
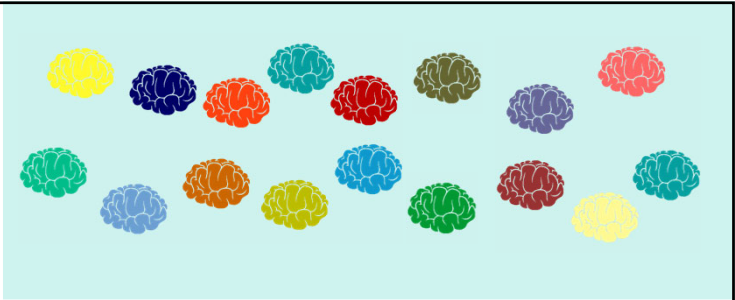


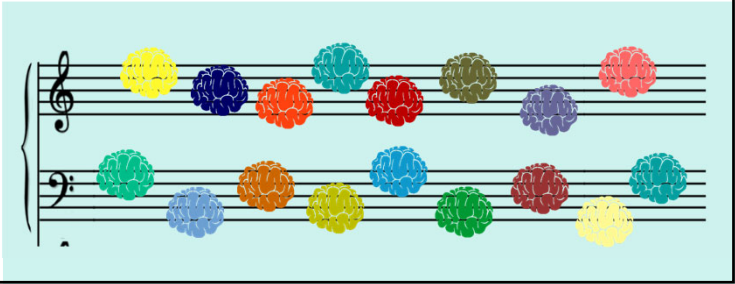
AUTISM in CONTEXT
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**sterkmakers
in autisme**
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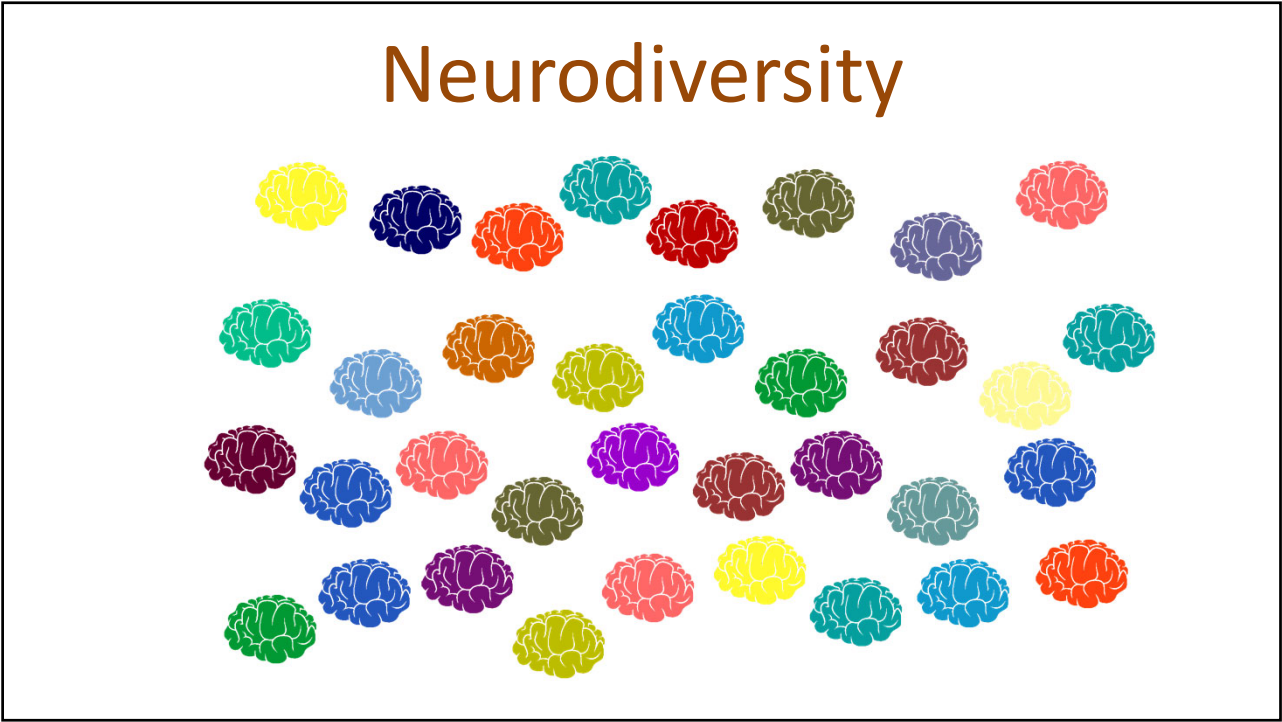
From neurodiversity to neuroharmony:
fostering a society that works for autistic people



