

# Autism spectrum disorder: developmental course from childhood to adulthood and predictors for societal participation

Published: 21-02-2017

Last updated: 15-04-2024

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<b>Ethical review</b>	Approved WMO
<b>Status</b>	Recruiting
<b>Health condition type</b>	Communication disorders and disturbances
<b>Study type</b>	Observational non invasive

## Summary

### ID

NL-OMON47212

### Source

ToetsingOnline

### Brief title

ASD: developmental course and societal participation

### Condition

- Communication disorders and disturbances

### Synonym

Autism spectrum disorder, contact problems

### Research involving

Human

### Sponsors and support

**Primary sponsor:** Kinder- en jeugdpsychiatrie/psychologie

**Source(s) of monetary or material Support:** Yulius voor Geestelijke Gezondheidszorg

## Intervention

**Keyword:** Autism spectrum disorder, developmental course, societal participation

## Outcome measures

### Primary outcome

The two main study parameters are: 1. ASD symptoms and co-occurring psychiatric symptoms in childhood, adolescence and adulthood (i.e. current study), and 2. societal participation, especially education and employment.

### Secondary outcome

Not applicable.

## Study description

### Background summary

Previous studies indicate that a large majority of adults with ASD do not achieve conventional markers of adulthood in societal participation like becoming self-supporting, living independently, getting education and a job and developing a network of friends (Howlin, Goode, Hutton, & Rutter, 2004; Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013). However, prospective studies concerning the long-term outcome of individuals with ASD symptoms in childhood are sparse. Also, most previous studies focussed on the most severely impaired individuals with ASD, i.e. autistic disorder (AD) and a cognitive impairment, while nowadays the majority (about 75%) of individuals classified with ASD are less severely impaired and they do not have a cognitive impairment (Postorino et al., 2016; Rogers & Dawson, 2010). More research is needed to evaluate the developmental course of these cognitively able individuals with milder ASD symptoms, and their societal participation in adulthood. This can ultimately contribute to more adequate and efficient treatment and/or support policies for this group.

### Study objective

The objective of this study is to determine the changes over time of ASD symptoms and co-occurring psychiatric symptoms from childhood to adulthood and

to investigate societal participation in adulthood, with an emphasis on education and employment.

## **Study design**

The current study is a prospective longitudinal study. The first two assessment waves have already taken place. The first assessment wave, took place between July 2002 and September 2004, when participants were six to twelve years old. Seven years later, the second assessment wave took place between June 2009 and May 2011, when participants were twelve to nineteen years old. Again seven years later, between January 2017 \* March 2019, we will conduct the third assessment wave (i.e. current MEC application) when participants will be 19 to 26 years old.

## **Study burden and risks**

The risk for participation in the current study will be negligible and the burden will be kept as minimal as possible. The participants will be asked to fill out several questionnaires and they will be asked to visit the outpatient department of Child and Adolescent Psychiatry/psychology once, with a maximum duration of two hours (after saturation effect approximately one hour) to assess current ASD symptoms and to collect information concerning societal participation. Parents, caregivers or the partner of the individuals will be asked to fill out a few questionnaires. If agreed upon, a semi-structured interview of half an hour will be conducted with employers. The benefits of participating in the current study will include a small offering for the young adults, their parents/caregivers/partner and their employers, and newsletters and a symposium concerning the outcomes and implications of the study.

## **Contacts**

### **Public**

Selecteer

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### **Scientific**

Selecteer

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## Trial sites

### Listed location countries

Netherlands

## Eligibility criteria

### Age

Adults (18-64 years)

Elderly (65 years and older)

### Inclusion criteria

In order to be eligible to participate in this study, the individuals must have participated during the first assessment wave. The participants that gave their permission to be approached for a follow-up study by signing a form, will be approached for the current wave of data collection.

### Exclusion criteria

Participants that emigrated to other countries or that have a serious physical disease will be excluded from the participation in the current data collection wave.

## Study design

### Design

**Study type:** Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Diagnostic

### Recruitment

NL

Recruitment status: Recruiting

Start date (anticipated):	19-05-2017
Enrollment:	103
Type:	Actual

## Ethics review

Approved WMO	
Date:	21-02-2017
Application type:	First submission
Review commission:	METC Erasmus MC, Universitair Medisch Centrum Rotterdam (Rotterdam)
Approved WMO	
Date:	12-06-2018
Application type:	Amendment
Review commission:	METC Erasmus MC, Universitair Medisch Centrum Rotterdam (Rotterdam)

## Study registrations

### Followed up by the following (possibly more current) registration

No registrations found.

### Other (possibly less up-to-date) registrations in this register

No registrations found.

### In other registers

Register	ID
CCMO	NL58326.078.16