



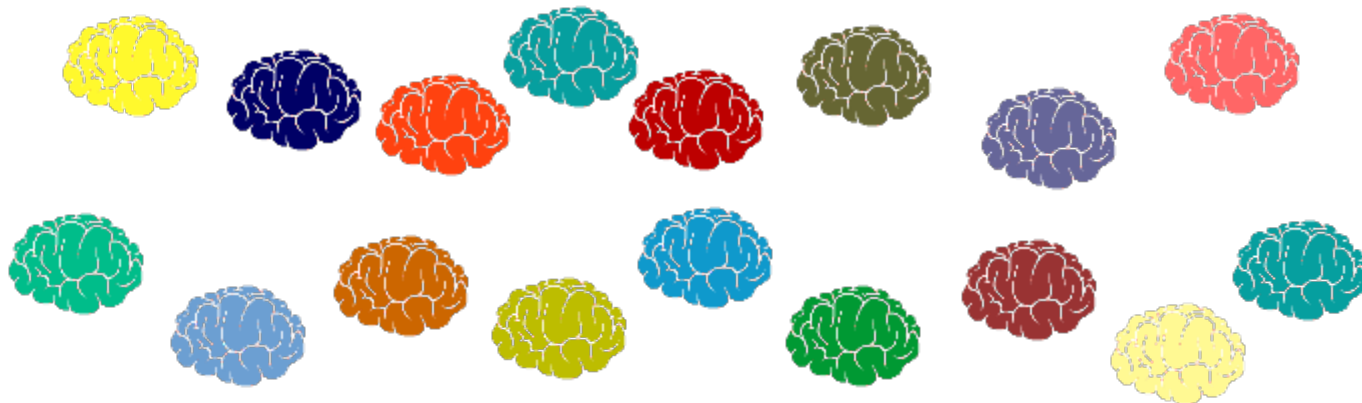
AUTISM in CONTEXT

from neurodiversity to neuroharmony

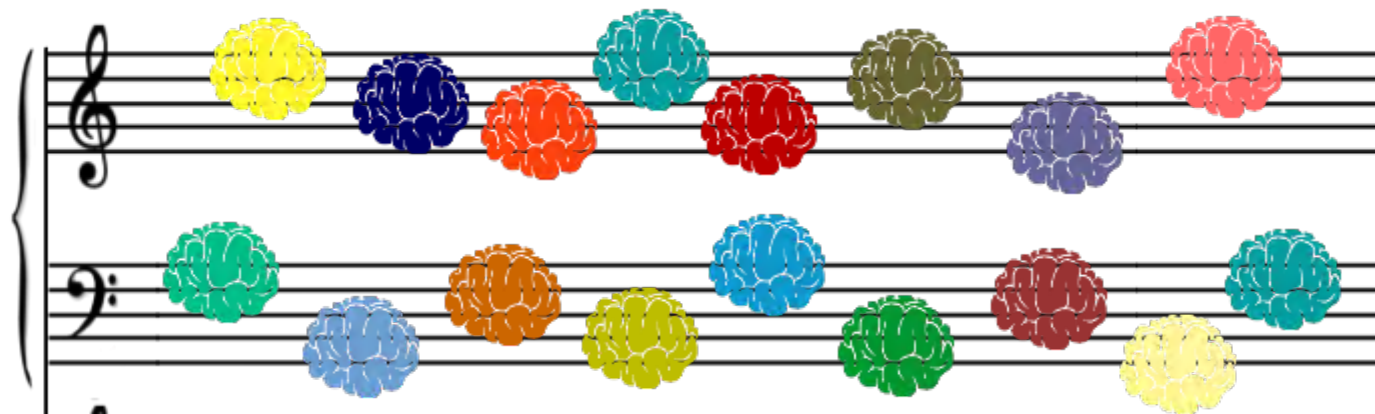
www.petervermeulen.be



[peter_autisme](https://twitter.com/peter_autisme)



