From neurodiversity to neuroharmony: fostering a society that works for autistic people
Neurodiversity

neuroharmony
Outcome studies

Outcomes in adulthood are highly variable

- Good
- Fair
- Poor
QoL lower for autistic people

Quality of life in autism across the lifespan: A meta-analysis

Barbara FC van Heijst¹ and Hilde M Geurts¹,²,³

Abstract

Autism is a lifelong neurodevelopmental disorder, with a known impact on quality of life. Yet the developmental trajectory of quality of life is not well understood. First, the effect of age on quality of life was studied in a meta-analysis. Our meta-analysis included 10 studies (published between 2004 and 2012) with a combined sample size of 486 people with autism and 1776 controls. Second, as there were no studies on quality of life of the elderly with autism, we conducted an empirical study on quality of life of the elderly (age range 53–83) with autism (N = 24) and without autism (N = 24). The meta-analysis showed that quality of life is lower for people with autism compared to people without autism, and that the mean effect is large (Cohen’s d = −0.96). Age did not have an effect on quality of life. The study concerning the elderly with autism showed that the difference in quality of life is similar in the elderly. Age, IQ and symptom severity did not predict quality of life in this sample. Across the lifespan, people with autism experience a much lower quality of life compared to people without autism. Hence, the quality of life seemed to be independent of someone’s age.

How do we describe this one?

Lacks blue
Does not fit in
Deficit in size
Often one-sided focus

How often do you see these words in a diagnostic report?

- Happy
- Well-being
- Satisfaction
- Pride
- Pleasure
- Amusement
- Pleasant
- Fun
- Enjoying
- Cheerful
- Nice
- Good feeling
It is time to start focussing also on the similarities, not only the differences.

We are not so different in terms of

- behaviour
- mind
- needs
All of us have much more in common than we think

There is no such category as “autistic behaviours,” only “human behaviours”. Let’s start from a shared human experience.

Barry Prizant
Universal human needs: Maslow’s hierarchy

Abraham Maslow

Find out what makes people feel good

AUTISM STRESS INVENTORY

PART I: STRESSORS

Judge to what extent the following situations cause stress for the person with autism.

1. no stress
2. slightly stressful
3. moderately stressful
4. severely stressful
5. extremely stressful

Sensory stimuli

- Cone of light, sound
- Cone of sound, sound
- Cone of smell, sound
- Cone of smell, sound
- Cone of touch, sound
- Being snared
- Being required
- Being监督
- Cone of loud

Other:

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What are we targeting?


What are we targeting? (Review 406 studies)

<table>
<thead>
<tr>
<th>Goal of the intervention</th>
<th>Percentages</th>
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</thead>
<tbody>
<tr>
<td>Criteria autism A: soc. / com.</td>
<td>158</td>
</tr>
<tr>
<td>Criteria autism B: rigidity</td>
<td>43</td>
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<tr>
<td>Challenging behaviors</td>
<td>47</td>
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<tr>
<td>Adaptive functioning</td>
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<tr>
<td>Medical issues</td>
<td>13</td>
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<tr>
<td>Quality of Life</td>
<td>3</td>
</tr>
<tr>
<td>Unclear</td>
<td>123</td>
</tr>
</tbody>
</table>
Interventions for adults

Most interventions focused on mitigating specific deficits.../... Few studies focus on outcomes that would provide evidence of the impact of interventions on the lives of people with ASD, such as mental health, well-being, quality of life.

This is how many think it works

LESS AUTISTIC → MORE WELL-BEING
QoL: no link with IQ and severity

Barbara FC van Heijst and Hilde Geurts

Abstract

Autism is a lifelong neurodevelopmental disorder, with a known impact on quality of life. Yet, the developmental trajectory of quality of life is not well understood. First, the effect of age on quality of life was studied with a meta-analysis. Our meta-analysis included 10 studies (published between 2004 and 2012) with a combined sample size of 496 people with autism and 17,776 controls. Second, as there were no studies on quality of life of the elderly with autism, we conducted an empirical study on quality of life of the elderly (age range 53–91) with autism (N = 24) and without autism (N = 24). The meta-analysis showed that quality of life is lower for people with autism compared to people without autism, and that the mean effect is large (Cohen’s d = 0.96). Age did not have an effect on quality of life. The study concerning the elderly with autism showed that the difference in quality of life is similar to the elderly. Age, IQ and symptom severity did not predict quality of life in this sample. Across the lifespan, people with autism experience a much lower quality of life compared to people without autism. Hence, the quality of life seemed to be independent of someone’s age.