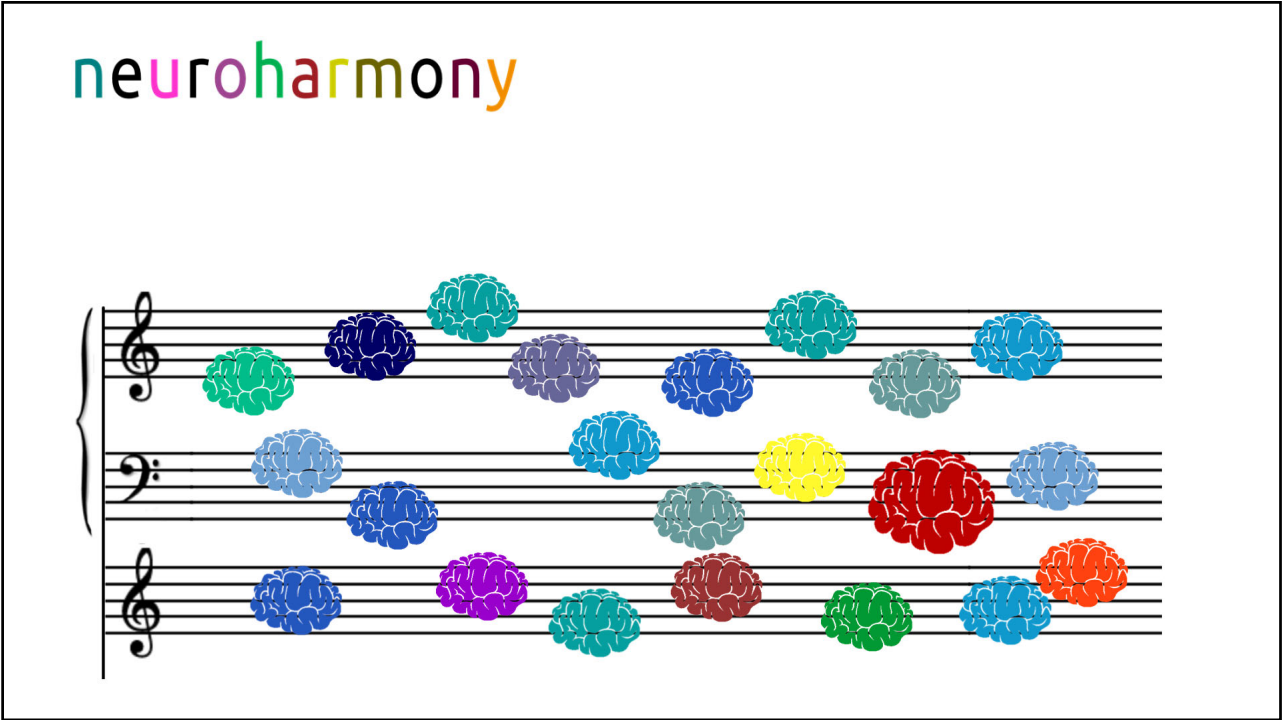
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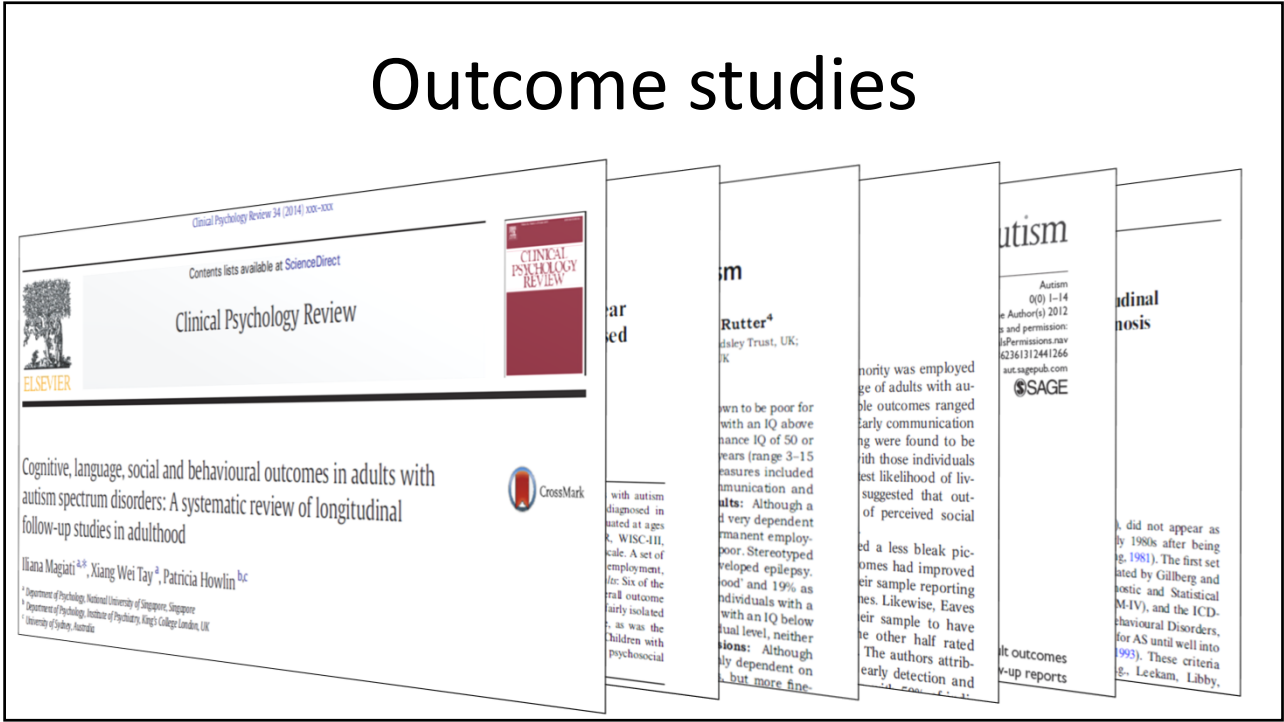


3



4

Outcome studies




5


Outcomes in adulthood are highly variable



6




Barbara van Heijst



Hilde Geurts

QoL lower for autistic people




Original Article

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

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

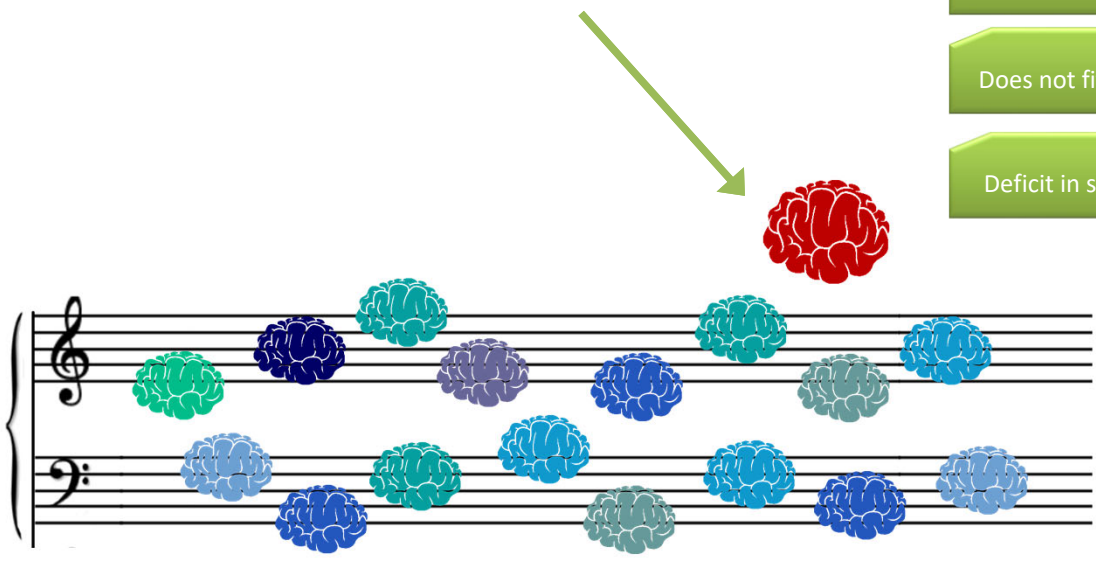
Abstract
Autism is a lifelong neurodevelopmental disorder, with a known impact on quality of life. Yet the developmental trajectory of quality of life is not well understood. First, the effect of age on quality of life was studied with a meta-analysis. Our meta-analysis included 10 studies (published 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.

