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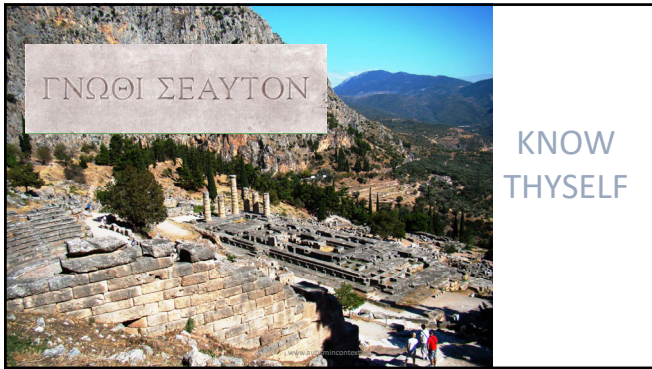
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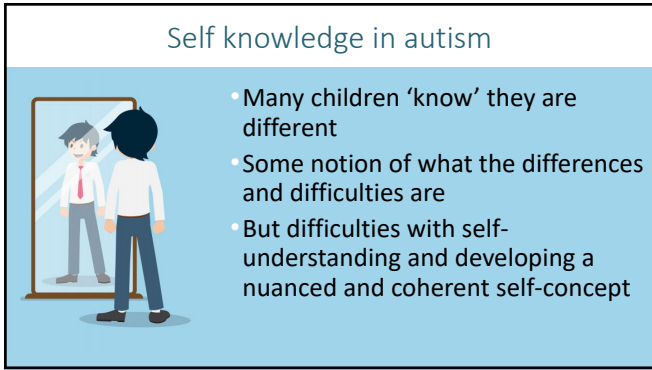
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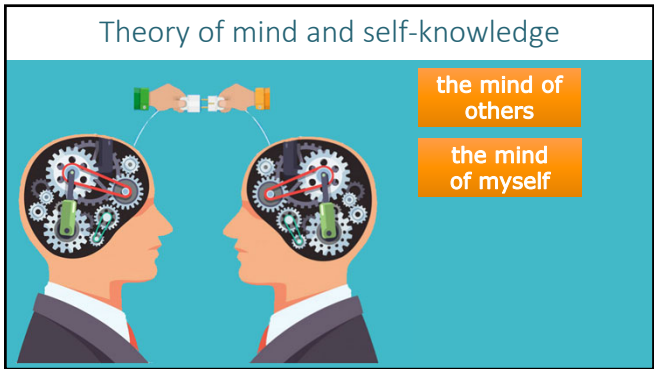
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'I am special': modular content

- **Part 1: I am unique**
  - my outside
  - my inside
  - interests and preferences, character, talents, not so strong points and personality
  - I am unique!



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'I am special': modular content

- **Part 2: My body**
  - the outside
  - the inside
  - my brain
  - my intelligence
  - we need our body



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'I am special': modular content

- **Part 3: Being different**
  - illness and disease
  - disability: person - environment
  - special education and assistance
  - an adapted environment
  - people experiencing a disability can be talented too
  - people experiencing a disability are different, not less



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'I am special': content

- **Part 4: Autism: a special disability**
  - What is more difficult because of my autism
  - What is easier because of my autism
  - Where does my autism not make a difference
  - The Autism Spectrum



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Changes in focus

Is learning about the DSM-5 criteria really what they want or need?



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**British Journal of Special Education** 

**AUTISM AND HIGHER EDUCATION**

'Why should I be like bloody Rain Man?!'  
Navigating the autistic identity

*Andrea MacLeod, Ann Lewis and Christopher Robertson*

This article explores the views of six higher education students with autism/Asperger syndrome. The research draws upon social identity theory to explore how participants made meaning of their label. There was consensus that information given at the point of diagnosis generally did not reflect their individual experiences. First-hand accounts

drome,\* drawing upon social identity theory to explore how participants made meaning of the label they had been given.

