

La felicidad en el autismo: ¿misión (im)posible?

Peter Vermeulen, PhD
Autisme Centraal

XVIII CONGRESO
AETAPI

SUMANDO
FORTALEZAS



17, 18 Y 19 NOV



Es hora de empezar a centrarse también en los parecidos, no solo en las diferencias

- Después de tantos años de centrarnos en las diferencias entre las personas neurotípicas y las autistas, tenemos que empezar a ver qué tienen en común todas estas personas
- De la neurodiversidad a la neuroarmonía

¿Qué tal les va a las personas con autismo en la vida?

Criterios aplicados en estudios de resultados:

Empleo

Relaciones/amigos

Salud

Funcionamiento cognitivo

Situación residencial

Síntomas de autismo

Fallos de los estudios de resultados

Los criterios objetivos no dicen gran cosa sobre la
calidad de vida...

Así que deberíamos añadir el criterio subjetivo del
bienestar

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

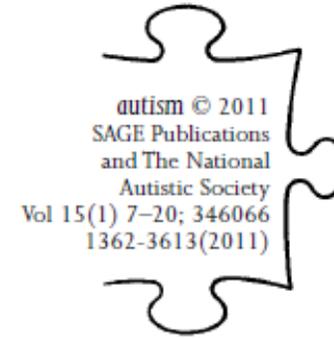
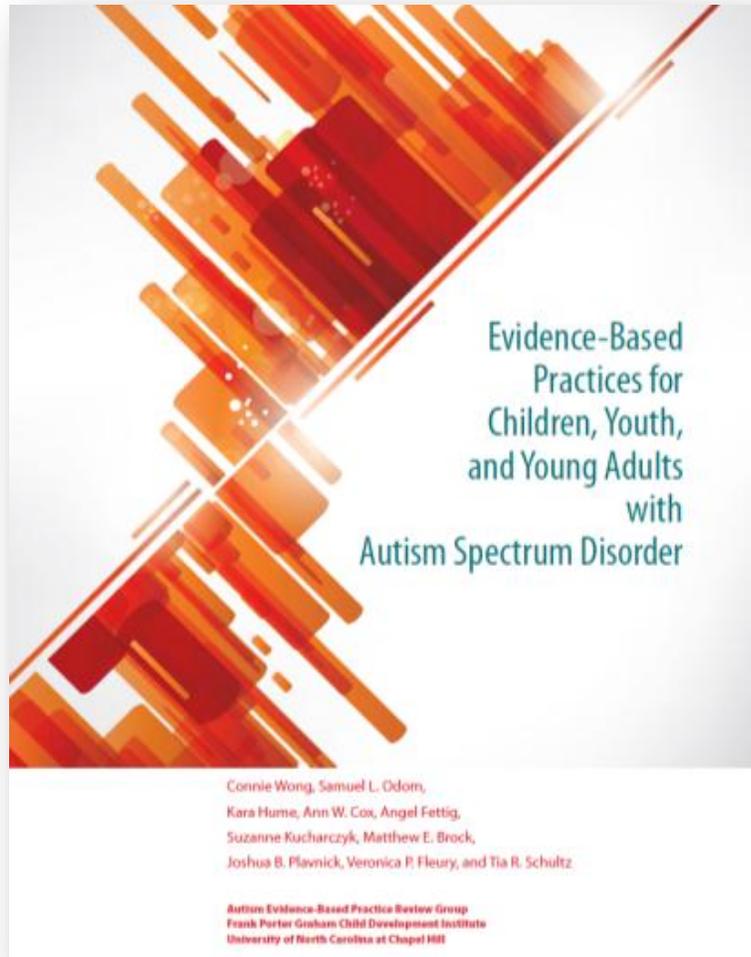


Table 2 Parent's/carer's estimation of the situation for their daughter/son/relative with **ASD** in aspects of quality of life/residential well being

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.

Demasiada poca atención en el bienestar



Resultados relacionados con	Estudios (N = 456)
Comunicación Capacidad de expresar deseos, necesidades, opciones, sentimientos o ideas	182 (39,9%)
Social Habilidades necesarias para interactuar con los demás	165 (36,2%)
Comportamientos retadores/que interfieren Reducir o eliminar los comportamientos que interfieren con la persona	158 (34,6%)
Juego Uso de juguetes o material de ocio	77 (16,9%)
Habilidades preparatorias para la escolarización Rendimiento en una tarea no directamente relacionado con el contenido de la tarea	67 (14,7%)
Preacadémico/Académico Rendimiento en tareas que suelen enseñarse y emplearse en un entorno escolar	58 (12,7%)
Adaptativo/Autoayuda Habilidades de vida independiente y de cuidado personal	57 (12,5%)
Atención conjunta Comportamientos necesarios para compartir intereses y/o experiencias	39 (8,6%)
Motor Movimiento, incluyendo habilidades motrices finas y gruesas , o relacionadas con el sistema/funcionamiento sensorial	18 (3,9%)
Cognitivo Rendimiento en medidas de inteligencia, función ejecutiva, resolución de problemas, razonamiento, teoría de la mente, memoria, creatividad o atención	15 (3,3%)
Profesional Empleo o preparación para el empleo o relacionar con las habilidades técnicas necesarias para un trabajo específico	12 (2,6%)
Salud mental Bienestar emocional	1 (0,2%)

