



**AUTISM in CONTEXT**  
from neurodiversity to neuroharmony

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**Autism and happiness:**  
from neurodiversity to neuroharmony



It is time to start focussing also on the similarities,  
not only the differences

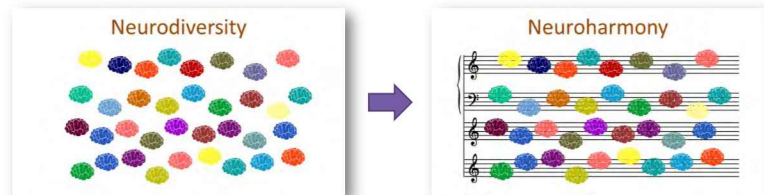
- Autistic and non-autistic people are not so different in terms of their basic needs
- All human beings want to be happy, safe, healthy etc.
- Maslow: hierarchy of universal human needs

Universal human needs: Maslow's hierarchy

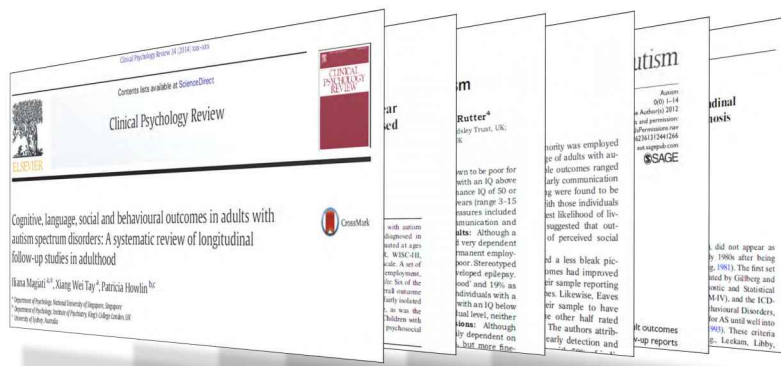


Abraham Maslow

From neurodiversity to neuroharmony



## Outcome studies



Outcome of autism in adulthood

- Outcome is highly variable
- Diagnosis is generally stable, although autism symptoms and adaptive skills often improve
- Outcome in integration and independence: +50% not good or even poor

## What are the criteria?



## Shortcoming of outcome studies

Objective criteria don't say much about **quality of life**...

Peter doing an activity  
in his group home

Mark's apartment

### Autism after Adolescence: Population-based 13- to 22-year Follow-up Study of 120 Individuals with Autism Diagnosed in Childhood

Eva Billstedt,<sup>1,3</sup> Carina Gillberg,<sup>1</sup> and Christopher Gillberg<sup>1,2</sup>

**Table 1.** Outcome in 120 Individuals with Autistic Disorder or Atypical Autism

Outcome variable	Autistic disorder N = 78	Atypical autism N = 42
Attrition	2 (3%)	4 (10%)
Dead at follow-up	3 (4%)	3 (7%)
Very poor outcome	38/73 (52%)	24/35 (69%)
Poor outcome	17/73 (23%)	6/35 (17%)
Restricted but acceptable outcome	12/73 (16%)	2/35 (6%)
Fair outcome	6/73 (8%)	3/35 (9%)
Good outcome	0	0
Independence	3/73 (4%)	1/35 (3%)

### Aspects of quality of life in adults diagnosed with autism in childhood

A population-based study



**Table 2** Parent's/carer's estimation of the situation for their daughter/son/relative with ASD in aspects of quality of life/residential well being

Category	N = 100 <sup>a</sup>
Very high residential well being	61
High residential well being	30
Average residential well being	5
Poor residential well being	2
Very poor residential well being	2

a. Missing information in 8 cases.

## Measuring outcome in autism



## And when we focus on well-being...

...then it is from a negative side: focus on the lack of well-being:

- Co-morbidity
- Mental health issues: anxiety, depression, ...
- All kinds of measurements and questionnaires have been developed to measure negative feelings in autistic people

# 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

Often one-sided focus on negative things

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

## Focus on (emotional) wellbeing, but...

- Avoid forcing a person with ASD into **neurotypical** concepts of happiness
- Avoid forcing a person with ASD into **stereotyped ideas** about autism
- So, ask people and do well-being assessment
  - Find out what makes people feel good
  - Assessment of interests