Autism
2015, Vol. 19(2) 158–167
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7

How do we describe this one?

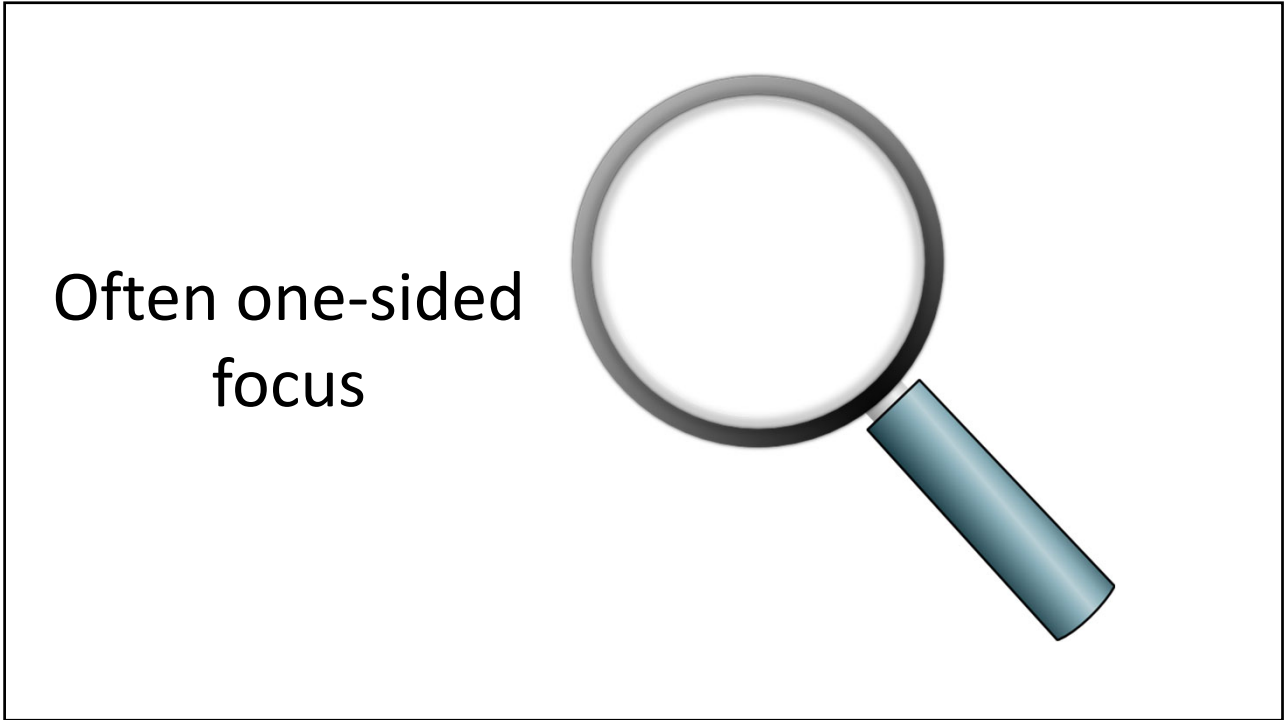


Lacks blue

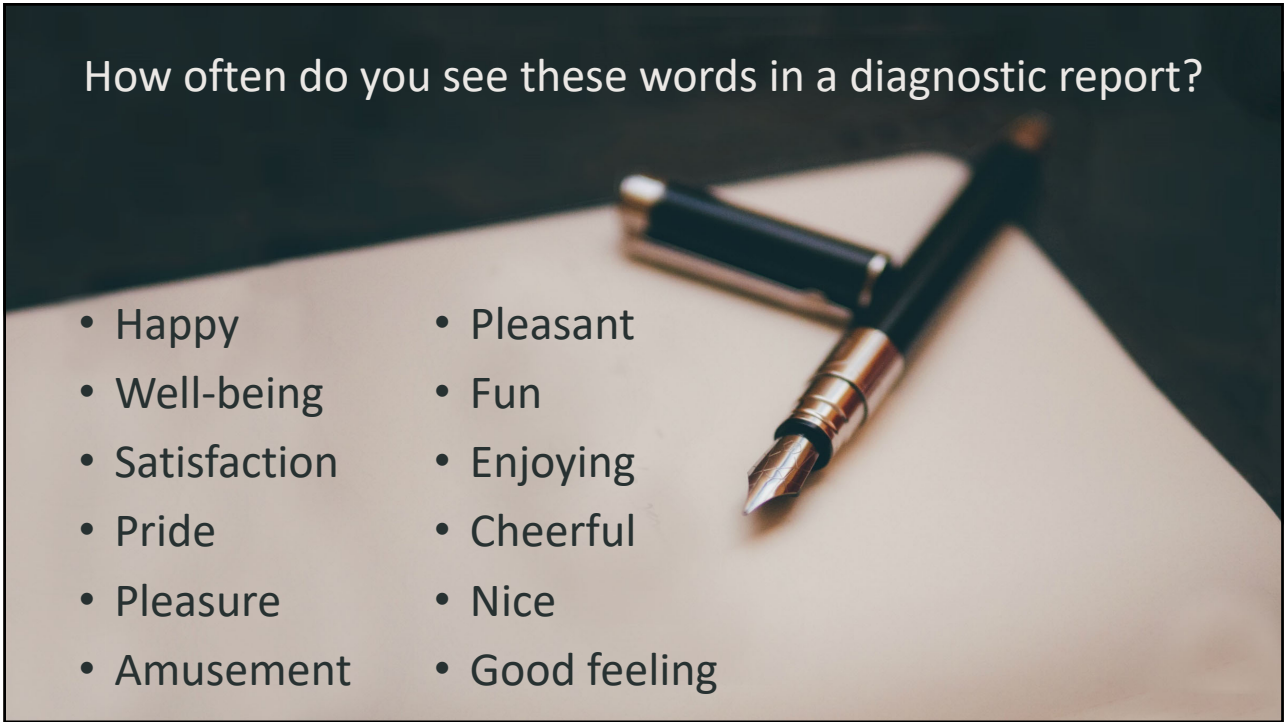
Does not fit in

Deficit in size

8



9



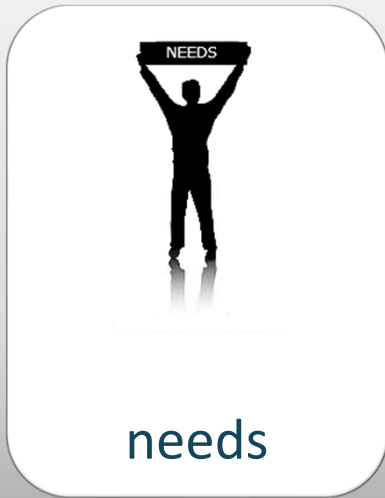
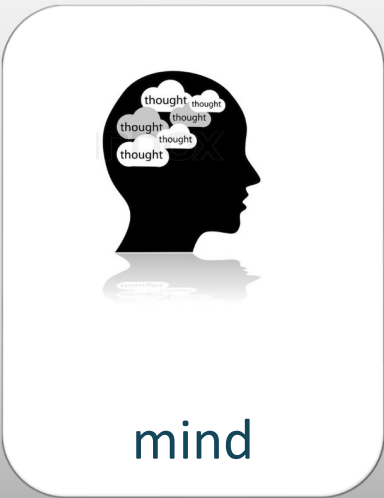
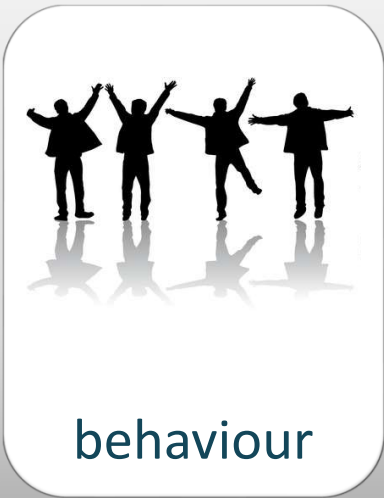
10

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



11

We are not so different in terms of



12

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



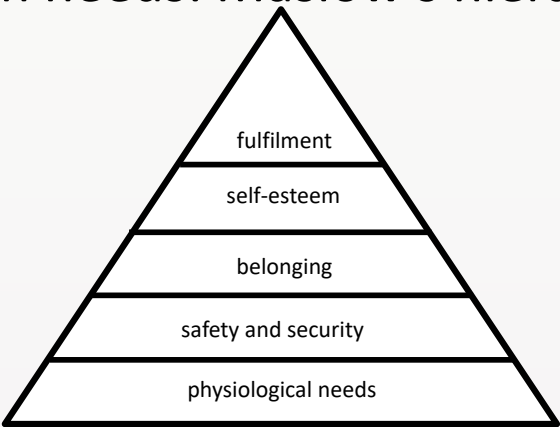
13



14

Universal human needs: Maslow's hierarchy

Abraham Maslow



15

Find out what makes people feel good

TRIAL VERSION - FOR PERSONAL USE ONLY



AUTISM in CONTEXT



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 Questionnaire

Spørreskjemaet inneholder referanser til alle slags ting som kan gi en person en god følelse. Men vi er selvsagt alle forskjellige. Hva som skaper en god følelse hos en person kan være svært ubehagelig for en annen.

Nedenfor kan du indikere hvor mye ting eller hendelser gir deg positive følelser. For hver kategori spørsmål finner du en bokser hvor du kan legge til ting som ikke står på listen.

