associated with different outcomes.

Keywords: Asperger syndrome; Autism Spectrum Disorder; Psychiatric comorbidity; Longitudinal study; Quality of Life; Diagnosis; Personality; Outcome

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