## Find out what makes people feel good

TRIAL VERSION - FOR PERSONAL USE ONLY

**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. highly stressful
5. severely stressful

Sensory stimuli	1	2	3	4	5
Certain kinds of light, usually...					
Certain kinds of noises, usually...					
Certain kinds of smells, usually...					
Certain kinds of tactile stimuli, usually...					
Being crowded					
Being ignored					
Being teased					
Certain kinds of food					
Other					

**Autism "Good Feeling" frågeformulär**

Frågeformuläret innehåller frågor / påståenden som beskriver alla möjliga saker som kan ge en person en bra känsla. Gilla/känt är nödvändigt olika. Det som ger en bra känsla för en person kan upplevas som obehagligt för en annan. Medan kan du ange i vilken utsträckning saker och handlingar gör dig en bra känsla. För varje kategori finns det plats att lägga till saker som inte nämns i listan.

Varje sak kan värderas på följande sätt:

1. Det gör mig en bra känsla - jag gillar detta väldigt mycket
2. Det gör mig en bra känsla - jag gillar detta
3. Det gör mig en genomsnittlig bra känsla - jag gillar detta lite
4. Det gör mig inte en bra känsla - jag gillar inte detta
5. (Neutral) Jag känner ingenting eller detta känns till och med obehagligt
6. Jag vet inte om detta gör mig en bra känsla

Den här listan är gillskatt inte uttömmande. Därför finns det utrymme att lägga till saker som får dig att må bra och som du gillar.

**Sensoriska aspekter**

	1	2	3	4	5
Vissa ljud, som t.ex.:					
Vissa ljud, som t.ex.:					
En viss typ av röst, som t.ex.:					
Tryck					
Vissa dofter, som t.ex.:					
Vissa smaker, smaker, som t.ex.:					
Beröring					
Blått ljus					
Värme					
Kyla					
Vissa mönster, som t.ex.:					
Vissa färger, som t.ex.:					
Vissa saker som jag gillar att röra vid, som t.ex.:					
Vissa upplevelser/händelser, som t.ex.:					
Ha en speciell ordning					



AUTISM IN CONTEXT PETER IN CONTEXT YOUR CONTEXT H.A.P.P.Y. -PROJECT CONT

AUTISM GOOD FEELING QUESTIONNAIRE

Autism Good Feeling Questionnaire

Search

Search ...

## Assessment of happiness and wellbeing in autism

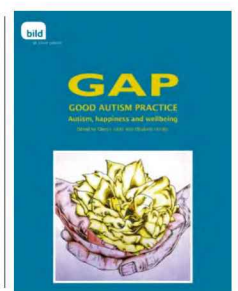
The practice of promoting happiness in autism

### The practice of promoting happiness in autism

Peter Vermeulen, Autisme Centraal, Gent, Belgium

#### Editorial comment

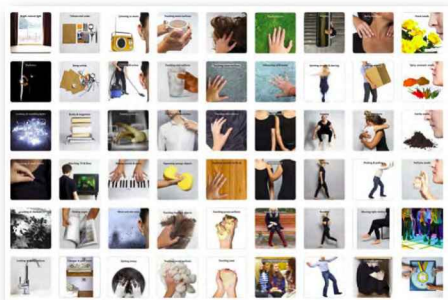
Emotional wellbeing and happiness have received little attention in the field of autism. When the focus is on wellbeing, it is often from a negative perspective, namely the lack of wellbeing and quality of life in autism. Based on the principles of positive psychology, Peter Vermeulen argues for a change in focus and suggests that instead of concentrating on the lack of emotional wellbeing in people with autism, strategies to facilitate their feeling of happiness should be developed. In this article, the main focus is on the first and most important step in promoting happiness in people with autism, namely the



## Assessment of sensory preferences



Good Feeling Sensory Circuit  
(Vermeulen, 2014)



Kingwood Sensory Preference Cards  
(Brand & Gaudion, 2012; Gaudion, 2015)

## Talent scouting

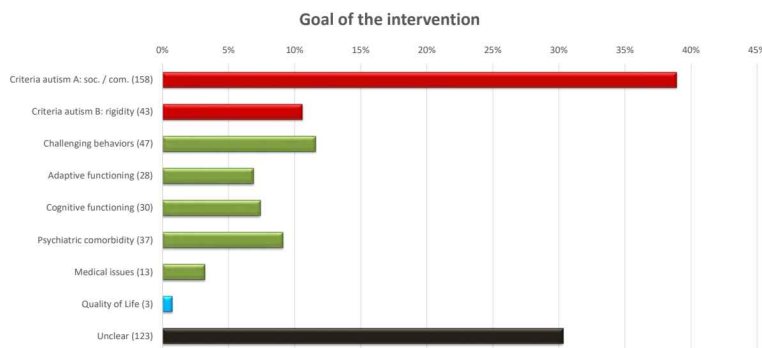
- The success stories in autism like Temple Grandin, Donald T. (no, not that one!) show that focusing on strengths and interests leads to a more happy and successful life with autism