Hvert spørsmål scores som følger:

- 5: Dette gir meg en veldig god følelse – jeg liker dette veldig godt
- 4: Dette gir meg en god følelse – jeg liker dette
- 3: Dette gir meg en litt god følelse – jeg liker dette litt
- 2: Dette gir meg ikke en god følelse – jeg liker ikke dette særlig (nøytral jeg føler ingenting eller jeg kan tli og med føle ubehag)
- 1: Jeg vet ikke om dette gir meg en god følelse

Listen er altså ikke uttømmende. Derfor kan du legge til ting som får deg til å føle velvære eller som du liker.

Sensoriske aspekter

	5	4	3	2	1	0	?
Noen hvilder, spesielt : ..							
Noen lyder, spesielt: ..							
Spesielle typer stemmer, spesielt: ..							
Stilhet							
Spesifikke lukter, spesielt: ..							
Spesifikke taktile stimuli, spesielt: ..							
Blå tatt på							
Få en klem, holdt rundt							
Blå kysset							
Varme							
Kulde							
Mat, spesielt: ..							
Drille, spesielt: ..							
Objekter som jeg liker å ta på, spesielt: ..							
Spesifikke værttyper (eventyrligst spesifiser: ..)							
Et teppe rundt meg							

16



17



18

What are we targeting?