Problemas de salud mental en el autismo

Prevalencia a lo largo de la vida

J Autism Dev Disord (2006) 36:849–861
DOI 10.1007/s10803-006-0123-0

ORIGINAL PAPER

Comorbid Psychiatric Disorders in Children with Autism: Interview Development and Rates of Disorders

Ovsanna T. Leyfer · Susan E. Folstein ·
Susan Bacalman · Naomi O. Davis · Elena Dinh ·
Jubel Morgan · Helen Tager-Flusberg ·
Janet E. Lainhart

BMC Psychiatry



Research article

Open Access

Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders

Björn Hofvander*¹, Richard Delorme^{2,7}, Pauline Chaste^{2,7}, Agneta Nydén³,
Elisabet Wentz^{3,4}, Ola Ståhlberg⁵, Evelyn Herbrecht^{2,6,7}, Astrid Stopin²,
Henrik Anckarsäter^{1,2,5}, Christopher Gillberg³, Maria Råstam⁸ and
Marion Leboyer^{2,6,7,9}

	TEA	Desarrollo típico
Trastorno ansiedad	10-65%	15-20%
Depresión	10-55%	10-30%

Así que nos centramos sobre todo en sentimientos negativos

The Development of a Stress Survey Schedule for Persons with Autism and Other Developmental Disabilities

June Groden,^{1,5} Amy Diller,¹ Margaret Bausman,¹ Wayne Velicer,² Gregory Norman,³ and Joseph Cautela⁴

The Stress Survey Schedule is an instrument for measuring stress in the lives of persons with autism and other developmental disabilities. Development of the survey and analysis of the underlying measurement structure of the instrument is reported in three studies. Through the use of exploratory and confirmatory analysis procedures, eight dimensions of stress were identified: Anticipation/Uncertainty, Changes and Threats, Unpleasant Events, Pleasant Events, Sensory/Personal Contact, Food Related Activity, Social/Environmental Interactions, and Ritual Related Stress. These stress dimensions are highly relevant to the problems of autism and have not been addressed by other stress surveys. The information obtained from the Stress Survey can be used to plan for strategies to reduce the stress before it occurs or results in maladaptive behavior.

KEY WORDS: Autism; stress survey.

Research in Autism Spectrum Disorders 5 (2011) 377–387

Contents lists available at ScienceDirect

 Research in Autism Spectrum Disorders

Journal homepage: <http://ees.elsevier.com/RASD/default.asp>



Anxiety in people diagnosed with autism and intellectual disability: Recognition and phenomenology

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ABSTRACT

Anxiety seems to occur frequently in individuals with autism, but varying prevalence estimates indicate uncertainties in identifying anxiety, especially in those with intellectual disability (ID). The present study explores the recognition of anxiety symptoms and aims to provide suggestions for the assessment of anxiety in individuals with autism and ID.

Two separate samples, a community sample of 62 individuals and a clinical sample of 9 individuals, were assessed with anxiety items from a screening checklist. Each item's scores were analyzed. In addition, in the clinical sample, checklist results were compared with clinical assessments.

The results indicate that anxiety can be recognized by symptoms similar to those in non-autistic individuals, but signs of physiological arousal seem difficult to recognize in this population. The results imply inclusion of general adjustment problems in order to identify individuals with anxiety problems by using a checklist. For diagnostic purposes, the use of an individual anxiety assessment seems indicated.

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Felicidad



Vida agradable

Sentimientos positivos

Alegría - placer

Ausencia de dolor

Seguridad

Actividades que te gustan



Vida con sentido

Satisfacción

Propósito en la vida

Crecimiento personal

Servicio a los demás

Satisfacción vital

¿Por qué centrarse en el bienestar?

- El bienestar subjetivo es menor en las personas autistas
- Los sentimientos positivos desencadenan un círculo virtuoso hacia el bienestar emocional (Fredrickson & Joner, 2002)
- Lleva a mejores resultados en muchos campos de la vida: empleo, salud, relaciones sociales (Lyubomirsky et al., 2005)

Calidad de vida en TEA

Calidad de vida subjetiva y objetiva en 169 adultos con TEA (IQ > 70), edad 19-30.



Comprehensive Psychiatry

Volume 55, Issue 2, February 2014, Pages 302–310



Quality of life: A case-controlled long-term follow-up study, comparing young high-functioning adults with autism spectrum disorders with adults with other psychiatric disorders diagnosed in childhood

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Leo M.J. de Sonneville^{a,b}

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^cDepartment of Child and Adolescent Psychiatry, Rudolf Magnus Institute of Neuroscience, University Medical Centre Utrecht, Utrecht, The Netherlands

Fuente: Barneveld et al. (2014)