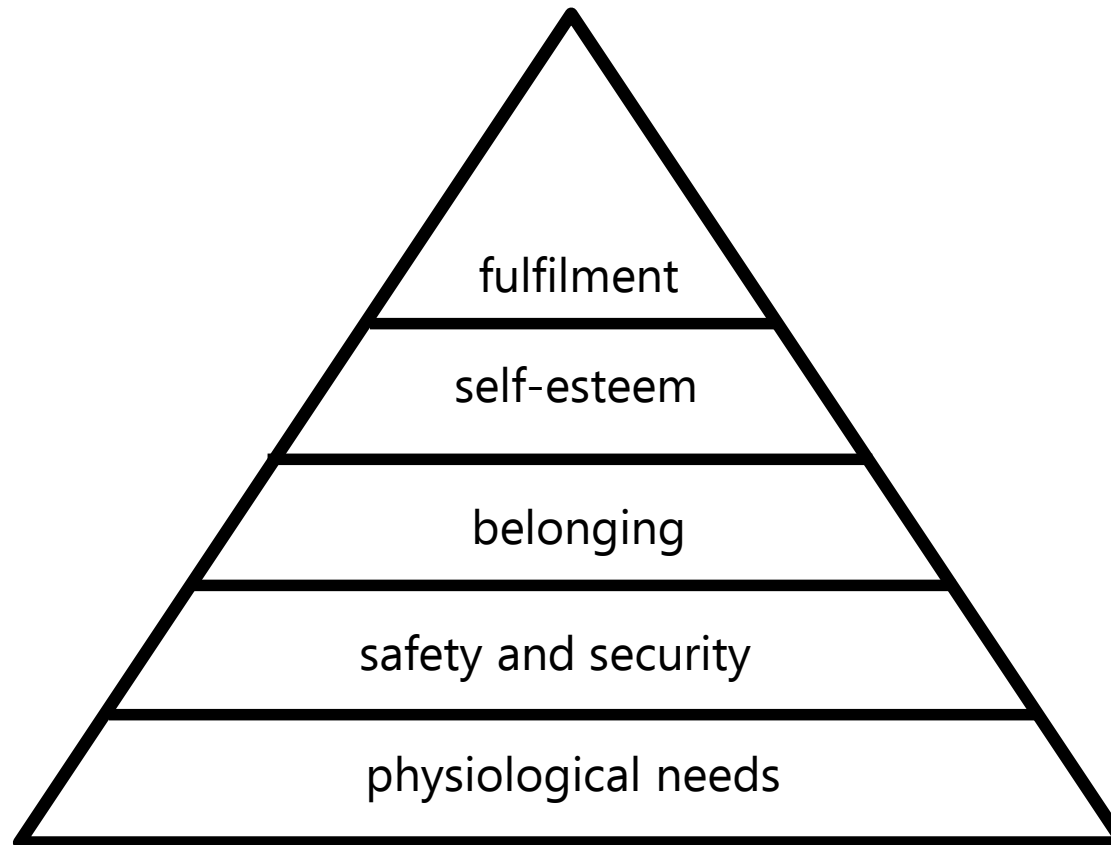
Autism and happiness:
from neurodiversity to neuroharmony



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

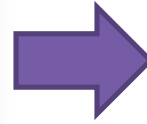
Universal human needs: Maslow's hierarchy



Abraham Maslow

From neurodiversity to neuroharmony

Neurodiversity



Neuroharmony



Outcome studies

Clinical Psychology Review 34 (2014) xxx–xxx

Contents lists available at ScienceDirect

Clinical Psychology Review



ELSEVIER



CrossMark

Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood

Liliana Magiati^{a,*}, Xiang Wei Tay^a, Patricia Howlin^{b,c}

^a Department of Psychology, National University of Singapore, Singapore

^b Department of Psychology, Institute of Psychiatry, King's College London, UK

^c University of Sydney, Australia

Rutter⁴

dsley Trust, UK;
JK

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50% of the

Autism

Autism
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e Author(s) 2012
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aut.sagepub.com

SAGE

lt outcomes
v-up reports

Longitudinal
Diagnosis

did not appear as
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stic and Statistical
M-IV), and the ICD-
behavioural Disorders,
for AS until well into
1993). These criteria
g., Leekam, Libby,

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?



employment



relations / friends



health



cognitive
functioning



living situation



autism
symptoms

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,^{1,3} Carina Gillberg,¹ and Christopher Gillberg^{1,2}

Table I. 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

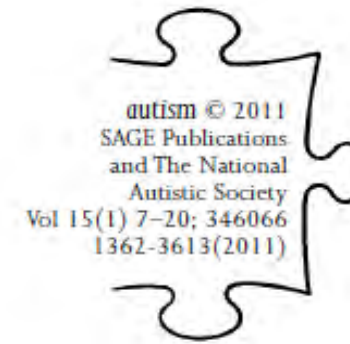
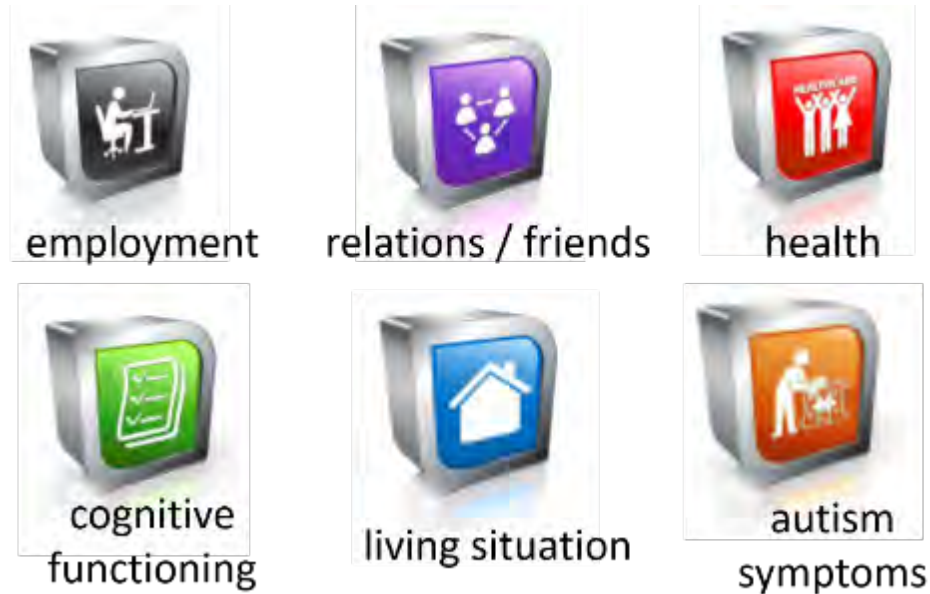