Social identity theory and social categorisation theory consider how the self-concept of an individual is influenced positively or negatively by his or her group membership and

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MacLeod et al., 2013

Receiving a diagnosis of autism too often means having to navigate through generalised information written by non-autistic professionals. The individual is then left unsupported in their efforts to apply this information to themselves in a meaningful way.

individuals need to be enabled to identify with a group that is perceived as constructive and empowering rather than detrimental and limiting. For this to happen, each child or adult receiving diagnosis must be given opportunities to learn about their condition in ways that are meaningful to them as individuals.

p. 47

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Changes in focus

1. Psycho-education should be **FUNCTIONAL**

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Communication disorder	They don't understand me!
Socially inappropriate	I am honest!
Lack of friends	I do have friends!
Abnormal, weird...	My brother does the same!
Difficulties	I don't have problems!

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Changes in focus

1. Psycho-education should be **FUNCTIONAL**
2. Make it **POSITIVE** but be honest



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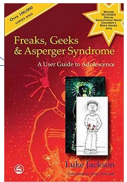
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Be careful with positive role models!



*I find these television programs depressing!  
I got all the nerdiness and freakishness but none of the genius.*

Luke Jackson



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Psychoeducation

- BLABLABLALA...
- A lot of talking
- Or...reading a lot of text



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### Interactive worksheets

**Tous or Inside?**

Wat zijn er voor verschillen? (What are the differences?)

Deel van het lichaam (Body part)	Wat is dat? (What is that?)	Wat doet dat? (What does it do?)
1. De hersenen (The brain)	Wat is dat?	Wat doet dat?
2. De ogen (The eyes)	Wat is dat?	Wat doet dat?
3. De oren (The ears)	Wat is dat?	Wat doet dat?
4. Het hart (The heart)	Wat is dat?	Wat doet dat?
5. De longen (The lungs)	Wat is dat?	Wat doet dat?
6. De maag (The stomach)	Wat is dat?	Wat doet dat?
7. De darmen (The intestines)	Wat is dat?	Wat doet dat?
8. De huid (The skin)	Wat is dat?	Wat doet dat?
9. De benen (The legs)	Wat is dat?	Wat doet dat?
10. De armen (The arms)	Wat is dat?	Wat doet dat?

Van Samen! (Together!)

**My body, the inside.**

Wij body die has en inside  
body the body part has in our body

Van Samen! (Together!)

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### Doing things, rather than only talking!

**Een lijst van wat kind allemaal goed kan:**

**OGEN:**

- Kind heeft oog voor details. Als iets is veranderd, dan merkt hij het snel op.

**OREN:**

- Kind hoort heel veel.

**NEUS:**

- Kind ruikt heel goed en veel.

**MOND:**

- Kind kan goed de taal spreken.
- Hij kan ook goed om met andere mensen.
- Hij kan ook goed communiceren met anderen.

**HANDEN:**

- Kind kan goed de bal vangen en vangen.
- Hij kan goed de bal gooien naar links.
- Hij heeft een sterke grip, want hij kan de auto sturen.
- Hij heeft een sterke grip.
- Hij werkt ook heel goed met de PC.

**VOETEN:**

- Kind is een goede klopper.
- Hij kan goed lopen, lang wandelen en goed fietsen.
- Hij heeft een heel sterke en zijn bewegingen.
- Hij heeft een heel goede evenwicht.

**HERSENEN:**

- Kind kan goed plannen (voorbereiden) om een baan, kookboekje!
- Hij is ook een goede, bijvoorbeeld in verenschap, de team.
- Hij kan heel goed de weg vinden, maar kan hij niet het adres van de weg.
- Hij kan heel goed de weg vinden, met bijvoorbeeld, met bijvoorbeeld, met bijvoorbeeld.
- Hij kan een goede van kleine dingen, zoals een verandering in de manier.