Situación residencial: TEA < contr

Trabajo/educación: TEA < contr

Condición física: TEA > contr

Relaciones sociales: TEA < contr

Perspectiva de futuro: TEA < contr

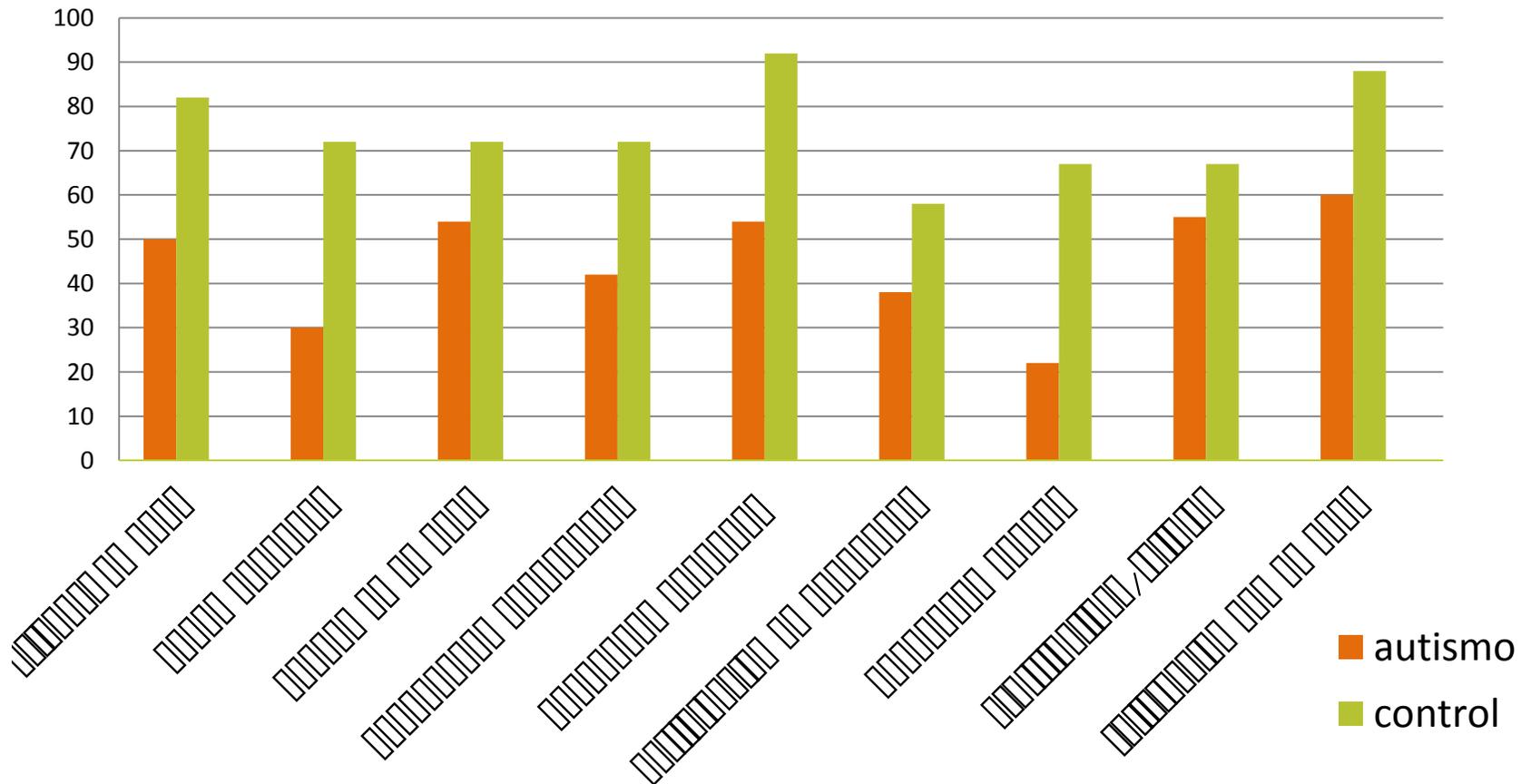
Grupo de control = adultos con otros trastornos psiquiátricos infantiles, como TDAH

Índice de bienestar personal (IBP) (Cummins et al; Deakin 2006)



Resultados IBP: comparación grupo de autismo RU vs. control

Grado de satisfacción con



Fuente: Richard Mills, 2016

CdV inferior para personas con autismo



Original Article

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

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

Autism

2015, Vol. 19(2) 158–167

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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.

¿Por qué centrarse en sentimientos positivos?

PSYCHOLOGICAL SCIENCE

Research Report

POSITIVE EMOTIONS TRIGGER UPWARD SPIRALS TOWARD EMOTIONAL WELL-BEING

Barbara L. Fredrickson¹ and Thomas Joiner² 2002

¹University of Michigan and ²Florida State University

- Relación entre sentimientos negativos y *centrarse en detalles* + *rigidez de pensamiento*
- Los sentimientos positivos aumentan
 - Funcionamiento cognitivo
 - Flexibilidad - Adaptabilidad