Table 2 Parent's/carer's estimation of the situation for their daughter/son/relative with **ASD** in aspects of quality of life/residential well being

Category	N = 100 ^a
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



Objective criteria
societal norms



Subjective criteria:
wellbeing

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 | ● Pleasant |
| ■ Well-being | ● Fun |
| ■ Satisfaction | ● Enjoying |
| ■ Pride | ● Cheerful |
| ■ Pleasure | ● Nice |
| ■ Amusement | ● 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: lightly stressful
- 3: moderately stressful
- 4: highly stressful
- 5: severely stressful

Sensory stimuli

	1	2	3	4	5
Certain kinds of light, namely...					
Certain kinds of noises, namely...					
Certain kinds of smell, namely...					
Certain kinds of tactile stimuli, namely...					
Being touched					
Being hugged					
Being kissed					
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. Självklart är människor olika. Det som ger en bra känsla för en person kan upplevas som obehagligt för en annan.

Nedan kan du ange i vilken utsträckning saker och händelser ger 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:

- 3: Det ger mig en bra känsla** – Jag gillar detta väldigt mycket
- 2: Det ger mig en bra känsla** – Jag gillar detta
- 1: Det ger mig en ganska bra känsla** – Jag gillar detta lite
- 0: Detta ger mig inte en bra känsla** – Jag gillar inte detta, (neutral, jag känner ingenting) eller detta känns till och med obehagligt
- ?: Jag vet inte om detta ger mig en bra känsla**

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

Sensoriska aspekter

	3	2	1	0		?
Visst ljus, som t.ex.:						
Vissa ljud, som t.ex.:						
En viss typ av röst, som t.ex.:						
Tystnad						
Vissa dofter, som t.ex.:						
Vissa taktila stimuli, som t.ex.:						
Beröring						
Bli kramad						
Bli pussad						
Värme						
Kyla						
Viss mat, som t.ex.:						
Viss dryck, som t.ex.:						
Vissa saker som jag gillar att röra vid, som t.ex.:						
Vissa väderleksförhållanden, som t.ex.:						
Ha en fleecefilt omkring mig						



AUTISM in CONTEXT

from neurodiversity to neuroharmony

[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

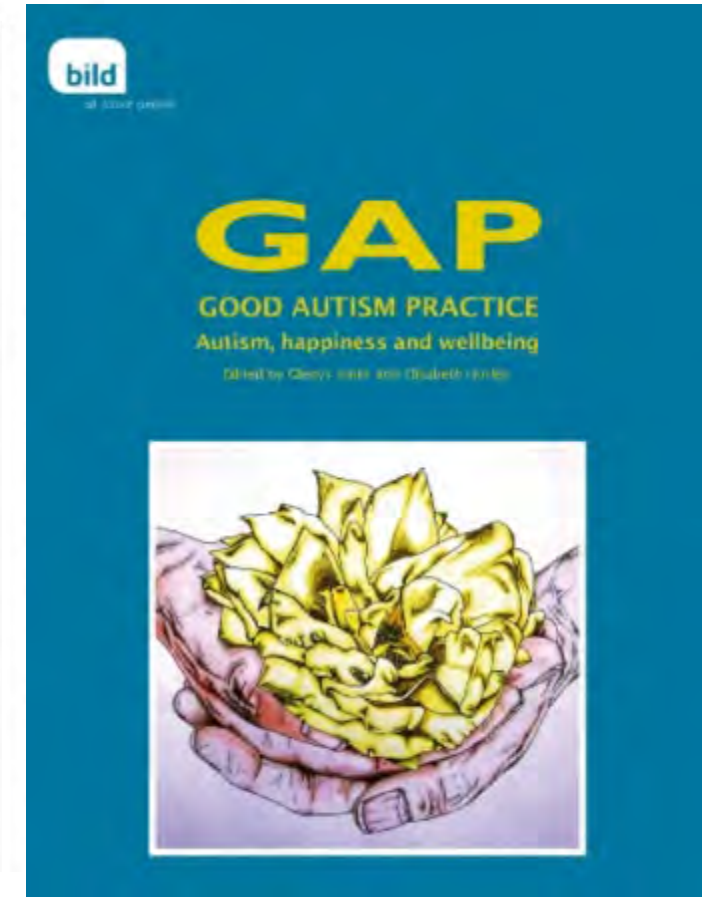
The practice of promoting happiness in autism