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Jessica Kingsley  
Publishers  
www.jkp.com

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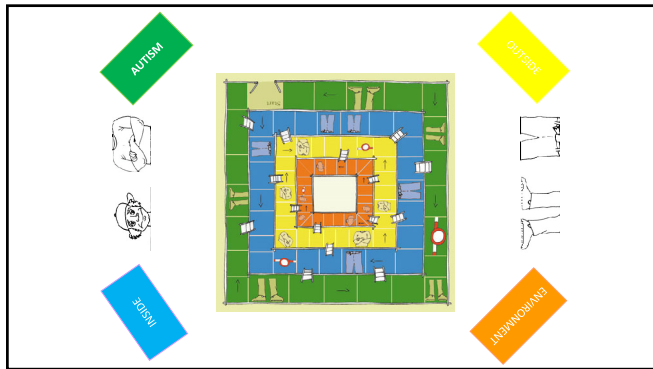
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Changes in focus

1. Psycho-education should be **FUNCTIONAL**
2. Make it **POSITIVE** but be honest
3. More **FUN**

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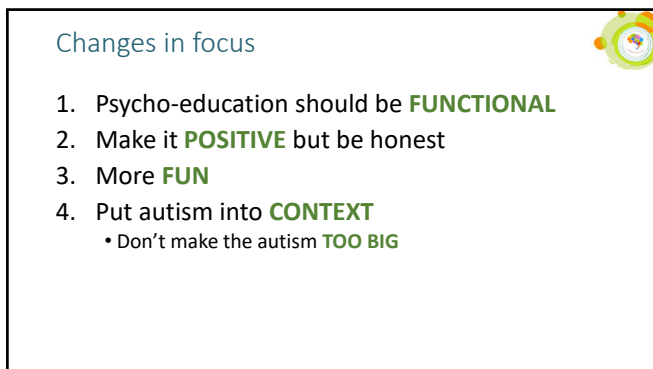
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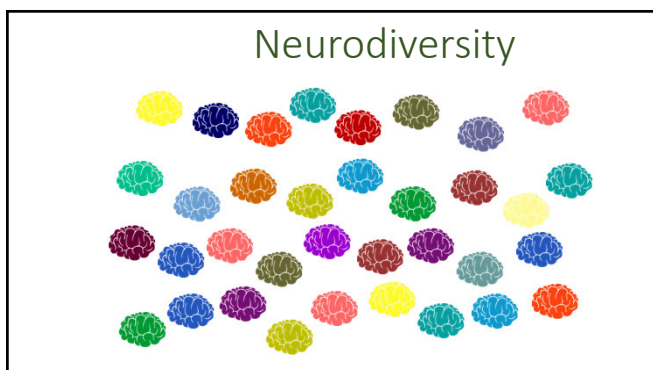
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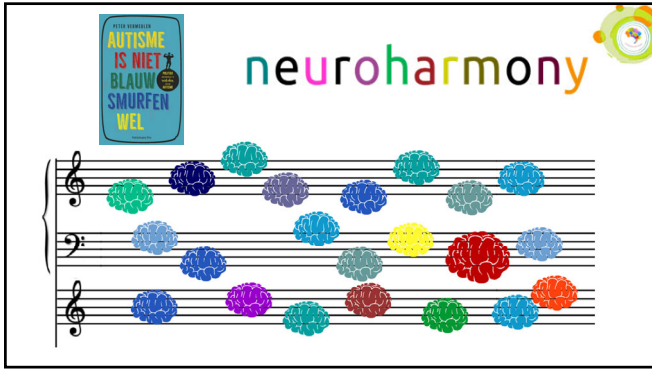
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We are not so different in terms of

behaviour	mind	needs

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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

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What are we targeting?

