



# Netherlands Autism Register





Netherlands Autism Register

## Collaborative project:



VU University

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Netherlands Association for Autism

- Bernadette Wijnker
- Swanet Woldhuis



## Nederlands Autisme Register

- 2013
- 2015
- 2016
- 2017
- 2018



Privacy

<https://www.nederlandsautismeregister.nl>



Netherlands Autism Register

## Longitudinal register


- Data of ± 2500 respondents with autism spectrum disorders (ASD)
- Average response rate each year: ± 65% (≈ 1200-1500)




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## Topics

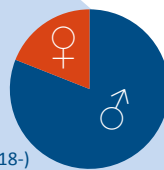
- Demographics, family
- Diagnosis, comorbidity, treatment
- Living, education, employment
- Social skills, relationships, wellbeing
- Specific topics (e.g. sensory perception, sexuality, special interests, cognitive functioning, anxiety, depression)

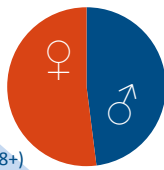
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## Demographics


- Gender



Children (18-)



Adults (18+)



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## Demographics

- Age range (4y0m – 84y8m)

	Girls (18-)	Boys (18-)	Woman (18+)	Man (18+)
N	120	510	630	577
Av. age	13,1y	13,1y	40,1y	44,9y

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## Respondents

One respondent per person with ASD

Adult (16+)	Child (16-)	Adult under legal representation (16+)
Self report	Parent/caregiver report	Legal representative report
N = 1132 (62%)	N = 616 (33%)	N = 89 (5%)

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## Results

- Factsheets

**75%** heeft 1 of meer interesses met autisme

**top 3** van bijzondere interesses

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## Participation & Individual feedback

“Together we know more”

Samen weten we meer

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## Feedback 2017: Wellbeing

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## Feedback 2017: independence

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## Participation

- Survey relevance of research topics (NAR)
- Autism Society Survey
- Representative panel of people with autism
- Collaboration with 'People with ASD' society ([www.pasnederland.nl](http://www.pasnederland.nl))
- Include ASD researcher with ASD



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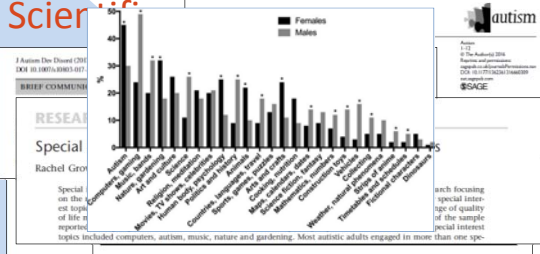
## General public output

Nederlands Autisme Register  
 Waar wonen mensen met autisme, als kind en als volwassene?



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## Scientific



Special interests of autistic adults: Computers, autism, music, nature and gardening. Most autistic adults engaged in more than one special interest.

Brief Report: Influence of gender and age on parent reported subjective well-being in children with and without autism


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## Benefits of having ASD

- Honesty (73%)
- Strong sense of justice (69%)
- Strong memory (64%)
- Able to focus on details (61%)
- Gender differences:

	Males	Females
Science, math, computers	44%	32%
Musical or creative abilities	23%	41%



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## Collaborations

- Dutch Universities
- King's College London
- University of New South Wales
- Rutgers stichting
- Netherlands Twin Register
- NHB-Psy (Gifted)

*We are always looking for new collaborations!*



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## NEW! Control group

"To help people WITH autism, we are looking for people WITHOUT autism"

Wilt u mensen met autisme helpen? Dat kan!

We vragen geen geld, maar tijd. Gemiddeld een half uur per jaar.

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Nederlands Autisme Register | Vrijwillers gezocht | Help met onderzoek

Somen weten we meer



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### Smartphone technology (ESM)

### Online interventions

NAR → EAR → WAR

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### Thank you for you time!

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Check us out:  
[www.nederlandsautismeregister.nl/english](http://www.nederlandsautismeregister.nl/english)  
for more information!