Netherlands Autism Register

Collaborative project:
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- Kawita Mataw
- Hans Koot
Netherlands Association for Autism
- Bernadette Wijnker
- Swanet Woldhuis

Nedersaks Autisme Register

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

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)

Demographics
- Gender

Children (18-)
Adults (18+)

Privacy
https://www.nederlandsautismeregister.nl
Demographics
- Age range (4y0m – 84y8m)

<table>
<thead>
<tr>
<th></th>
<th>Girls (18+)</th>
<th>Boys (18-)</th>
<th>Woman (18+)</th>
<th>Man (18+)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>120</td>
<td>530</td>
<td>630</td>
<td>577</td>
</tr>
<tr>
<td>A. age</td>
<td>13.3y</td>
<td>13.1y</td>
<td>40.1y</td>
<td>44.9y</td>
</tr>
</tbody>
</table>

Respondents
- One respondent per person with ASD

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Self report</th>
<th>Parent/caregiver report</th>
<th>Legal representative report</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult (16+)</td>
<td>N = 1132 (62%)</td>
<td>N = 616 (33%)</td>
<td>N = 89 (5%)</td>
</tr>
<tr>
<td>Child (16-)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult under legal representation (16+)</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Results
- Factsheets

Participation & Individual feedback
“Together we know more”

Feedback 2017: Wellbeing

Feedback 2017: independence
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)
- Include ASD researcher with ASD

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

<table>
<thead>
<tr>
<th></th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>Science, math,</td>
<td>44%</td>
<td>32%</td>
</tr>
<tr>
<td>computers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Musical or creative</td>
<td>23%</td>
<td>41%</td>
</tr>
<tr>
<td>abilities</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

NEW! Control group
“To help people WITH autism, we are looking for people WITHOUT autism”
Future plans

Municipality feedback

Smartphone technology (ESM)

Online interventions

Thank you for your time!

Check us out: www.nederlandsautismeregister.nl/english for more information!