The practice of promoting happiness in autism

Peter Vermeulen, Autisme Centraal, Gent, Belgium

Editorial comment

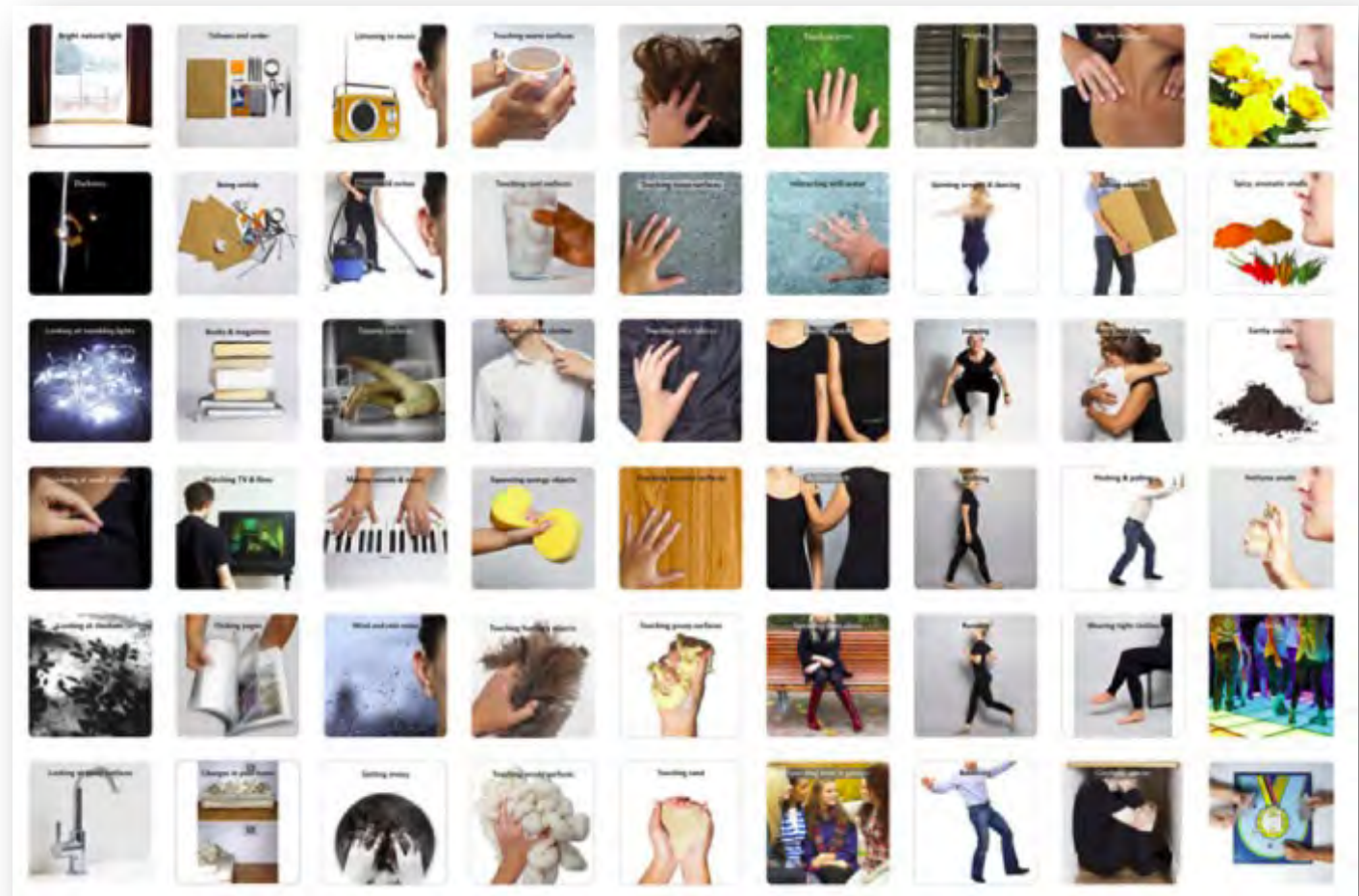
Emotional wellbeing and happiness have received little attention in the field of autism. When the focus is on wellbeing, it is often from a negative perspective, namely the lack of wellbeing and quality of life in autism. Based on the principles of positive psychology, Peter Vermeulen argues for a change 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