The adult outcome of children referred for autism: typology and prediction from childhood

Andrew Pickles, James B. McCarthey, Lauren A. Pepa, Marisela Huerta, and Catherine Lord

Background: Autism Spectrum Disorder is highly heterogeneous, no more so than in the complex world of adult life. Being able to summarize that complexity and have some notion of the confidence with which we could predict outcome from childhood would be helpful for clinical practice and planning. Methods: Latent class profile analysis is applied to data from 123 participants from the Early Diagnosis Study (Lord et al., Archives of General Psychiatry, 2006, 63, 639) to summarize in a typology the multifaceted early adult outcome of children referred for autism around age 2. The form of the classes and their predictability from childhood is described. Results: Defined over 15 measures, the adult outcomes were reduced to four latent classes, accounting for much of the variation in cognitive and functional measures but little in the affective measures. The classes could be well and progressively more accurately predicted from childhood IQ and symptom severity measurement taken at age 2 years to age 9 years. Removing verbal and nonverbal IQ and autism symptom severity measurement from the profile of adult measures did not change the number of the latent classes; however, there was some change in the class composition and the the models were more difficult to predict. Conclusion: While an empirical summary of adult outcome is possible, careful consideration needs to be given to the aspects that should be given priority. An outcome typology that gives weight to cognitive outcomes is well predicted from corresponding measures taken in childhood, even after account for prediction bias from fitting a complex model to a small sample. However, subjective well-being and adaptive aspects of adult outcome were weakly related to functional outcomes and poorly predicted from childhood. Keywords: Childhood, autism spectrum disorders, adult outcome, prediction.
This is how many think it works

LESS AUTISTIC → MORE WELL-BEING

But it works like this

LESS AUTISTIC → MORE WELL-BEING
Happier people are more successful in life

Not less autistic, but “autistically happy”
Happiness

**Pleasant life**
- Positive feelings
- Joy - Pleasure
- Absence of pain
- Safety
- Activities you like

**Meaningful life**
- Contentment
- Purpose in life
- Personal growth
- Serving others
- Life satisfaction

H.A.P.P.Y.

Happiness in Autism Personal Project for Young people

[www.petervermeulen.be](http://www.petervermeulen.be)
Our goals and desired outcomes

**Pleasant life**
- Positive feelings
- Joy - Pleasure
- Absence of pain
- Safety
- Activities you like

**Meaningful life**
- Contentment
- Purpose in life
- Personal growth
- Serving others
- Life satisfaction

Meaningful and purposeful life

What can society offer to autistic people?  What can autistic people offer to society?
Every autistic person has something to offer. So, therefore society can expect them to contribute to society.
Employment is a predictor of QoL

**RESEARCH ARTICLE**

**Predictors of Quality of Life for Autistic Adults**

David Mason, Helen McConachie, Deborah Garland, Alex Petrou, Jacqui Rodgers, and Jeremy R. Parr

**Abstract:** Research with adults on the autism spectrum is as yet limited in scope and quality. The present study describes quality of life (QoL) of a large sample of autistic adults in the UK and investigates characteristics that may be predictive of QoL. A total of 370 autistic adults from the Adult Autism Spectrum Cohort-UK (ASC-UK) completed the WHOQOL-BREF, and the Social Responsiveness Scale (SRS, autism symptom severity), along with the ASC-UK registration questionnaire giving information on mental health and their life situation. QoL for autistic adults was lower than for the general population for each WHOQOL domain. Younger participants reported higher QoL than older participants in psychological and environment domains. Males reported higher physical QoL than females, and females reported higher social QoL than males. Significant positive predictors of QoL were: being employed (physical QoL), receiving support social and environment QoL, and being in a relationship (social QoL). Having a mental health condition and higher SRS total score were negative predictors of QoL across all four domains. Autistic adults require access to effective mental health interventions, and informal and formal support for their social difficulties, to improve their quality of life.
Neurodiversity inclusion far outweighs the necessary adjustments.

Luchthaven Zaventem stelt mensen met autisme te werk aan bagagecontrole

Op de luchthaven van Zaventem werken sinds kort mensen met autisme aan de bagagecontrole. Zij hebben vaardigheden die belangrijk zijn voor die job. Het gaat om een proefproject met zes mensen.
Different ways of making a difference

• Volunteer work
• All kind of fundraising activities
• Jobs at all kind of events (rock festival, theatre, ...)
• Running / cycling for cancer or other diseases
• Charity work
• ...
I am a valued part and I contribute!

THANK YOU FOR YOUR ATTENTION!