Impact of COVID-19 on children and adolescents with autism spectrum disorder (ASD) and their families

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

Summary

ID

NL-OMON54902

Source
ToetsingOnline

Brief title
Autism & COVID-19

Condition

- Developmental disorders NEC

Synonym
autism spectrum disorder; autism

Research involving
Human

Sponsors and support

Primary sponsor: Erasmus Universiteit Rotterdam
Source(s) of monetary or material Support: ZonMw COVID-19 2e aandachtsgebied beurs

Intervention

Keyword: autism, children, COVID-19, impact

Outcome measures

Primary outcome

The primairy outcome variables are:

- General functioning:

o Child Behavior Checklist (CBCL): T0 vs. T1 vs. T2

o Youth Self Report (YSR): T0 vs. T1

- Autism characteristics:

o Social Responsiveness Scale (SRS-2/SRS-A): T0 vs. T1 vs. T2

- Individual parent interviews to chart family functioning and (current) care-

and informational needs.

Secondary outcome

- Quality of life of the child (PedSQL): T1 vs. T2

- Impact of COVID-19: e.g. behavior, stress, anxiety; atmosphere at home,

effect on child: T1 vs. T2

- Parenting load (OBVL): T1 vs. T2

Study description

Background summary

Children & adolescents with autism spectrum disorder (ASD) and their parents are hit hard by the COVID-19 measures. ASD is a developmental disorder that is characterized by limitations in social communication, repetitive behavioral patterns, and restricted interests and activities. The current circumstances

greatly task capacities that children and adolscents with ASD normally already struggle with, particularly social contact and dealing with changes. we expect that many children and adolescents with ASD, given the diagnostic criteria, and comorbid problems, as a conequence of the COVID-19 measurements, experience more stress, anxiety, depression, loneliness, a setback in functioning, and confusion due to the ever-changing information about the pandemic. This is also something parents of typically developing children express, especially now the rules are loosening a bit. In addition, we expect that parents of children with ASD, who have to take on more care tasks, in addition to their own stress, worries and work obligations during COVID-19, experience more psychological and emotional problems. On the contrary, it is also feasible that some families experience more room now the expectations and pressure of society have diminished. The concurrence of the events at least put both the children and families for challenges, that influence the functioning and quality of life of both children and parents. As children with ASD and their families generally have limited resilience, there is a realistic change that the impact of COVID-19 will be long lasting with far reaching consequences. Our collaboration partners (3 mental health care institutions in the region of South-Holland) signal the challenges the measurements are causing, which is why we are combining forces to investigate which children and adolescents with ASD/families run into issues or not, where the worries are the greatest and how we may provide support.

Study objective

Our goals are to investigate 1) the impact of COVID-19 on families with children with ASD, 2) the risk and protective factors of functioning and 3) care and information needs. Our results can inform clinical care, parents, and the government on how to best work with children and adolescents with ASD during crises.

Study design

The study design is an observational mixed-methods cohort study, in which functioning of a large group of children and adolescents with ASD and their families is charted during the course of 3 months, by both quantitative (WP1 & WP3) and qualitative research methods (WP2).
For WP1 we ask participants (T0: N = 68 parents; T1: n = 57 parents and 4 adolescents/young adults) to fill out a survey (which partially overlaps with intake/routine outcome measurement (ROM) data), now (T1) and after 6 months (T2). By asking information now in a COVID-19 peak (T1) and in the fall of 2021 (T2), a possibly calmer period in terms of COVID-19, we get a longitudinal insight of the impact (in relation to resilience) as well as an indication of the impact of changes in the measurements taken. Part of the survey data will be compared to intake information and ROM-data (T0: maximum 1 year old from March 1, 2020). These data are regarding general functioning, ASD

characteristics, and such things and is completely seperate of COVID-19. This way a natural experiment occurs, in which we can compare relevant data to pre-COVID-19 functioning of all participants (T0 --> T1 --> T2). In addition, WP1 will provide information about riks and protective factors.
For WP2 we ask a subgroup of parents (N=27) to participate in individual semi-structured interviews, to provide more in-depth knowledge with regard to quality of life, the impact of COVID-19 on family functioning, and (current) care- and informational needs.
In addition, by collaborating with the Generation R study we can also draw a comparison between (parents with) children with or without ASD (WP3). Generation R contacts about 3000 parents and adolescents in the same timeperiod as our T1 with harmonized questions. By collaborating we can then identify the impact on families with children with ASD to families with children without ASD. The Generation R study/data collection is completely seperate of the current study.

Study burden and risks

Filling out the two surveys (2x 45 minutes) both by parents and children, and the participation in the interview (60 minutes) cost the participants time, which is a downside of participating. For filling out the surveys participants are compensated (T1 survey = 10 euro bol.com gift certificate, T2 survey = 25 euro bol.com gift certificate). Participants of the interviews receive compensation in the form of a 25 euro (T1) and 50 euro (T2) bol.com gift certificate. Other than that, the burden is minimal for the participants, as it is spread out over a period of approximately 6 months. There are, besides the time investment no downsides to participating in the study.
The children and parents participating in the study will continue to receive their care as usual, like medication, supportive contact or individual meetings aimed at the ASD problems, comorbidity, and parent guidance. This also means there are no risks to be expected.

Contacts

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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)

Inclusion criteria

1) child is between the ages of 4 to 21 years old;
2) there is a clinical diagnosis of ASD;
3) there are measurements available pre-COVID-19 measures (either intake or ROM-data)

Exclusion criteria

1) parent and/or client do not master the Dutch language sufficiently to be able to participate
2) parent/client cannot or will not give informed consent for participation.

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:	Health services research

Recruitment

NL

Recruitment status:	Recruiting
Start date (anticipated):	04-01-2021
Enrollment:	68
Type:	Actual

Ethics review

Approved WMO Date:	20-11-2020
Application type:	First submission
Review commission:	METC Erasmus MC, Universitair Medisch Centrum Rotterdam (Rotterdam)
Approved WMO Date:	08-09-2021
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	NL74892.078.20