Review

What are we targeting when we treat autism spectrum disorder? A systematic review of 406 clinical trials

Umberto Provenzano<sup>1</sup>, Laura Fusar-Poli<sup>1,2</sup>, Natascia Brondino<sup>1</sup>, Stefano Damiani<sup>1</sup>, Marco Vercesi<sup>1</sup>, Nicholas Meyer<sup>3</sup>, Matteo Rocchetti<sup>1</sup> and Pierluigi Politi<sup>1</sup>

Review study 2019: 406 controlled trials between 1980 and 2016

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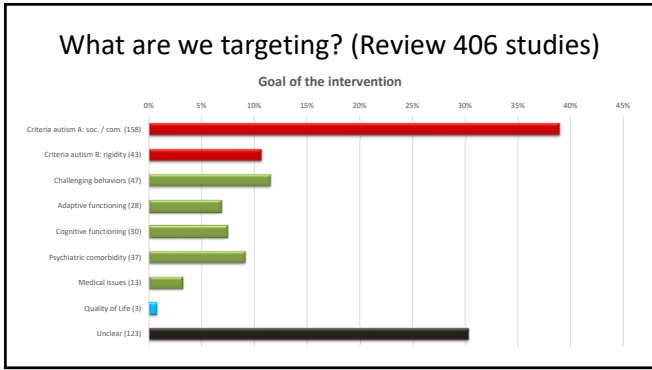
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**QoL: no link with IQ and severity**

Original Article

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

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 12776 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.



Autism  
2015, Vol. 15(2), 148–147  
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DOI: 10.1177/1364264314557863  
aut.sagepub.com  
SAGE

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**QoL: no link with IQ and severity**


The Journal of Child Psychology and Psychiatry

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

Andrew Pickles,<sup>1</sup> James B. McCauley,<sup>2</sup> Lauren A. PAPA,<sup>3</sup> Mariela Huerta,<sup>4</sup> and Catherine Lord<sup>5</sup>

<sup>1</sup>Department of Biostatistics and Health Informatics, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK; <sup>2</sup>Department of Psychiatry, University of California, Los Angeles, Los Angeles, CA; <sup>3</sup>Centre for Autism and the Developing Brain, Weill Cornell Medicine, New York, NY; <sup>4</sup>Priority House, New York, NY, USA

**Background:** Autism Spectrum Disorder is highly heterogeneous, so more so than in the complex world of adult life. It is 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, 694) 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. Remaining 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 they were more difficult to predict. **Conclusions:** 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 self-rated support of adult outcome were weakly related to functional outcomes and poorly predicted from childhood.** **Keywords:** Childhood; autism spectrum disorders; adult outcome; prediction; EDD.



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**This is how many think it works**

LESS AUTISTIC

➔

MORE WELL-BEING

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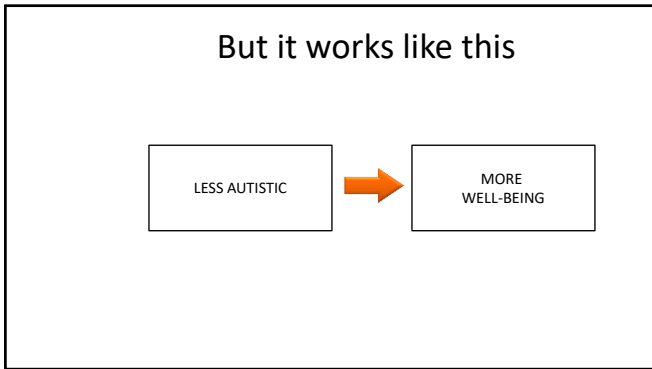
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**What parents want...**

J Autism Dev Disord (2018) 48:1041–1051  
DOI 10.1007/s10803-017-2522-2

CrossMark

**5.1. PARENTING CHILDREN WITH ASD**

**Parents Suggest Which Indicators of Progress and Outcomes Should be Measured in Young Children with Autism Spectrum Disorder**

Helen McConachie<sup>1</sup>, Nicola Libby<sup>1,2\*</sup>, Christopher Morris<sup>1</sup>, Bryony Bredford<sup>1</sup>, Ann Le Couteur<sup>1</sup>, Paul Gringras<sup>1</sup>, Deborah Garland<sup>1</sup>, Glenn Jones<sup>1</sup>, Geraldine Macdonald<sup>1,3</sup>, Katrina Williams<sup>1</sup>, Jeremy R. Parr<sup>4</sup>

Published online: 31 August 2017  
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**What parents want...**