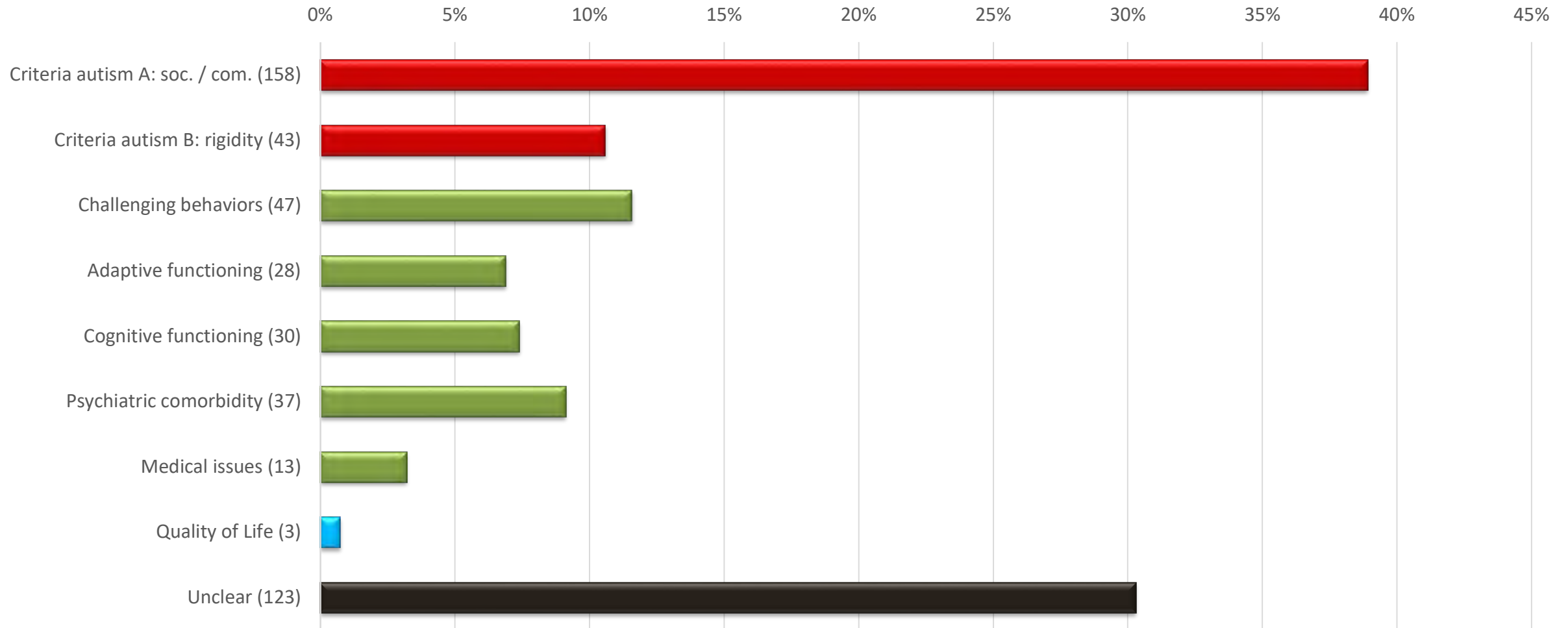
What are we targeting?



Review study 2019: 406 controlled trials
between 1980 and 2016

What are we targeting? (Review 406 studies)

Goal of the intervention



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



Original Article

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

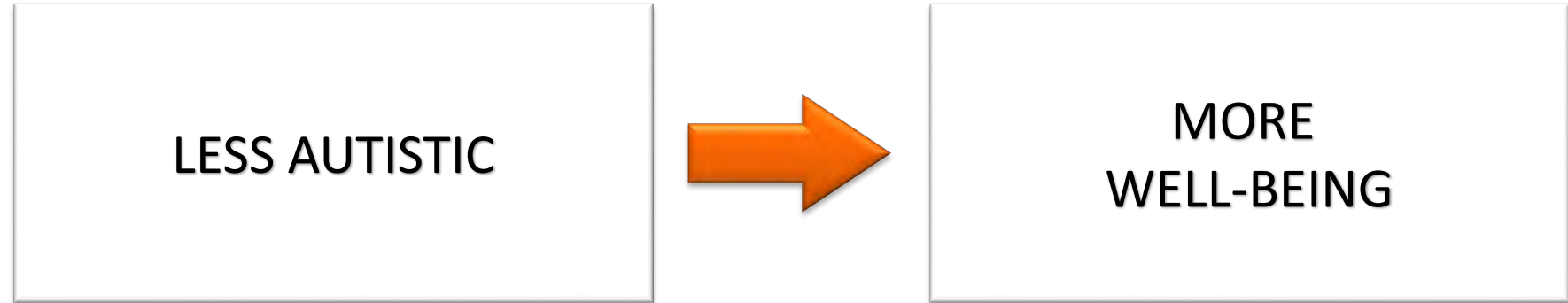
Autism
2015, Vol. 19(2) 158–167
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sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/1362361313517053
aut.sagepub.com
The SAGE logo consists of a circular emblem containing a stylized 'S' followed by the word 'SAGE' in a bold, uppercase, sans-serif font.