Review

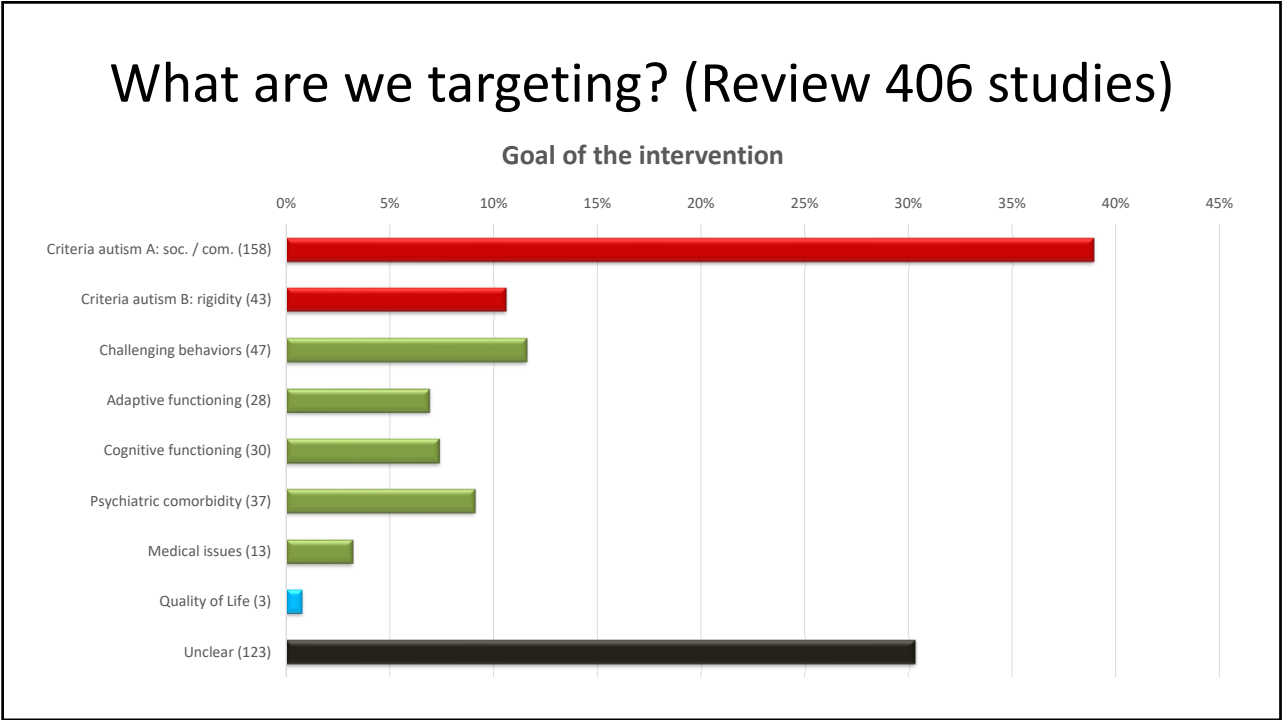
What are we targeting when we treat autism spectrum disorder? A systematic review of 406 clinical trials

Umberto Provenzani^{1*}, Laura Fusar-Poli^{1,2*},
Natascia Brondino¹, Stefano Damiani¹, Marco Vercesi¹,
Nicholas Meyer³, Matteo Rocchetti^{1†} and Pierluigi Politi^{1†}

Review study 2019: 406 controlled trials between 1980 and 2016

Autism
1–11
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19



20

Interventions for adults

autism

Autism
1–15
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Review

Support for adults with autism spectrum disorder without intellectual impairment: Systematic review

Theo Lorenc¹, Mark Rodgers¹, David Marshall¹, Hollie Melton¹, Rebecca Rees², Kath Wright¹ and Amanda Sowden¹

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

RESEARCH

21

This is how many think it works




LESS AUTISTIC

MORE WELL-BEING


22

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11



Barbara van Heijst



Hilde Geurts

QoL: no link with IQ and severity


Original Article

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


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.

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23



Andrew Pickles

QoL: no link with IQ and severity


The Journal of Child Psychology and Psychiatry
Journal of Child Psychology and Psychiatry ***(2020), pp **-***
doi:10.1111/jcpp.13185


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

Andrew Pickles,¹ James B. McCauley,² Lauren A. Pepa,³ Marisela Huerta,⁴ and Catherine Lord²


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

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, 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. 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 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 affective aspects of adult outcome were weakly related to functional outcomes and poorly predicted from childhood.** **Keywords:** Childhood; autism spectrum disorders; adult outcome; prediction; EDX.





24



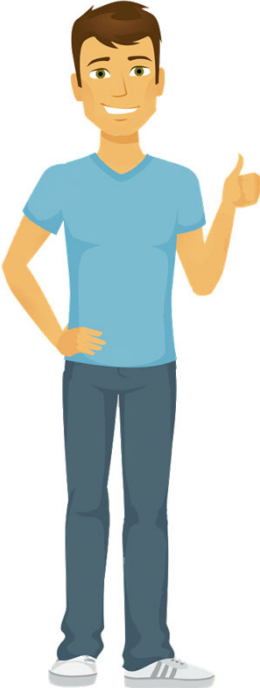
This is how many think it works

LESS AUTISTIC

➔

MORE WELL-BEING

25



But it works like this

LESS AUTISTIC

➔

MORE WELL-BEING

26

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

Happiness

(Long-Term
Propensity to
Frequently
Experience
Positive Emotions)


Causal

Successful
Outcomes

(Valued by
Society)