**Table 2** Parents' top ranked 10 constructs for measurement of progress or outcome

Parents: important areas to measure	Rank
Happiness	1
Anxiety, unusual fears	2
Discomfort with being touched, too much noise, bright lights, certain tastes, etc. (hypersensitivity)	3.5
Positive views of self (self-esteem)	3.5
Distress	5
Understanding visual information and solve problems using visual reasoning (nonverbal ability)	7
Relationships with brothers and sisters	7
Parent stress (body symptoms, poor sleep, etc)	7
Fighting, hitting others (aggression)	10
Long time to fall asleep; wake up in night	10
Experiences rejection by others; is bullied (social exclusion)	10

Source: Helen McConachie et al., 2018

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## Happy people are more successful in life

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

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## 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 statements cause stress for the person with autism.

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

Stressor	1	2	3	4	5
Constant levels of light, sounds					
Constant levels of odors, smells					
Constant levels of touch, textures					
Constant levels of tactile stimuli, sensory					
Being touched					
Being hugged					
Being kissed					
Constant levels of food					
Other					

**AUTISM in CONTEXT**

**Autism Good Feeling Questionnaire**

Rate how often you experience the following feelings in the past 12 months (from 0 = not at all to 4 = very often).

0 = not at all  
1 = a little  
2 = somewhat  
3 = quite a bit  
4 = very often

1. I feel happy  
2. I feel content  
3. I feel satisfied  
4. I feel pleased  
5. I feel joyful  
6. I feel optimistic  
7. I feel enthusiastic  
8. I feel energetic  
9. I feel confident  
10. I feel proud  
11. I feel grateful  
12. I feel appreciative  
13. I feel loving  
14. I feel caring  
15. I feel kind  
16. I feel generous  
17. I feel helpful  
18. I feel forgiving  
19. I feel understanding  
20. I feel patient  
21. I feel tolerant  
22. I feel respectful  
23. I feel courteous  
24. I feel polite  
25. I feel considerate  
26. I feel thoughtful  
27. I feel sensitive  
28. I feel empathetic  
29. I feel compassionate  
30. I feel merciful  
31. I feel lenient  
32. I feel indulgent  
33. I feel forgiving  
34. I feel understanding  
35. I feel patient  
36. I feel tolerant  
37. I feel respectful  
38. I feel courteous  
39. I feel polite  
40. I feel considerate  
41. I feel thoughtful  
42. I feel sensitive  
43. I feel empathetic  
44. I feel compassionate  
45. I feel merciful  
46. I feel lenient  
47. I feel indulgent

Feeling	0	1	2	3	4
1. I feel happy					
2. I feel content					
3. I feel satisfied					
4. I feel pleased					
5. I feel joyful					
6. I feel optimistic					
7. I feel enthusiastic					
8. I feel energetic					
9. I feel confident					
10. I feel proud					
11. I feel grateful					
12. I feel appreciative					
13. I feel loving					
14. I feel caring					
15. I feel kind					
16. I feel generous					
17. I feel helpful					
18. I feel forgiving					
19. I feel understanding					
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25. I feel considerate					
26. I feel thoughtful					
27. I feel sensitive					
28. I feel empathetic					
29. I feel compassionate					
30. I feel merciful					
31. I feel lenient					
32. I feel indulgent					

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**AUTISM in CONTEXT webshop**

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Autism Good Feeling Questionnaire Spanish

