

# Grip on Behavior: Influencing factors on societal participation, especially education and work, of young adults with average intelligence and autism spectrum disorder with behavior problems

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To gain insight in needs for support and factors that support or hinder participation in school / education and work, with special attention for the transition from school / education to work, for young adults (16-25 years) with an average...

<b>Ethical review</b>	Approved WMO
<b>Status</b>	Recruiting
<b>Health condition type</b>	Developmental disorders NEC
<b>Study type</b>	Observational non invasive

## Summary

### ID

NL-OMON47851

### Source

ToetsingOnline

### Brief title

Grip on Behavior

### Condition

- Developmental disorders NEC

### Synonym

autism spectrum disorder & behavior problems, conduct disorder, Developmental disorder

### Research involving

Human

## Sponsors and support

**Primary sponsor:** Yulius

**Source(s) of monetary or material Support:** ZonMw

## Intervention

**Keyword:** autism, behavior problems, school, work

## Outcome measures

### Primary outcome

The needs for support and factors that support or hinder participation in school / education and work, with special attention for the transition from school / education to work, for young adults (16-25 years) with an average intelligence (IQ > 70) with an autism spectrum disorder and externalizing problem behavior.

### Secondary outcome

NA

## Study description

### Background summary

In recent years, a lot has changed for people with an autism spectrum disorder (ASD), their immediate environment and the authorities involved. With the transfer of tasks to the municipalities (Jeugdzorg, AWBZ), the introduction of the Wet Passend Onderwijs and the Participatiewet, the government appeals to the self-management and the own responsibilities of people in need of support. If support is needed, this should be organized closely to the citizen, in close cooperation with the school / education and other parties involved, such as youth care, WMO-care and the labor market. The parties involved signal that these changes lead to a higher risk for adolescents and young adults with ASD of dropping out of school or not being able to get or hold a job. It involves mainly adolescents and young adults with an average intelligence, ASD and

additional problem behavior, in particular externalizing behavior problems. These problems make participation in education and / or work more difficult and they have negative consequences for sustainable participation in school / education or work. This puts independent participation in social life, as far as possible, at stake. The problems of this group of young adults are especially prominent between the ages of 16 and 25 years. Over the last two decades there has been an increase in the number of people diagnosed with ASD. About 1% of all people, or possibly even more, have ASD. Many people with ASD also have a second diagnosis, in about 60% of these people the second diagnosis is a behavioral problem. Having psychiatric problems, such as behavioral problems, in addition to ASD, leads to an even greater negative impact on day-to-day functioning such as participation in school / education and work. Only one third of the young adults with ASD attend regular education and only 25-30% of people with ASD over the age of 18 have income from labor as the main source of income. Being unable to participate in school / education and work because of ASD and externalizing behavior problems is an undesirable situation, as this is a prerequisite for overall health and functioning in society. Informal support from one's own network can influence social functioning positively. During the treatment it is important to imbed the role of the social network in the intervention. Patients are in treatment for a certain period of time, but rely later mainly on their own network.

## **Study objective**

To gain insight in needs for support and factors that support or hinder participation in school / education and work, with special attention for the transition from school / education to work, for young adults (16-25 years) with an average intelligence ( $IQ > 70$ ) with an autism spectrum disorder and externalizing problem behavior.

This study will provide a framework for a tool that integrates the knowledge gathered in this study. We aim to increase the expertise of professionals with regard to early detection, so that they can intervene at an early stage, to minimize or prevent stagnation of societal participation.