27

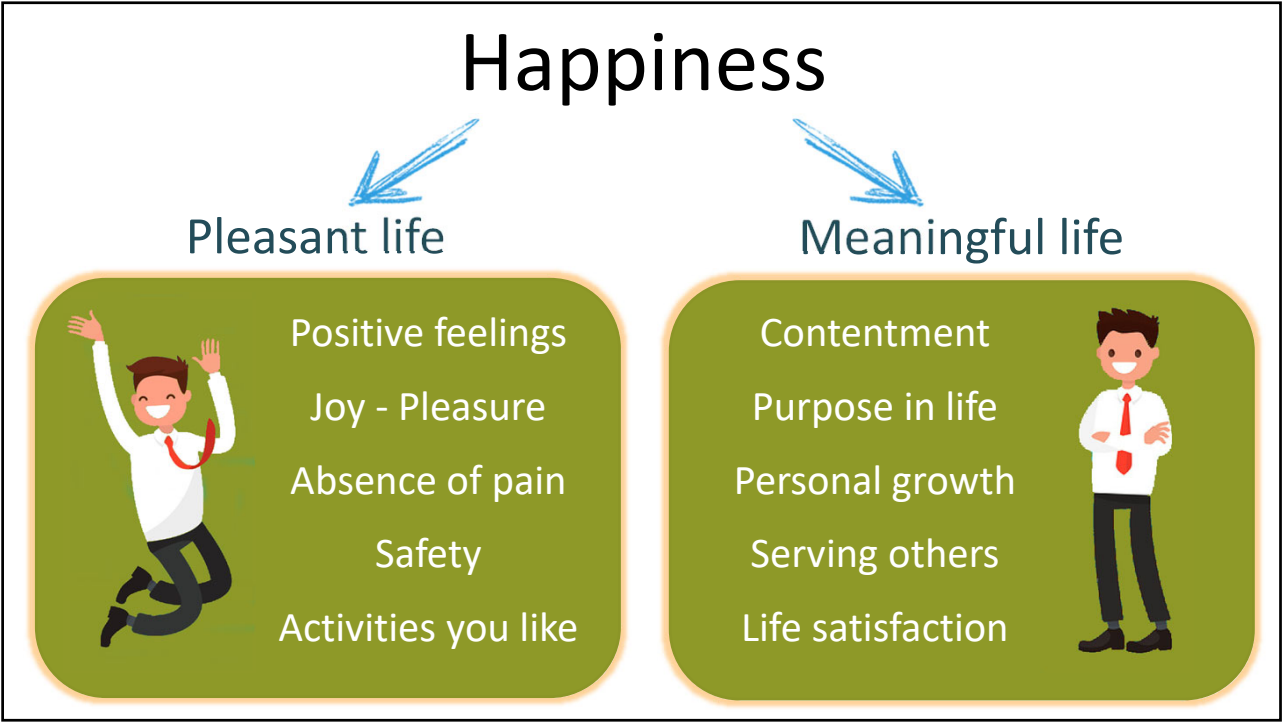
Not less autistic, but “autistically happy”



28

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14




29



30


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

31

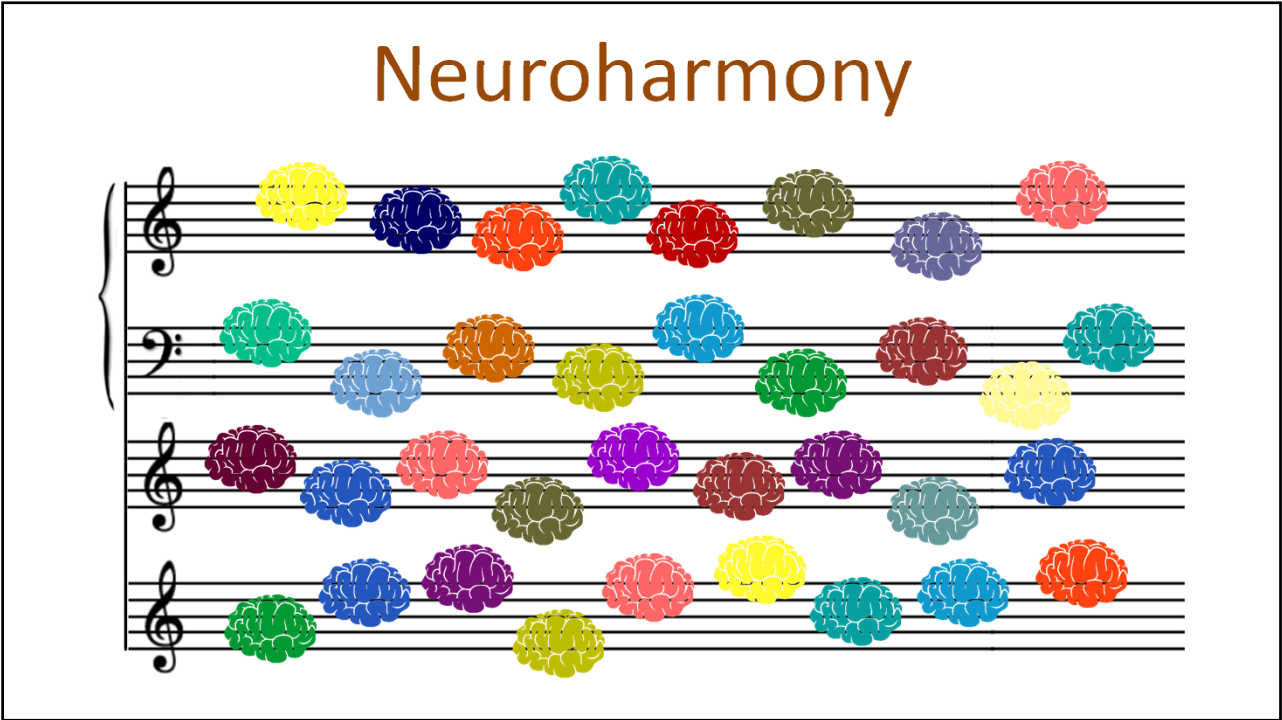
Meaningful and purposeful life



What can society offer to autistic people?

What can autistic people offer to society?