Las personas más felices tienen más éxito en la vida

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

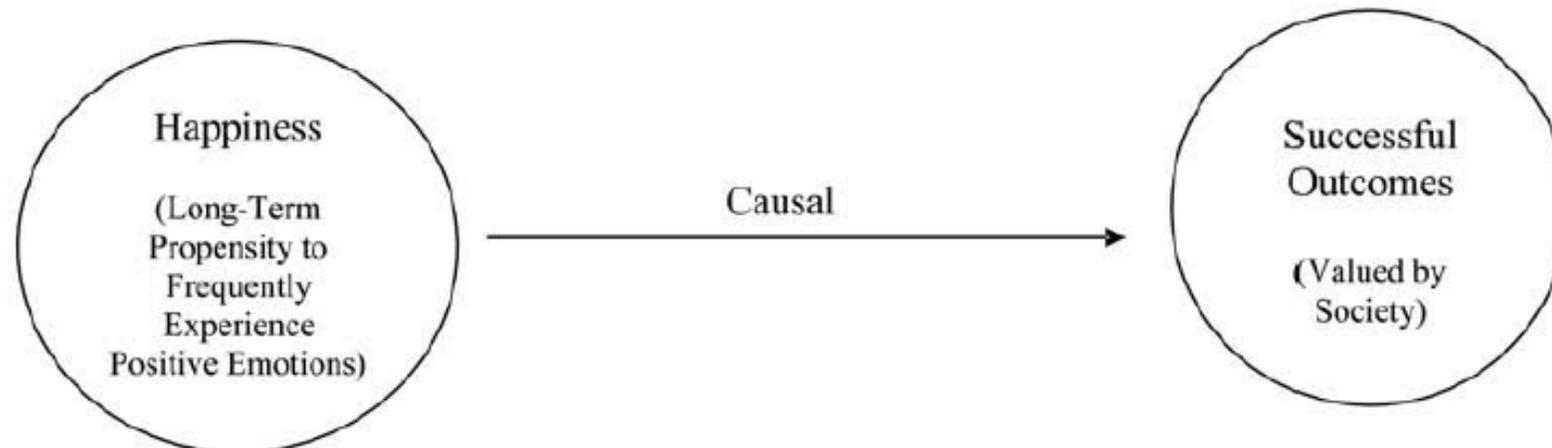
Copyright 2005 by the American Psychological Association
0033-2909/05/\$12.00 DOI: 10.1037/0033-2909.131.6.803

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



**No menos autistas,
pero
“autísticamente felices”**

Evaluación del bienestar

- Evitar proyecciones neurotípicas
- Evitar estereotipos sobre el autismo

ASÍ QUE... ¡PREGÚNTALE A LA GENTE!

Hay herramientas

The Satisfaction with Life Scale

By Ed Diener, Ph.D.

DIRECTIONS: Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item by placing the appropriate number in the line preceding that item. Please be open and honest in your responding.

- 1 = Strongly Disagree
- 2 = Disagree
- 3 = Slightly Disagree
- 4 = Neither Agree or Disagree
- 5 = Slightly Agree
- 6 = Agree
- 7 = Strongly Agree

- _____ 1. In most ways my life is close to my ideal.
- _____ 2. The conditions of my life are excellent.
- _____ 3. I am satisfied with life.
- _____ 4. So far I have gotten the important things I want in life.
- _____ 5. If I could live my life over, I would change almost nothing.

WHO (Five) Well-Being Index (1998 version)

Please indicate for each of the five statements which is closest to how you have been feeling over the last two weeks. Notice that higher numbers mean better well-being.

Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, put a tick in the box with the number 3 in the upper right corner.

	<i>Over the last two weeks</i>	All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
1	I have felt cheerful and in good spirits	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
2	I have felt calm and relaxed	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
3	I have felt active and vigorous	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
4	I woke up feeling fresh and rested	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
5	My daily life has been filled with things that interest me	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0