This tool is aimed at:

- What is needed to (keep) participating in school / work
- Advices how to provide \*informal\* support
- What are the elements of treatment that aid the target population

We will formulate recommendations that will be integrated in the Care Standard ASD

## **Study design**

In this exploratory mixed-method study qualitative and quantitative research methods are used parralelly to evaluate the influencing factors on societal

participation of young adults with ASD and externalizing problems. These factors will be retrieved through:

1. A literature study, with both scientific and grey literature;
2. Focus groups with diverse perspectives; young adults with ASD, \*nearest and dearest\* of the target population, professionals, employees of educational institutions & employers who have employees that belong to the target population
3. Interviews with:
  - Young adults with average intelligence, ASD and externalizing behavior problems, who had or are having problems with societal participation and received ambulant treatment or were admitted in an in-patient mental health clinic for ASD and externalizing behavioral problems ((sub)clinical score on the YSR of CBCL or a treatment goal) one to two years before the start of the study.
  - Nearest and dearest of the young adults who play(ed) an important role regarding societal participation of the target population.

In the third part of the study (the interviews), the young adult is asked permission to examine their electronic medical file in the mental health clinic on the extent to which potential influencing factors of societal participation were of concern during the treatment.

Three experience experts (\*ervaringsdeskundigen\*) are included in the projectgroep of this study and provide input right from the start to incorporate the ideas of the target population in the gathering of knowledge and the development of appropriate products.

## **Study burden and risks**

The risk of participating in this study is negligible because the study is mainly focused on the retrieval of information (of non-therapeutical nature). The same goes for the nearest and dearest / professionals / key figures from education and employers, and other people involved in this study.

An introductory conversation will take place before hand, by telephone, with a duration of approximately 15 minutes. In this conversation the researcher will determine if the person is suitable for inclusion in the study. The target population who cooperate with the interview will complete a questionnaire prior to the interview, the duration of this is thirty minutes. The interview will be held at a location the participant prefers, and will last one hour at most (including arrival and concluding and ending the conversation) . The interviews with the nearest and dearest will be held by telephone and will last a halve hour at most.

The focus groups with the target population will last ninety minutes at most. The focus groups with the other perspectives will last 2 hours. All focus groups will be held at central location. Travel expenses will be reimbursed.

## Contacts

### Public

Yulius

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Barendrecht 2994 GC  
NL

### Scientific

Yulius

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## Trial sites

### Listed location countries

Netherlands

## Eligibility criteria

### Age

Adolescents (12-15 years)  
Adolescents (16-17 years)  
Adults (18-64 years)  
Elderly (65 years and older)

### Inclusion criteria

General target population (young adults with ASD)

- ASD diagnosis, determined with DSM-IV by a psychiatrist and/or GZ-psychologist
- Age 16-25 years at the moment of inclusion; Target population (interview)
- Inclusion criterion as formulated for the general target population
- Receiving ambulant treatment or being admitted in an in-patient mental health clinic for ASS and externalizing behavioral problems (i.e. (sub)clinical score on the ASEBA Youth Self Report Form (YSR) or Child Behavior Check List (CBCL), or treatment goal), one to two year before the start of the study, at the following youth mental health clinics:
  - o Yulius \* de Steiger
  - o Yulius/Horizon

- o Dr. Leo Kannerhuis \* Behandelcentrum Jongeren
- o Dimence \* Perspectief of Orthopsychiatrische Woonvoorziening Autisme; 'Nearest and dearest' of the target population, (mental) health professionals, representatives of special education and employers
- Involved, through empathy or work related, with the societal participation of the target population

## Exclusion criteria

- Nonconfirmation to the conditions of the study (no signing of the informed consent form)
- Unmotivated to participate and unwilling to make time.
- Not sufficiently capable to articulating one's thoughts during a conversation (interview) or in a group discussion (focusgroup)
- IQ below 70
- Serious physical condition
- Limited mastering of the Dutch language
- Emigrated

## Study design

### Design

**Study type:** Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Health services research

### Recruitment

NL

Recruitment status: Recruiting

Start date (anticipated): 06-04-2018

Enrollment: 58

Type: Actual

## Ethics review

Approved WMO

Date:	23-08-2017
Application type:	First submission
Review commission:	MEC-U: Medical Research Ethics Committees United (Nieuwegein)
Approved WMO	
Date:	25-09-2018
Application type:	Amendment
Review commission:	MEC-U: Medical Research Ethics Committees United (Nieuwegein)

## 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	NL61759.101.17