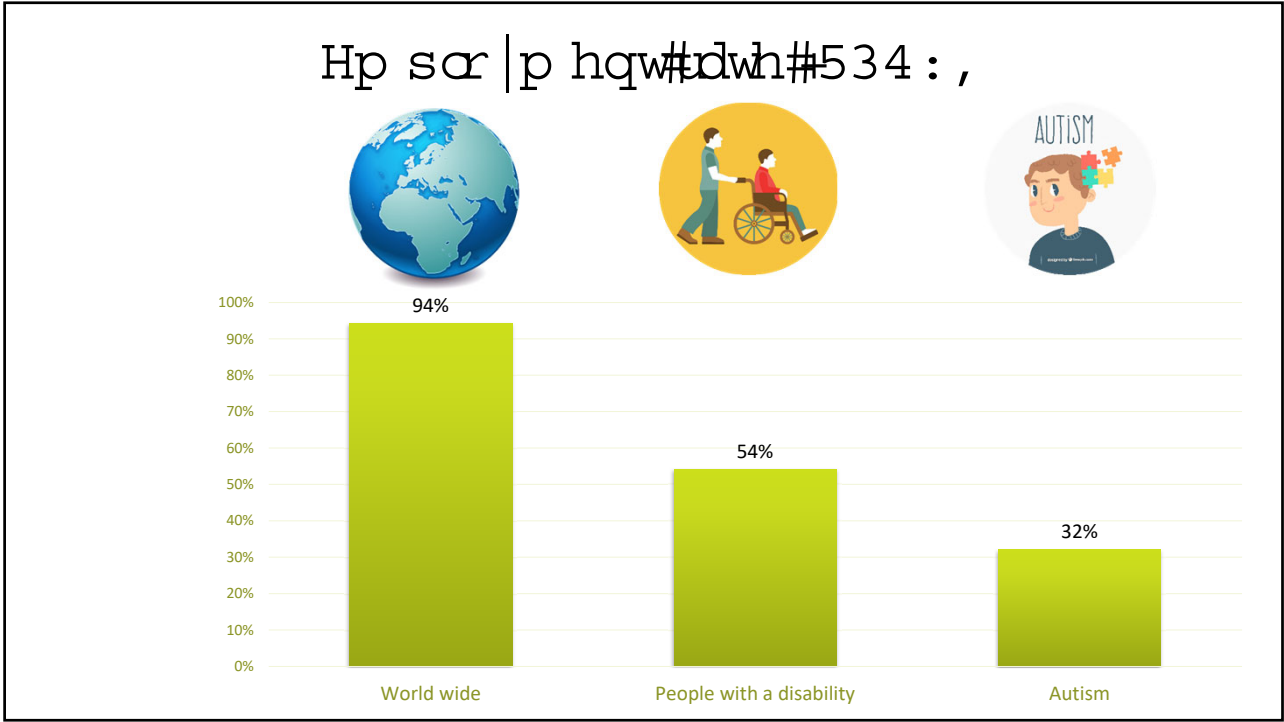
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34



35

Helen McConachie

David Mason

Employment is a predictor of QoL

RESEARCH ARTICLE

Predictors of Quality of Life for Autistic Adults

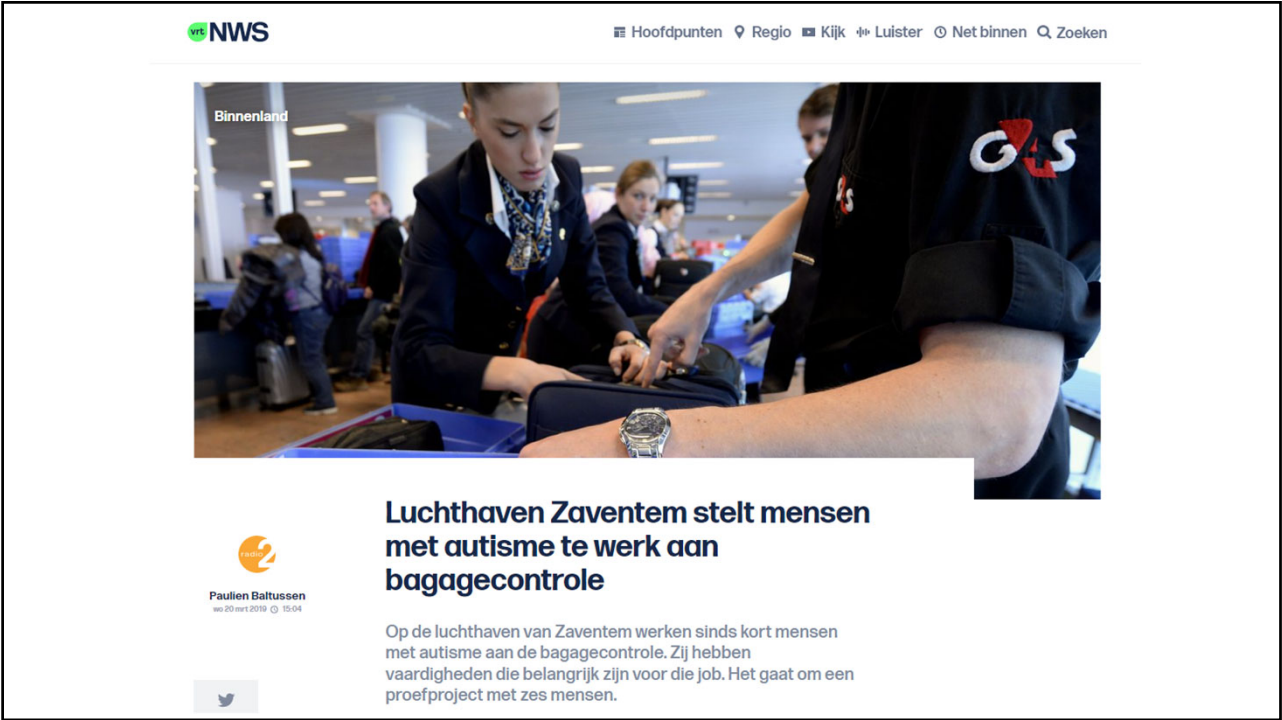
David Mason, Helen McConachie, Deborah Garland, Alex Petrou, Jacqui Rodgers, and Jeremy R. Parr

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.