Autism Good Feeling Questionnaire Swedish

Autism Good Feeling Questionnaire Portuguese

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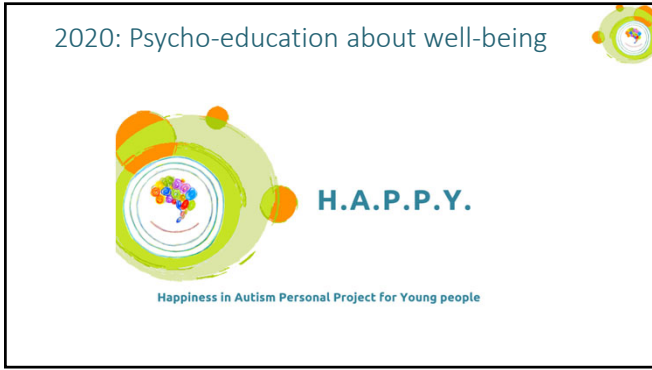
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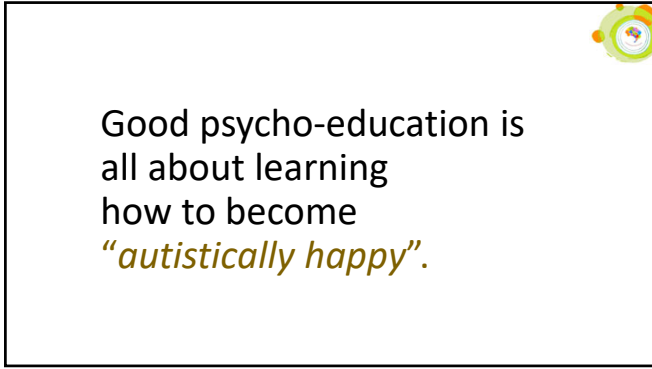
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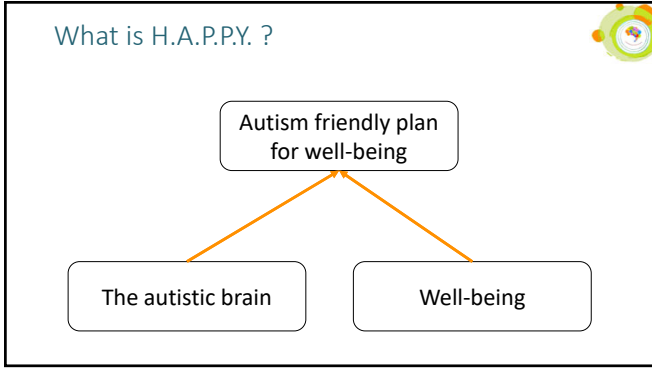
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Well-being strategies need to be adapted




**Autism and Mindfulness**  
A therapy that can help people with autism to actively create a more peaceful mind

Home  
Theory of Mindfulness  
Book  
Articles

**Home**

**Autism and Mindfulness**

Mindfulness is a relatively new therapy that can help people with autism to actively create a more peaceful mind. Regular mindfulness interventions are usually 'too vague' for people with autism. This motivated us about six years ago to develop a mindfulness intervention specifically intended for adults with ASD, which takes into account their cognitive strengths and weaknesses. This resulted in a



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Postulates of the H.A.P.P.Y.-programme

- happiness is within reach of all people with autism, regardless of the nature and profile of their autism, their intellectual abilities and their age
- a programme for happiness and wellbeing should be underpinned by scientific findings
- a programme for happiness and wellbeing for autistic people should make the regular evidence based wellbeing interventions autism friendly
- a programme for happiness and wellbeing for autistic people should be individualized

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H.A.P.P.Y.

developing evidence based, personalized and autism friendly strategies that aim at increasing the wellbeing of an autistic individual

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### 10 well-being strategies

1. Accepting and loving yourself
2. Good Feeling toolbox
3. Flow activities
4. Physical exercise
5. Problem focused coping strategies
6. Emotion focused coping strategies
7. Positive thinking
8. Gratitude
9. Kindness
10. Personal projects: learning something new

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### H.A.P.P.Y. : A flexible programme

- Two basic versions:
  - Children and adolescents
  - (Young) Adults
- Individual or in group
- No fixed number of 'sessions'
- Live and/or online

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What I have learnt in the past 25 years

1. Psycho-education should be **FUNCTIONAL**
2. Make it **POSITIVE** but be honest
3. More **FUN**
4. Put autism into **CONTEXT**
  - Don't make the autism **TOO BIG**
5. Focus on information and strategies that increase **WELL-BEING**

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THANK YOU  
FOR YOUR ATTENTION!



**AUTISM in CONTEXT**  
from neurodiversity to neuroharmony  
[www.petervermeulen.be](http://www.petervermeulen.be)



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