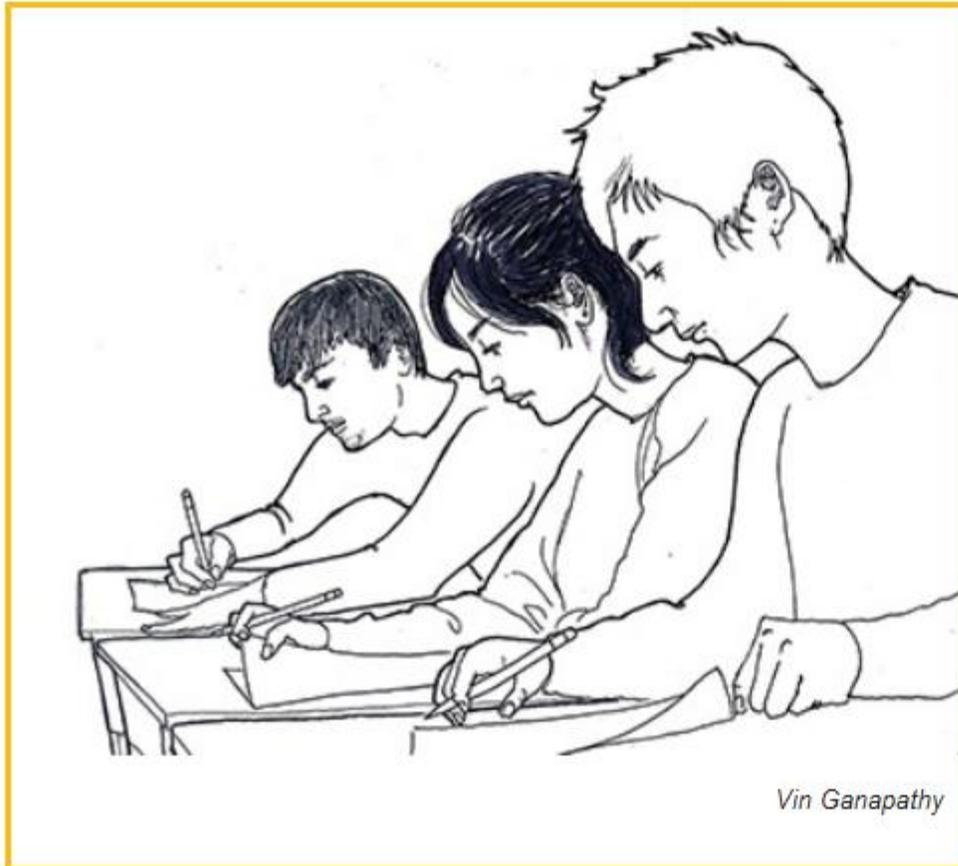
Cuidado con los autoinformes

Researchers dispute value of self-reports for autism traits

Nicholette Zeliadt

18 March 2014

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Several self-report surveys allow adults in the general population to assess any traits of autism they may have, such as difficulties with social interactions or communication. In the past decade, it has become commonplace for researchers to rely on these tests to measure autism symptoms in research participants.

A new study challenging the validity of these questionnaires has touched off a debate, with the developers of one test saying the researchers misused it.

The study, published 17 December in *the Journal of Autism and Developmental Disorders*, suggests that some self-administered questionnaires for adults don't distinguish between traits of autism and conditions that often co-occur with the disorder.

[Takeshi Nishiyama](#) and his colleagues at the Aichi Medical University in Japan compared the reliability

Teoría de la mente

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graph TD; A[Teoría de la mente] --> B[La "mente" de los demás]; A --> C[Tu propia "mente"];
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La “mente” de los demás

Tu propia “mente”

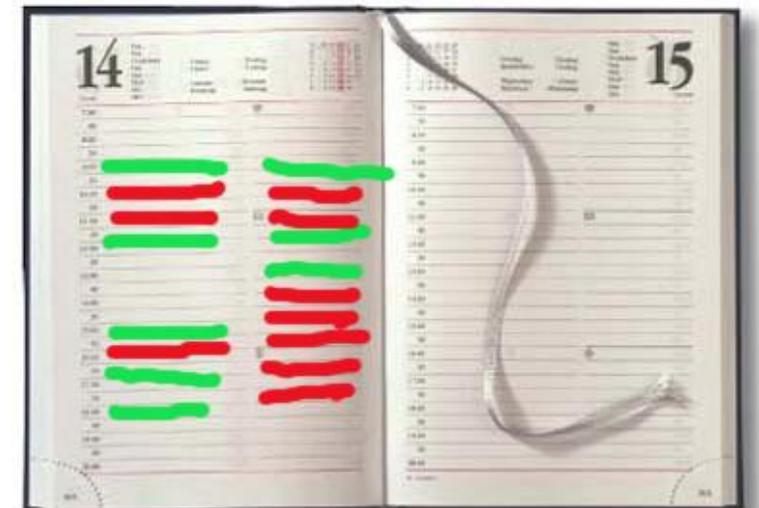
Si a las personas con TEA les resulta difícil pensar en la mente de los demás, debe resultarles igual de difícil pensar en sus propios estados mentales.

Teoría de tu propia mente

A las personas con autismo puede resultarles más difícil entender sus propias ideas que las de los demás. (Williams & Happé, 2010)

Evaluación de la felicidad adaptada al autismo

- Hacer concretos los conceptos abstractos
- Usar palabras concretas y no ambiguas
- Visualizar



¿Qué hace que la gente se sienta bien?

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 Questionnaire

The questionnaire contains items referring to all sorts of things that can give a person a good feeling. Obviously, each person is different. What gives a good feeling to one person, can be very unpleasant for another person. Below, you can indicate the extent to which things or events give you a good feeling. For each category of items, there is place to add things that are not mentioned in the list.

Each 'item' can be scored as follows:

- 3: This gives me a good feeling** - I enjoy this very much
- 2: This gives me a good feeling** - I enjoy this
- 1: This gives me a little bit of good feeling** - I enjoy this a little
- 0: This does not give me a good feeling** - I don't enjoy this in particular (neutral, I feel nothing) or I even find this unpleasant
- ?: I do not know if this gives me a good feeling**

Obviously this list is not exhaustive. Therefore, there is room left to add things that make you feel good or that you enjoy.