## What are we targeting?



Review study 2019: 406 controlled trials  
between 1980 and 2016

## What are we targeting? (Review 406 studies)



## 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

## QoL: no link with IQ and severity



Barbara FC van Heijst<sup>1</sup> and Hilde M Geurts<sup>1,2,3</sup>

### Abstract

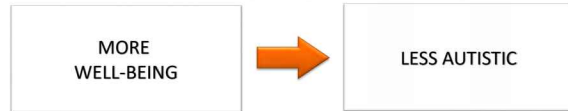
Autism is a lifelong neurodevelopmental disorder, with a known impact on quality of life. Yet the developmental trajectory of quality of life is not well understood. First, the effect of age on quality of life was studied with a meta-analysis. Our meta-analysis included 10 studies (published between 2004 and 2012) with a combined sample size of 486 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 53–83) 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.



This is how many think it works



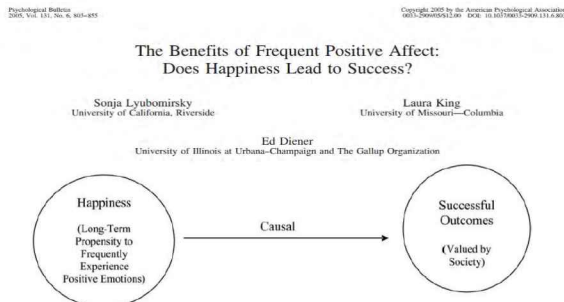
But it works like this



Put happiness on the I.E.P.



Happier people are more successful in life



Not less autistic, but “autistically happy”

Why focusing on wellbeing and happiness?

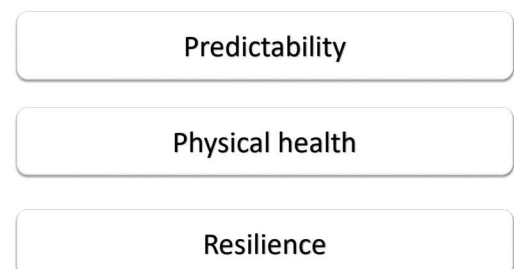
Because happy autistic people will have better outcomes in:



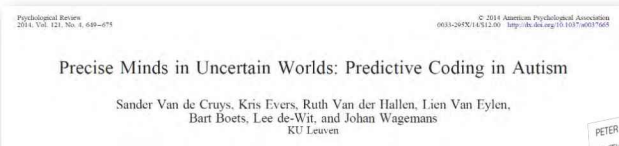
Working on good feelings

- Relaxation
- CBT (and other therapies) Are OK, but...
- Mindfulness

Working on happiness: the forgotten strategies



## Main source of distress in autism



Absolute thinking in a relative world



confusion – misunderstanding - uncertainty

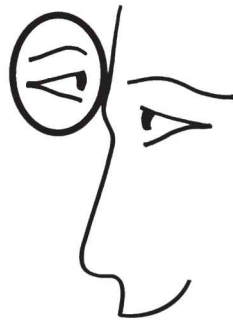


## Universal human needs: Maslow's hierarchy

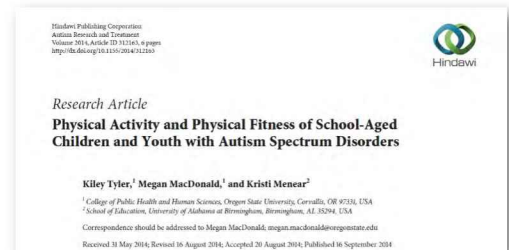


## Want to make autistic people happy?

Be autism friendly:  
Give **clarity** and  
**predictability** first,  
All the rest comes later



## Physical health and fitness in autism



School-aged children with ASD: less physically active and fit than typically developing peers.

## Physical health and fitness in autism



Physical activity rates are reduced in 6–11 year old children with ASD:

- Physical activity every day: **ASD 17%** - NT 33%
- No physical activity whatsoever: **ASD 18%** - NT 4%

## Start to run! (Or to cycle...or to swim... or...)

Physical activities lower cortisol level and anxiety in autistic people (Hillier e.a., 2010, Hillier e.a., 2011, Carraro & Gobi, 2012)

Happiness is not the absence of problems; but the ability to deal with them.

