

*Neurodiversity and autism: some
ethical aspects and their relevance
for (oral/dental) health care*

Pier Jaarsma PhD



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Pier Jaarsma



Senior Lecturer

My research area is the ethics of prioritization/resource allocation concerning autism spectrum disorder. My teaching duties mainly concern nursing.


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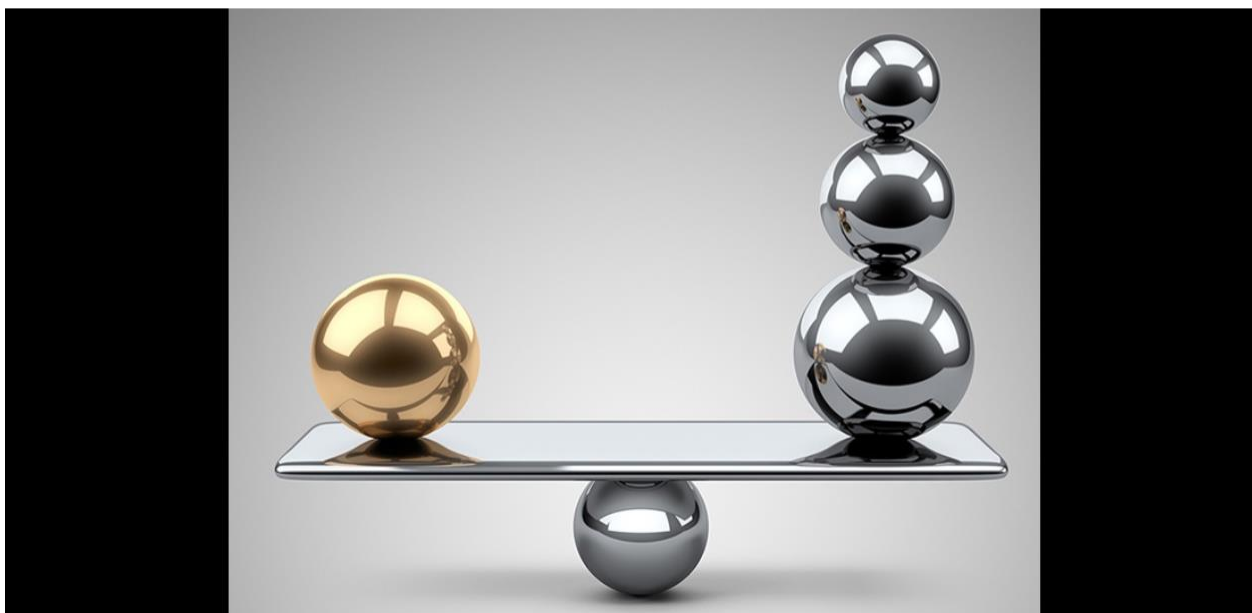
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-  Division of Health Care Analysis (HSA)

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Care has limited resources - how should they be fairly distributed?



*Medium-Range Narratives as a
Complementary Tool to Principle-Based
Prioritization in Sweden: Test Case
“ADHD”*

Pier Jaarsma & Petra Gelhaus

Journal of Bioethical Inquiry
An interdisciplinary forum for ethical
and legal debate

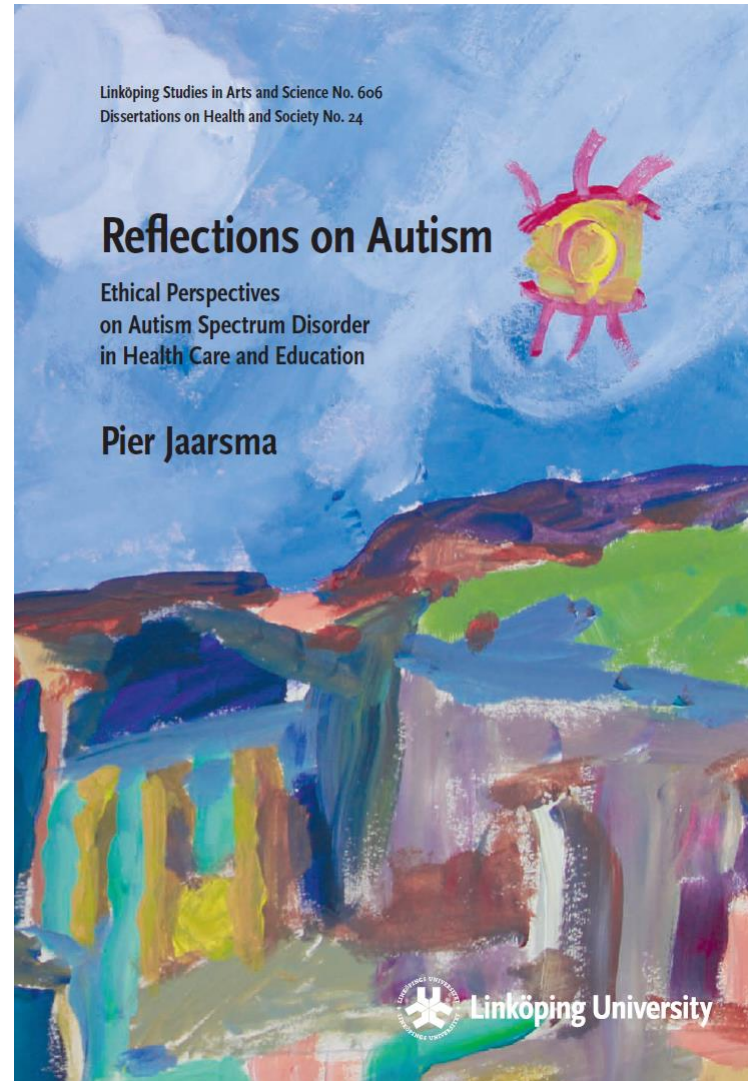
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Reflections on Autism