Sensory aspects

	3	2	1	0	?
Certain light, namely: ..					
Certain sounds, namely: ..					
A certain kind of voice, namely: ..					
Silence					
Certain smells, namely: ..					
Certain tactile stimuli, namely: ..					
Being touched					
Being cuddled					
Being kissed					
Heat					
Cold					
Certain foods, namely: ..					
Certain beverages, namely:					
Certain items that I like to touch, namely: ..					
Certain weather conditions (please specify:.....)					
A fleece blanket around me					

Evaluación de la felicidad y el bienestar en el autismo

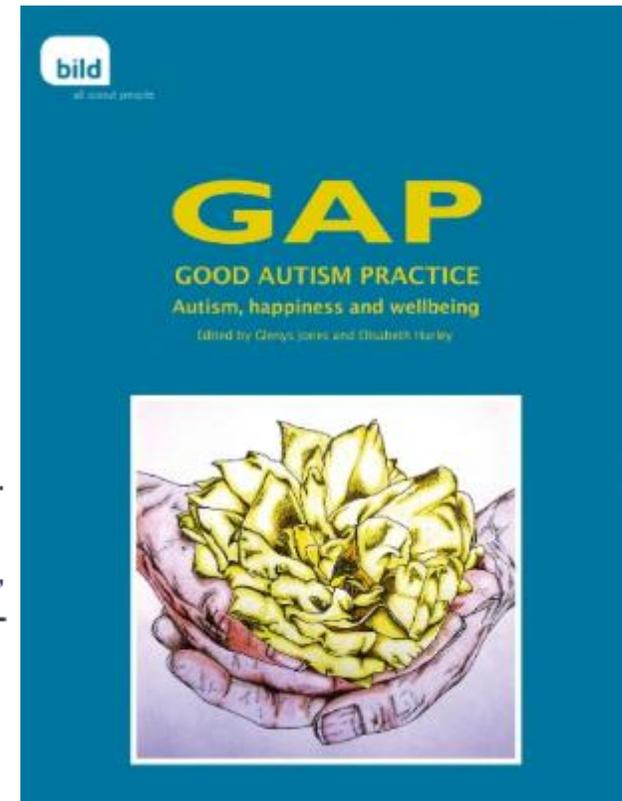
The practice of promoting happiness in autism

The practice of promoting happiness in autism

Peter Vermeulen, Autisme Centraal, Gent, Belgium

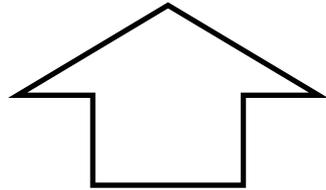
Editorial comment

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

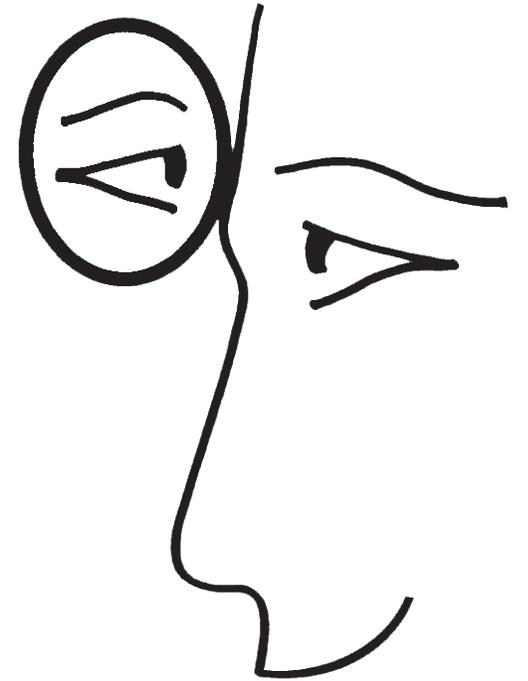


Entorno adecuado para el autismo

Bienestar



Adecuación al autismo



No es lo mismo que evitar dificultades y obstáculos
Se trata de ayudar a las personas con autismo a
enfrentarse a las dificultades y superar los obstáculos

Bienestar: cuestión de equilibrio



IJW

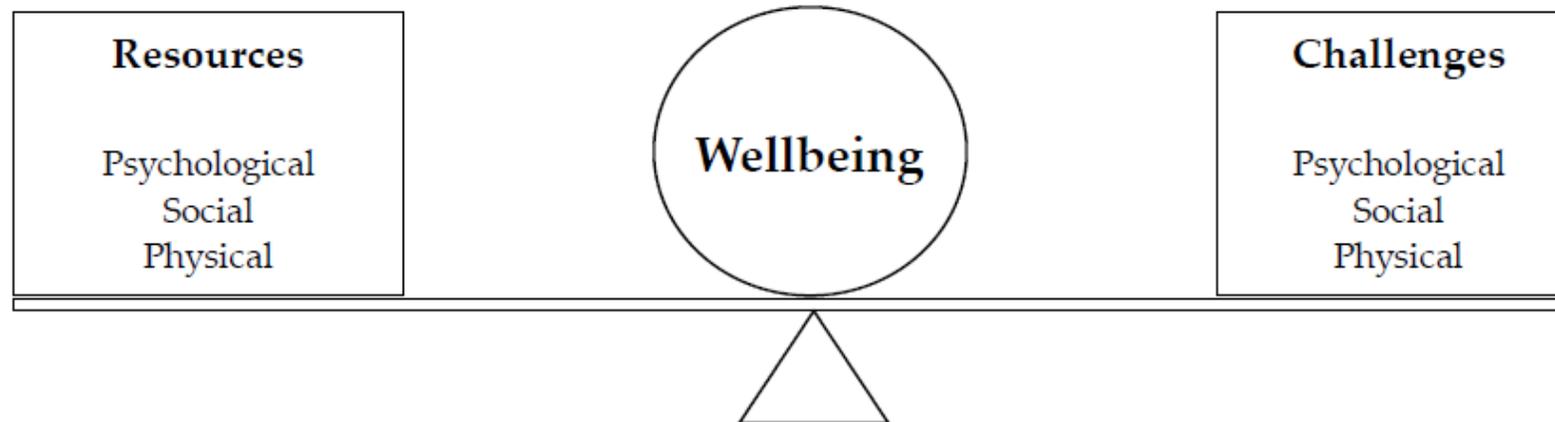
Dodge, R., Daly, A., Huyton, J., & Sanders, L. (2012). The challenge of defining wellbeing. *International Journal of Wellbeing*, 2(3), 222-235. doi:10.5502/ijw.v2i3.4