Barbara FC van Heijst¹ and Hilde M Geurts^{1,2,3}

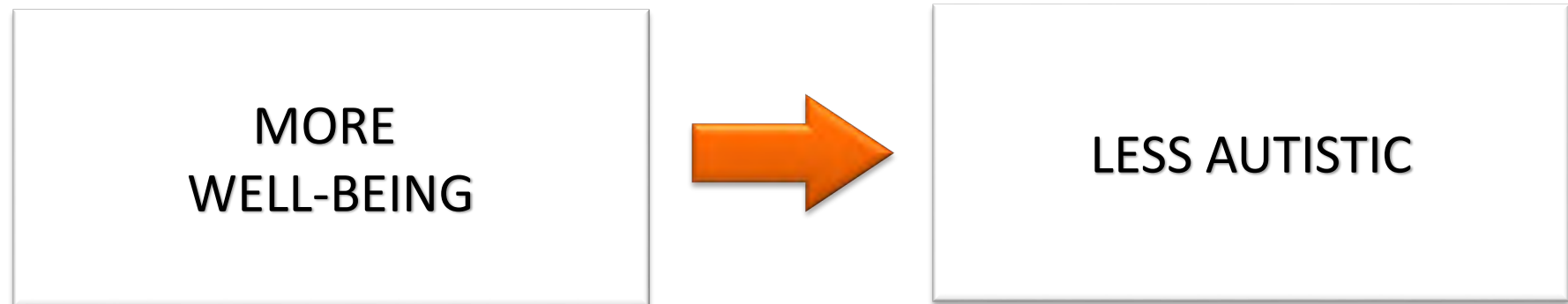
Abstract

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 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.



H.A.P.P.Y.

Happiness in Autism Personal Project for Young people

www.petervermeulen.be

Happier people are more successful in life

Psychological Bulletin
2005, Vol. 131, No. 6, 803–855

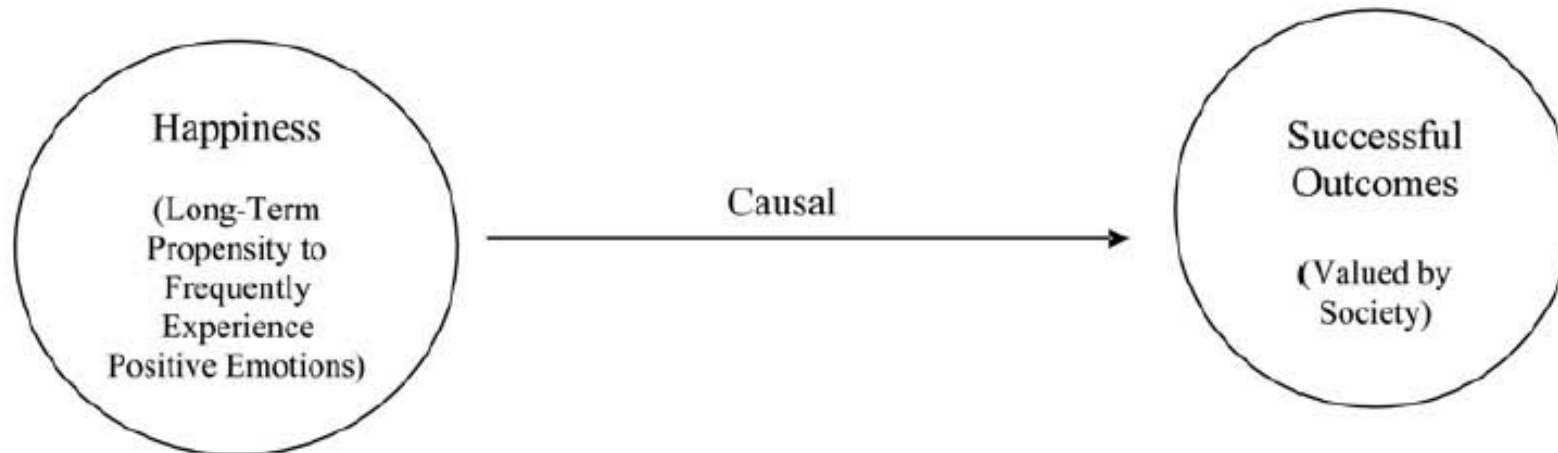
Copyright 2005 by the American Psychological Association
0033-2909/05/\$12.00 DOI: 10.1037/0033-2909.131.6.803

The Benefits of Frequent Positive Affect: Does Happiness Lead to Success?