Ethical Perspectives
on Autism Spectrum Disorder
in Health Care and Education

Pier Jaarsma



Linköping University



Health Care Analysis
All Volumes & Issues

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In this issue (6 articles)

Original Paper

[Enacting Ethics: Bottom-up Involvement in Implementing Moral Case Deliberation](#)

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Original Article

[Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement](#)

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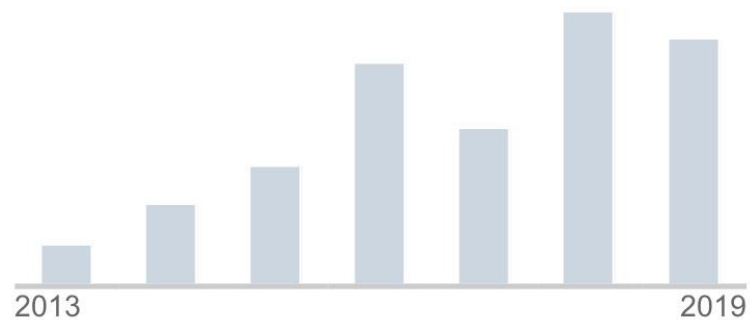
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CITATIONS PER YEAR



Aim of this presentation

- neurodiversity
- moral responsibility
- autists
- neurodiversity movement
- Asperger's syndrome
- high-functioning autism

What is autism?

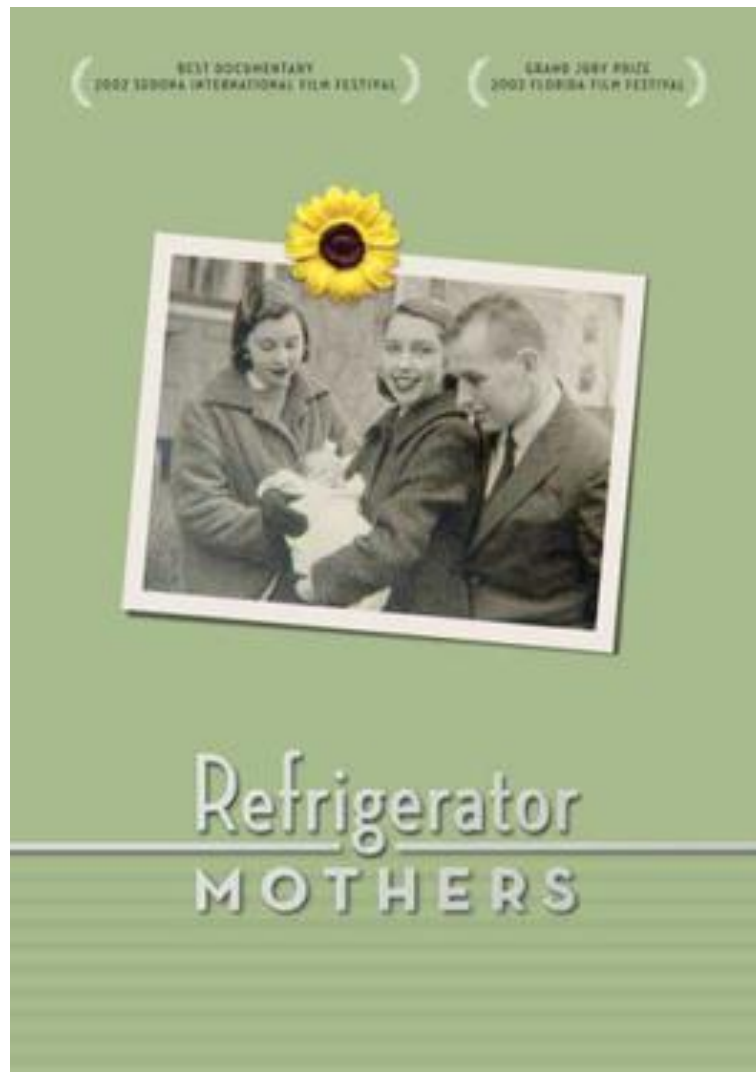
- Leo Kanner :
- autistic aloneness
- obsession with routine
- profound problems with communication