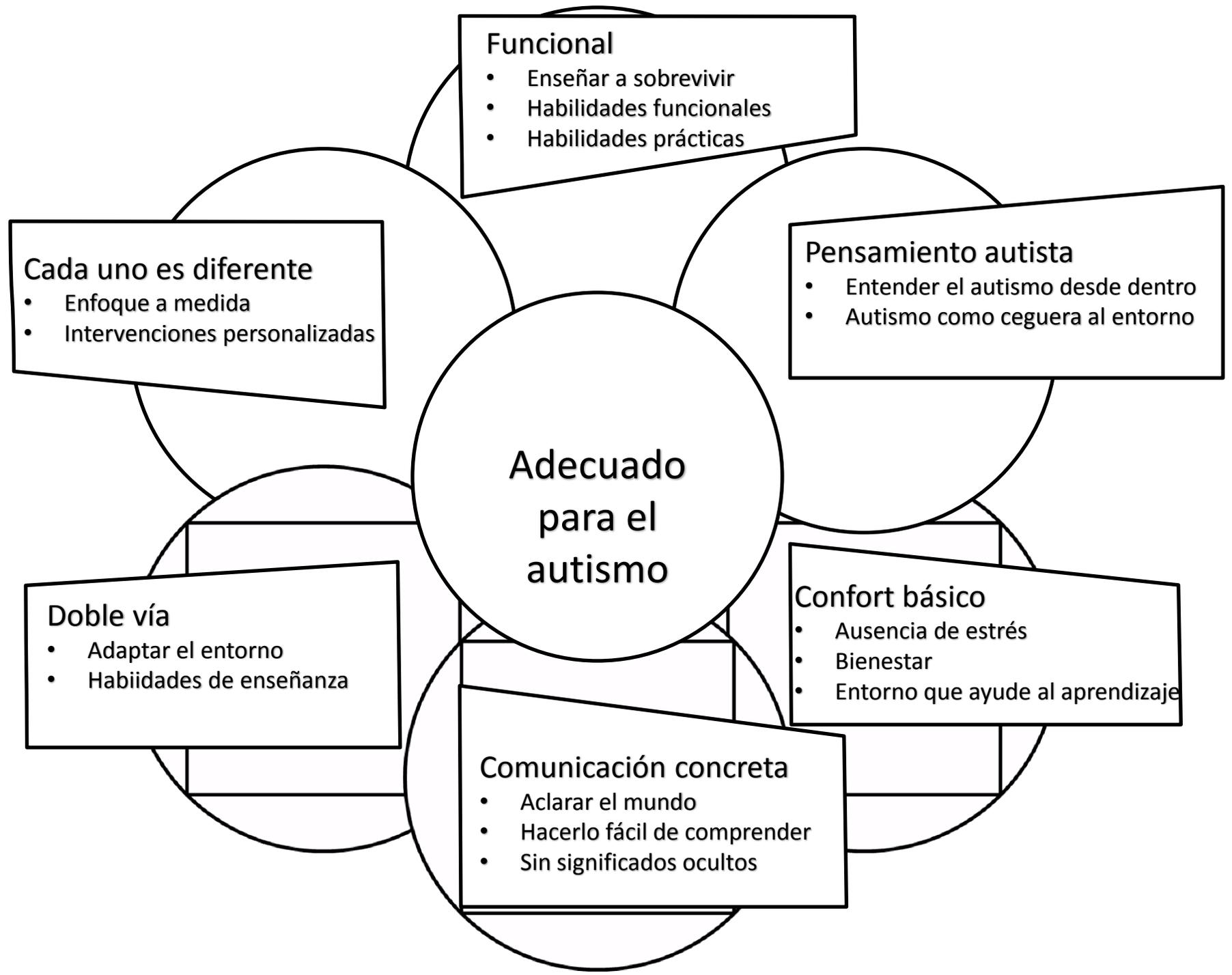
ARTICLE

The challenge of defining wellbeing

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

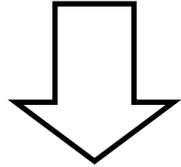
Figure 4. Definition of Wellbeing





Enfoque de doble vía

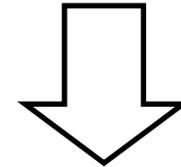
Sociedad



Cambiar el entorno

Adaptar

Persona autista



Cambiar la persona

Enseñar

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

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A pesar de las dificultades con el funcionamiento en la vida diaria, muchos parecen poder enfrentarse a la adversidad y los desafíos