Sonja Lyubomirsky
University of California, Riverside

Laura King
University of Missouri—Columbia

Ed Diener
University of Illinois at Urbana–Champaign and The Gallup Organization



Not less autistic, but “autistically happy”

Why focusing on wellbeing and happiness?

Because happy autistic people will have better outcomes in:



employment



relations / friends



health



cognitive functioning



living situation



autism symptoms

Working on good feelings

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

Working on happiness: the forgotten strategies

Predictability

Physical health

Resilience

Main source of distress in autism

Psychological Review
2014, Vol. 121, No. 4, 649–675

© 2014 American Psychological Association
0033-295X/14/\$12.00 <http://dx.doi.org/10.1037/a0037665>

Precise Minds in Uncertain Worlds: Predictive Coding in Autism

Sander Van de Cruys, Kris Evers, Ruth Van der Hallen, Lien Van Eylen,
Bart Boets, Lee de-Wit, and Johan Wagemans
KU Leuven

Absolute thinking in a relative world

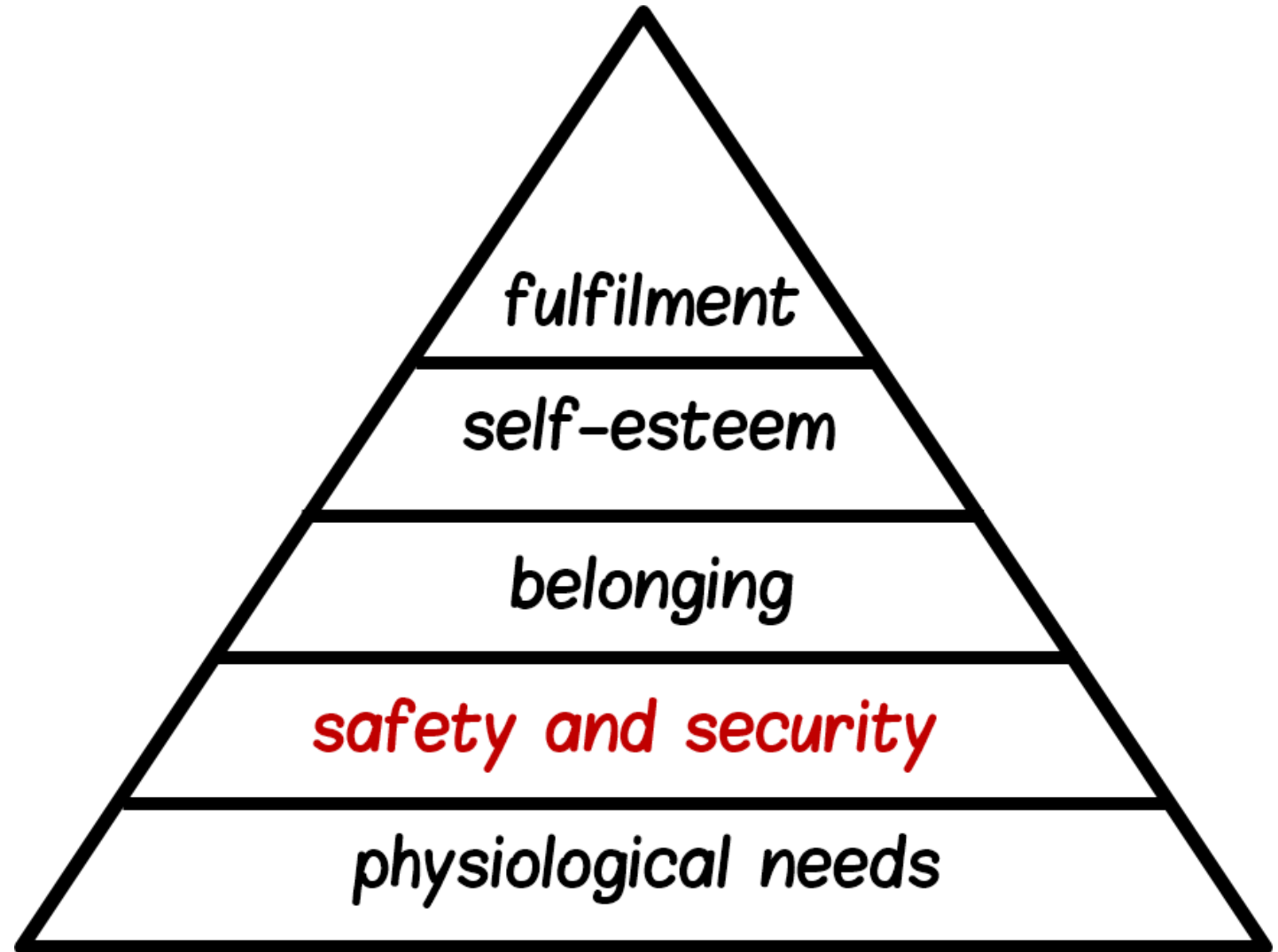


confusion – misunderstanding - uncertainty



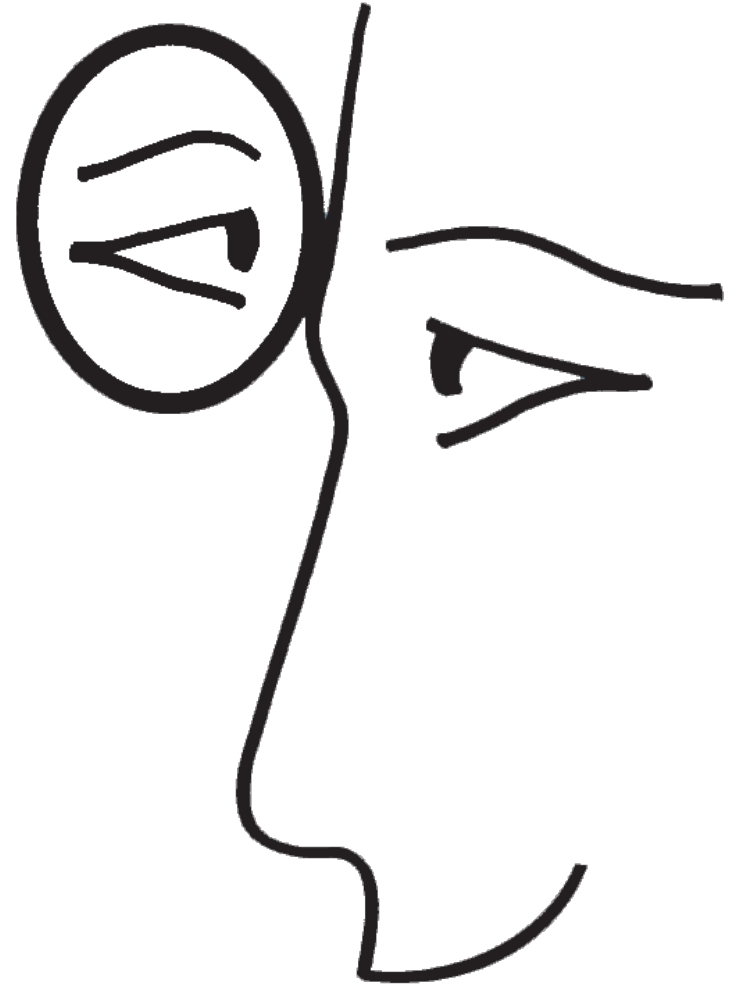
Universal human needs: Maslow's hierarchy

Abraham Maslow



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

Hindawi Publishing Corporation
Autism Research and Treatment
Volume 2014, Article ID 312163, 6 pages
<http://dx.doi.org/10.1155/2014/312163>



Research Article

Physical Activity and Physical Fitness of School-Aged Children and Youth with Autism Spectrum Disorders

Kiley Tyler,¹ Megan MacDonald,¹ and Kristi Menear²

¹ College of Public Health and Human Sciences, Oregon State University, Corvallis, OR 97331, USA

² School of Education, University of Alabama at Birmingham, Birmingham, AL 35294, USA

