

Sexuality in high-functioning boys with autism .

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This study focuses on collecting data on knowledge, attitudes, skills, experiences and needs related to sexuality and relational functioning in high-functioning Dutch boys with autism between 15 and 18 years old (up to and including 17). Data are...

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

Summary

ID

NL-OMON39074

Source

ToetsingOnline

Brief title

autism and sexuality

Condition

- Developmental disorders NEC

Synonym

autism; autism spectrum disorder

Research involving

Human

Sponsors and support

Primary sponsor: GGZ Eindhoven (Eindhoven)

Source(s) of monetary or material Support: het onderzoek wordt uitgevoerd in het kader van de opleiding tot specialist Klinisch Psycholoog. Het wordt uitgevoerd met de beschikbare middelen en binnen de opleidingstijd.

Intervention

Keyword: adolescent, autism, interpersonal relations, sexual behavior

Outcome measures

Primary outcome

Parameters are the amount of boys/young man that report or show specific behaviors, knowledge, attitudes, expectancies and needs. Focus will be on proportions and on relations between different factors. The frequencies based on the questionnaires filled in by the participants will be compared with data of boys in the general population (gathered in another study) and with data gathered from the parents. Answers on the questions of the two questionnaires and the derived scale-scores are the primary study parameters.

Secondary outcome

none

Study description

Background summary

The amount of research publications on the development of the sexual and relational functioning of people with autism is limited but growing. The available results of research learn us that a major part of the people with autism show an interest in sexuality, display sexual behaviours and are interested in person-orientated sexual activities and relationships. On the other hand it seems that there are adolescents who reacted anxious on the physical changes during puberty, that there's only a minority who has experience with a relationship and sexual contact and that some people with autism are frustrated because of this. Parents and caregivers of people with autism report inappropriate sexual behaviours (e.g. a lack of privacy, touching others without consent), distinct behaviour such as the use of objects during masturbation and bizarre sexual preferences. There seems to be growing attention on sex-education and the way it should be delivered. The existing research offers important insights but shows inevitable

shortcomings. Challenges for future research are to include enough people to obtain statistical power. This population should not only be living in residential facilities, but should represent the population of people with HFA. Other important aspects: obtain data from an adequate comparison-group, valid instruments to diagnose autism and to use multiple information sources. Research based on direct reporting by adolescents and young adults is very limited (Mehzabin & Stokes, 2011) but important, because of the assumed greater compliance to privacy-rules by the HFA-population. Apart from this, direct reporting by HFA-adolescents and young adults will offer the opportunity to compare with data from the general population ('sex under 25'years II' by RNG).

Study objective

This study focuses on collecting data on knowledge, attitudes, skills, experiences and needs related to sexuality and relational functioning in high-functioning Dutch boys with autism between 15 and 18 years old (up to and including 17). Data are collected by asking the boys and their parents to complete a questionnaire. To improve the conclusions on this data, they will be compared with data collected in the general population during a study of the Rutgers-Nisso-group. The objective is to clarify the influence of autism on the relational and sexual functioning, and on influencing factors.

Study design

This study is cross-sectional with one moment for data-gathering for each participant. Data are gathered using a questionnaire and an interview in 4 centers in the northern part of Brabant, the Netherlands.

By using this computer-based questionnaire ('seks onder je 25ste II': the second version of 'sex before 25') in our sample of boys with HFA between the age of 15 and 18 years old, comparison will be possible with the results of a group without autism in the same cultural context. The questionnaire is hierarchically constructed, in a way that there are first questions to screen for behaviours that a youngster recognizes. Only those behaviours are questioned further. The questions concern experiences, behaviours, thoughts and wishes about sexuality and relationships. Apart from this, the parents of the boys will be asked to complete a questionnaire (Sexual Behaviour Scale - Dutch Version) and some supplementary questions. The SBS is developed earlier to investigate the social and sexual functioning of children with autism and their need for specialized sex-education. The additional questions concern sexual behaviours and are meant to compare with the adolescent-data. In this way it will be possible to compare information from multiple sources and to compare the results of the HFA-group with the results of the larger survey in the normal population.

Study burden and risks

Inclusion is possible based on the following data:

- ADI-R conducted with the parents (max. 180 minutes)
- ADOS conducted with the youngster (within 6 months before inclusion, duration 60 minutes) and an intelligencetest (WISC-III or WAIS-III) (120 minutes)

These instruments are part of the clinical guidelines for diagnosing autism and are expected to be present. If not, they can be done for this project.

The time needed to complete this interview, test and observation can be a burden for the adolescent and/or his parents, but they include no risks.

The actual research-instruments are

- an web-based questionnaire to be completed by the adolescent (45 - 60 min) (seks onder je 2ste II)
- a questionnaire to be completed by the parents (SBS-Dutch version and additional questions).

The time needed to complete this interview, test and observation can be a burden (time) for the adolescent and/or his parents, but they include no risks.

Major developments on the domain of sexuality and relational functioning take places during adolescence. Direct questioning of adolescents and their parents is relevant in the HFA-group because of the assumed greater adherence to privacy-rules in this group. Comparison of the information of the parents and the information of their sons will clarify this. Direct reports are also the best way to explore knowledge, expectations and attitudes of the adolescents. Burdens are limited to the time needed to complete the questionnaires and interviews. There are no risks related to this research.

Contacts

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age

Adolescents (12-15 years)

Adolescents (16-17 years)

Inclusion criteria

male between 15 and 18 years old (up to and including 17)

diagnosed with Autism or Asperger's syndrome

ADI-R (Autism Diagnostic Interview - Revised) algorithm: PDD-NOS criteria (Risi et al., 2006)

ADOS (Autism Diagnostic Observation Schedule) algorithm: Above cut-off for Autism spectrum disorder

TIQ > 70

Exclusion criteria

positive psychotic symptoms, affecting reality-testing

limited mastering of Dutch language

first or second generation after migration from out of Western world

Study design

Design

Study type:	Observational non invasive
Intervention model:	Other
Allocation:	Non-randomized controlled trial
Masking:	Open (masking not used)
Control:	Active
Primary purpose:	Basic science

Recruitment

NL
Recruitment status: Recruiting
Start date (anticipated): 01-12-2011
Enrollment: 45
Type: Actual

Ethics review

Approved WMO
Date: 20-06-2011
Application type: First submission
Review commission: METC Brabant (Tilburg)
Approved WMO
Date: 08-02-2013
Application type: Amendment
Review commission: METC Brabant (Tilburg)

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	NL34563.097.11