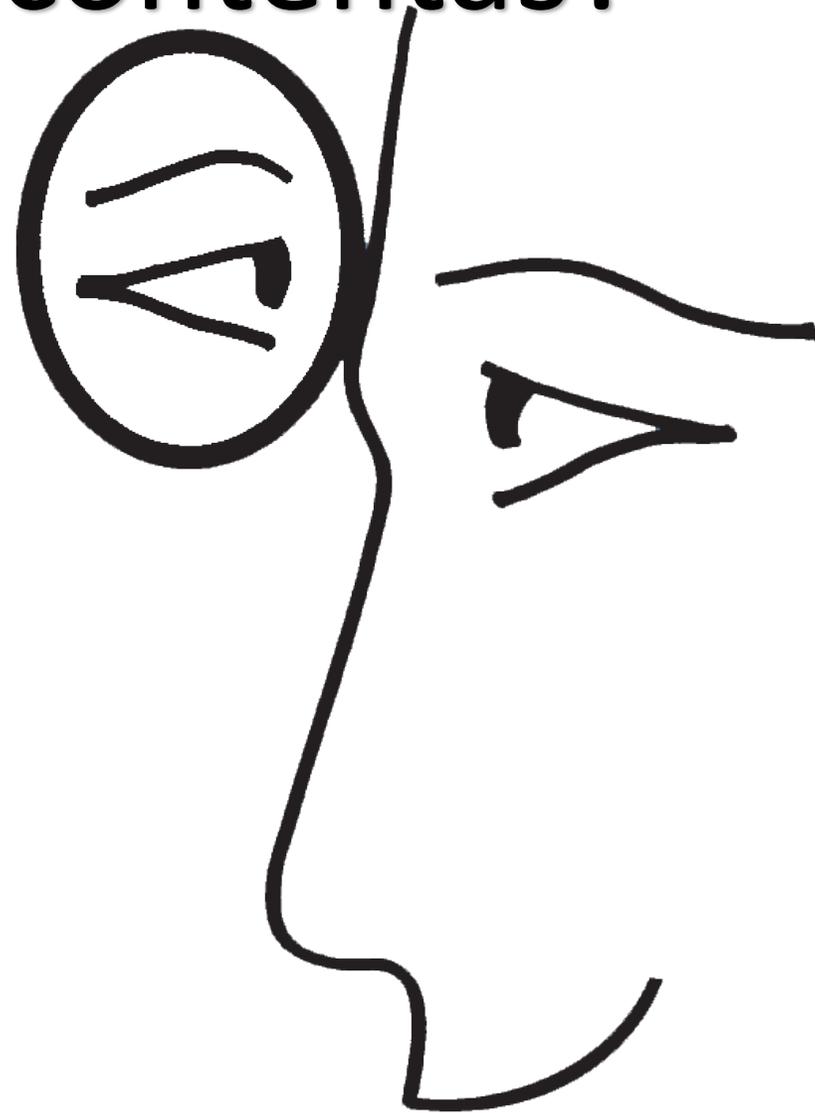
Intentar evitar el desvalimiento aprendido (Martin Seligman)

No evitar los desafíos, dar control y hacer que los desafíos se adapten al autismo

¿Quieres que las personas con autismo estén contentas?

Adáptate al autismo:
Empieza por la
claridad y la
predictabilidad.

Todo lo demás, va
después



Trabajar el sentirse bien

- Relajación
- TCC (y otras terapias)
- Plena conciencia
(Mindfulness)

Autismo y bienestar: ¡trabaja la salud!

- Salud física:
 - Las actividades físicas bajan los niveles de cortisol y la ansiedad en las personas con autismo (Hillier e.a., 2010, Hillier e.a., 2011, Carraro & Gobi, 2012)
 - El deporte, igual de eficiente que los antidepresivos y la psicoterapia (Cooney et al., 2013, Cochrane review)
 - CdV relacionada con problemas de sueño en TEA (Delahaye et al., 2014)
 - Los problemas alimentarios son bastante habituales en TEA

Una vida buena y plena de significado

- **Adaptación al autismo:** ¿cómo podemos aportar placer y alegría a las vidas de las personas con autismo para hacerles felices?
(una vida buena)
- **Adaptación por parte de las personas autistas:** ¿qué pueden hacer las personas con autismo para hacer felices a los demás?
(una vida con significado) ¿Qué pueden ofrecer a la sociedad las personas con autismo?

Las personas con autismo tienen mucho que ofrecer

- Un trabajo: trabajar con sus puntos fuertes e intereses
- Enseñar: amabilidad y gratitud
- Hacer felices a los demás te hace feliz a ti
 - Ouweneel, Le Blanc, & Schaufeli (2014). On being grateful and kind: results of two randomized controlled trials on study-related emotions and academic engagement. *J. of Psychology*, 148(1):37-60.
 - Otake, et al. (2006). Happy people become happier through kindness: A counting kindnesses intervention. *Journal of Happiness Studies*, 7(3), 361–375.

El empleo puede ser terapéutico

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**

El empleo puede llevar a mejoras en los síntomas del autismo y mejora el bienestar y la calidad de vida

¡GRACIAS
POR SU ATENCIÓN!



www.autisme.be



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