Correspondence should be addressed to Megan MacDonald; megan.macdonald@oregonstate.edu

Received 31 May 2014; Revised 16 August 2014; Accepted 20 August 2014; Published 16 September 2014

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



IJW

Dodge, R., Daly, A., Huyton, J., & Sanders, L. (2012). The challenge of defining wellbeing. *International Journal of Wellbeing*, 2(3), 222-235. doi:10.5502/ijw.v2i3.4

ARTICLE

The challenge of defining wellbeing

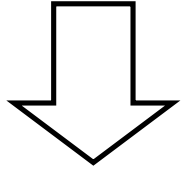
Rachel Dodge · Annette P. Daly · Jan Huyton · Lalage D. Sanders

Figure 4. Definition of Wellbeing



Double track approach

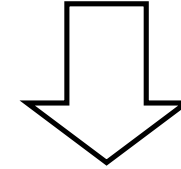
Society



Changing the
environment

adapting

Autistic person



Changing the
person

teaching

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

**Adam Helles^{1,2}, I Carina Gillberg¹, Christopher Gillberg¹
and Eva Billstedt¹**

Autism

1–12

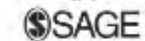
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DOI: 10.1177/1362361316650090

aut.sagepub.com



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



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?

Employment may be therapeutic

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

J Autism Dev Disord
DOI 10.1007/s10803-013-2010-9

ORIGINAL PAPER


Engagement in Vocational Activities Promotes Behavioral Development for Adults with Autism Spectrum Disorders

**Julie Lounds Taylor • Leann E. Smith •
Marsha R. Mailick**

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



AUTISM in CONTEXT

from neurodiversity to neuroharmony

www.petervermeulen.be



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