## Autism friendly environment

Is not the same as avoiding challenges and obstacles  
It is about helping autistic people to face the challenges and overcome the obstacles

## Autism is never an excuse

Temple Grandin

*“Mother just knew how hard to push me”*

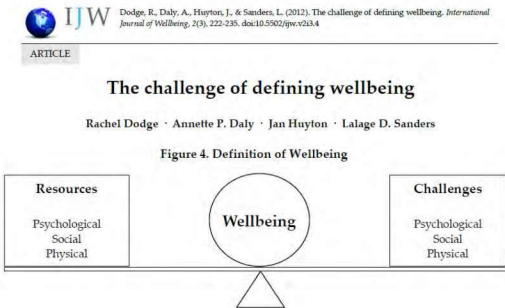
*“My mother had high expectations for my behaviour”*

Ros Blackburn

*“I need high expectations and high levels of support”*

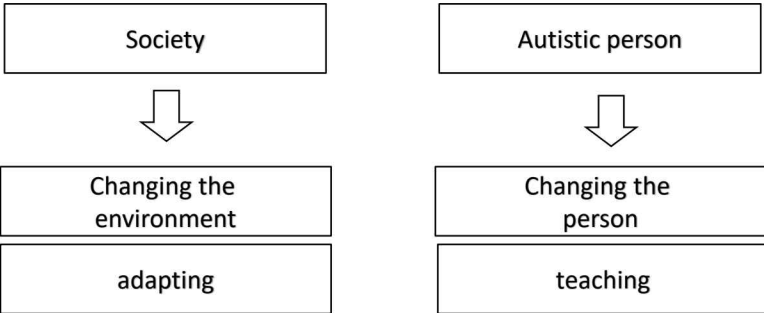
*“Give me moments of disappointment and frustration, so I can learn to deal with it”*

### Wellbeing: a matter of balance



p. 230

### Double track approach



Original Article

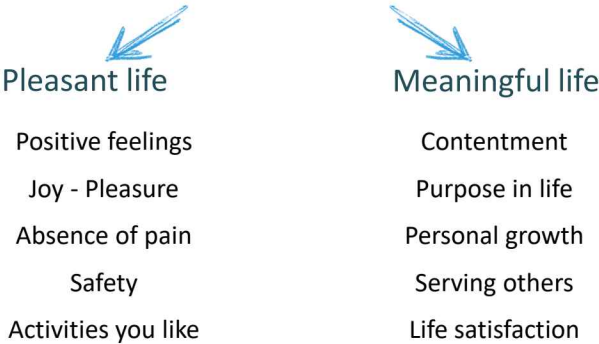
**Asperger syndrome in males over two decades: Quality of life in relation to diagnostic stability and psychiatric comorbidity**

Adam Helles<sup>1,2</sup>, I Carina Gillberg<sup>1</sup>, Christopher Gillberg<sup>1</sup> and Eva Billstedt<sup>1</sup>



Despite difficulties with functioning in everyday life, many seem to be able to deal with adversity and cope well with challenges

### Adulthood: The more enduring happiness



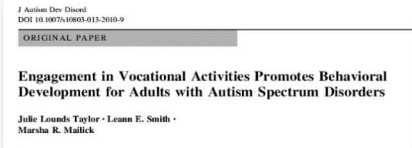
## Meaningful and purposeful life

What can society offer to autistic people?

What can autistic people offer to society?

## Employment may be therapeutic

Employment may lead to improvement in autism symptoms and enhances well-being and quality of life



## 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. *Autism Res* 2018, 0: 000-000. © 2018 The Authors. Autism Research published by International Society for Autism Research and Wiley Periodicals, Inc.

## A well filled day

- prevents you from
  - boredom
  - getting stuck in stereotyped activities / obsessions
  - worrying and anxiety
  - challenging behaviour...
- creates opportunities to
  - learn new skills
  - reach higher levels of functioning

## How to make 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
- ...

## Ways to neuroharmony

- See the similarities, not only the differences
- Start from (individual) needs, not from diagnoses or labels: our name is the most important label
- Find out what makes a person happy
- Not less autistic, but autistically happy
- Put happiness and well-being on the IEP
- Balance between changing the person and changing the environment
- Create opportunities for a meaningful life





## More information



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