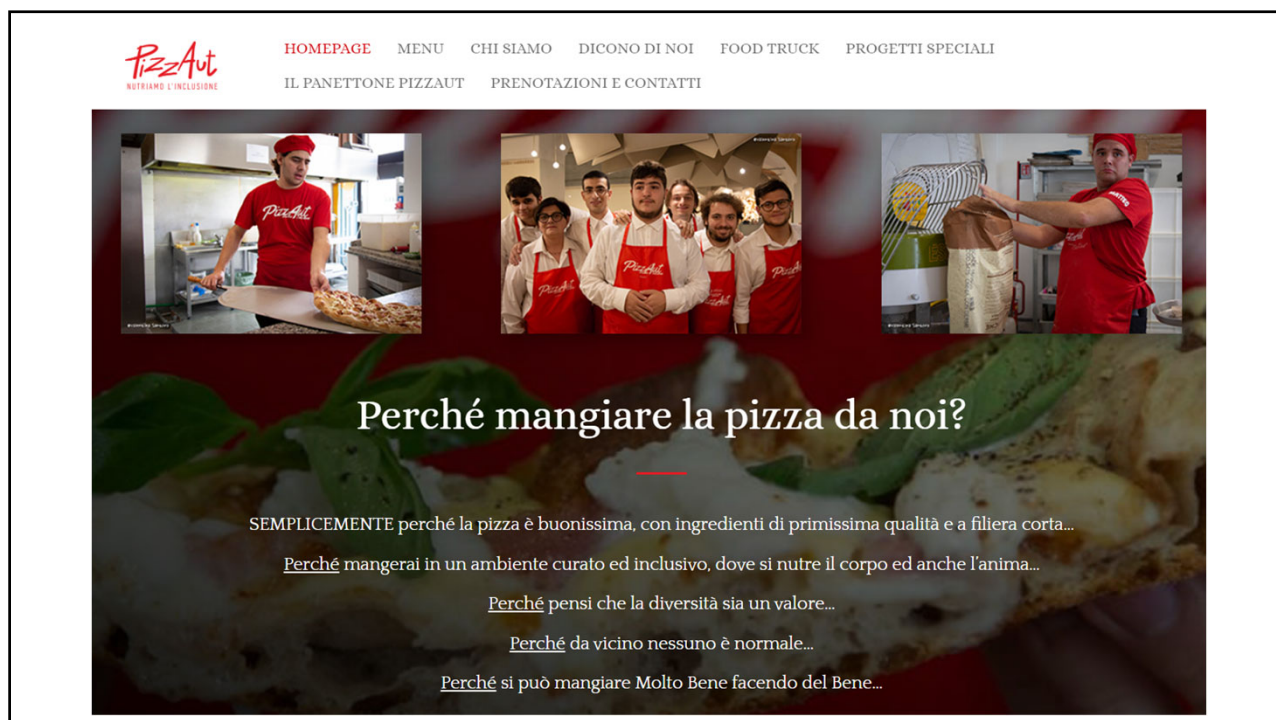
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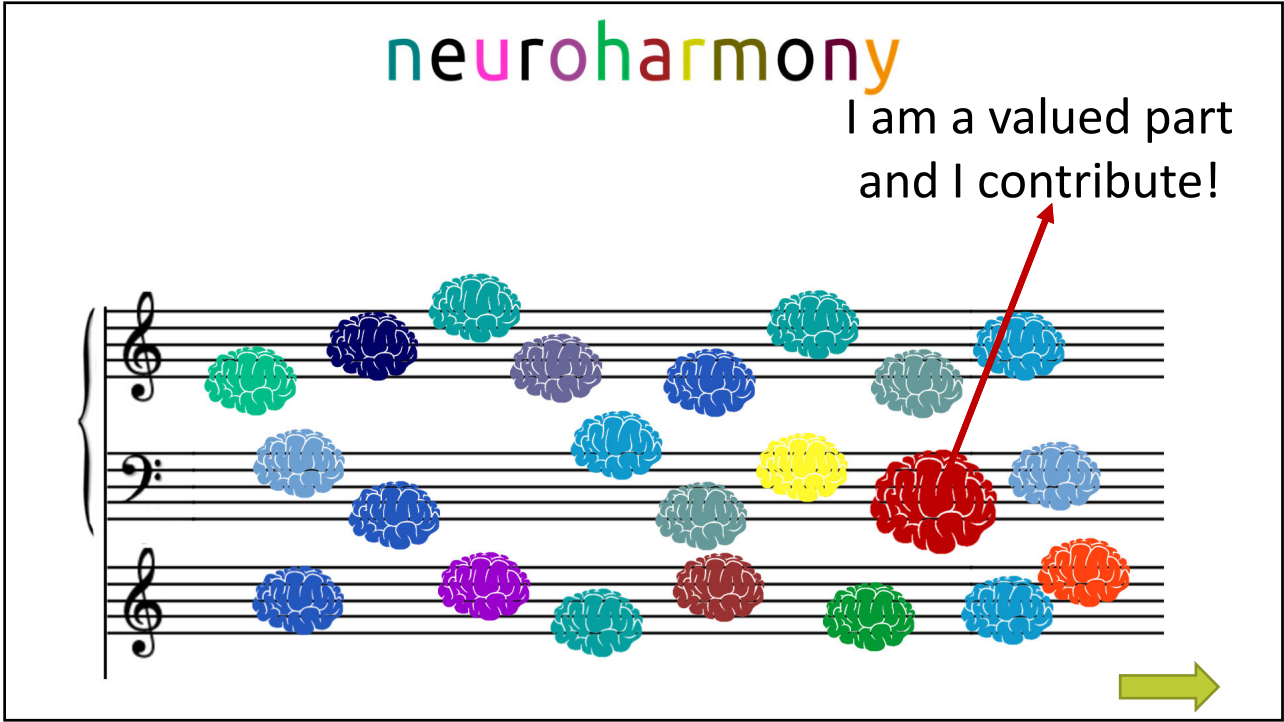


39

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
- ...

40



41

THANK YOU
FOR YOUR ATTENTION!



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42