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Impairments in autism

- Social
- Communicative
- Imaginative



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Unusual sensory processing

- in relation to
 - sound
 - vision
 - touch
 - taste
 - smell
- hyper- and hyposensitivity
- general sensory overload
 - (Crane, Goddard and Pring 2009)

THE PREVALENCE OF AUTISM

- USA
 - 1 in 88 (2012)
 - 1 in 59 (now)
- Worldwide
 - About 1 in 100

overrepresentation
of males is 5.5:1

Causes of higher prevalence

- changes in diagnostic practices
- public and expert awareness
- availability of professional help'
 - (Bölte and Hallmayer, 2011)

PSYCHIATRY OF AUTISM (BEHAVIORAL LEVEL)

- DSM-IV-TR (2000)
 - Autistic Disorder
 - (3 criteria: 1,2,3)
 - Asperger's Disorder
 - (6 criteria: A to F)
- DSM-5 (2013)
 - Autism Spectrum Disorder
 - (5 criteria: A to E)



Early Second Trimester Maternal Serum Steroid-Related Biomarkers Associated with Autism Spectrum Disorder

Deborah A. Bilder^{1,5} · M. Sean Esplin^{1,2} · Hilary Coon¹ · Paul Burghardt³ · Erin A. S. Clark¹ · Alison Fraser^{1,4} · Ken R. Smith^{1,4} · Whitney Worsham¹ · Katlin Chappelle³ · Thomas Rayner¹ · Amanda V. Bakian¹

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Autism Spectrum Disorder in DSM-5

- Persistent deficits in social communication and social interaction across multiple contexts
- Restricted, repetitive patterns of behavior, interests, or activities
- Symptoms must be present in the early developmental period
- Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning
- These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay
 - (American Psychiatric Association, 2013)

PSYCHOLOGY OF AUTISM (COGNITIVE LEVEL)

- Theory of mind
- Weak executive function
- Weak central coherence
- Empathizing-systemizing theory



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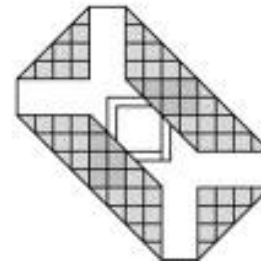
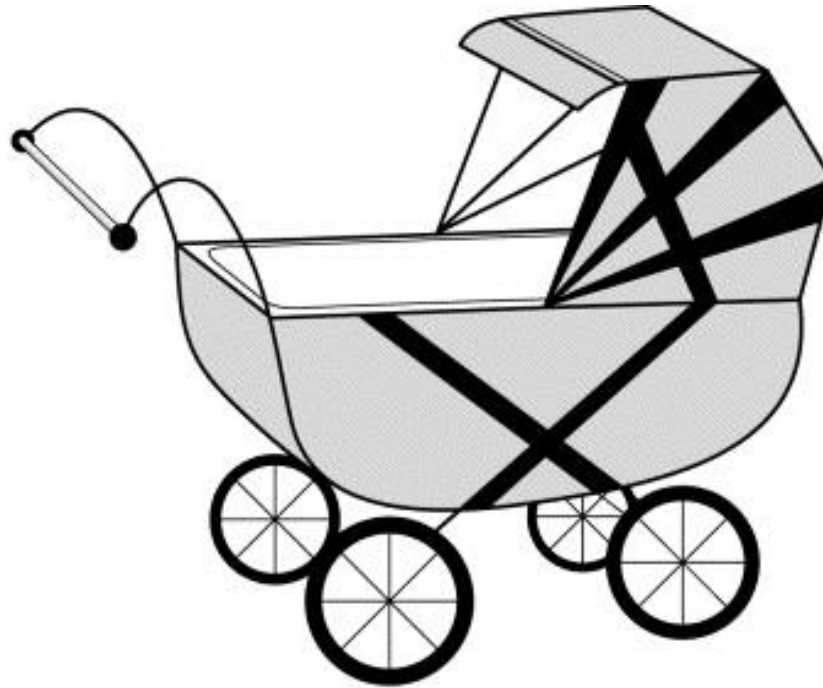




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Central coherence

- not merely parts, but wholes
- draw together details so as to recognize the meaning of the entire picture



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Empathizing-Systemizing theory of Autism

- delays and deficits in empathizing
- intact or even superior skill in systemizing
 - (Baron-Cohen, 2008)

Systemizing

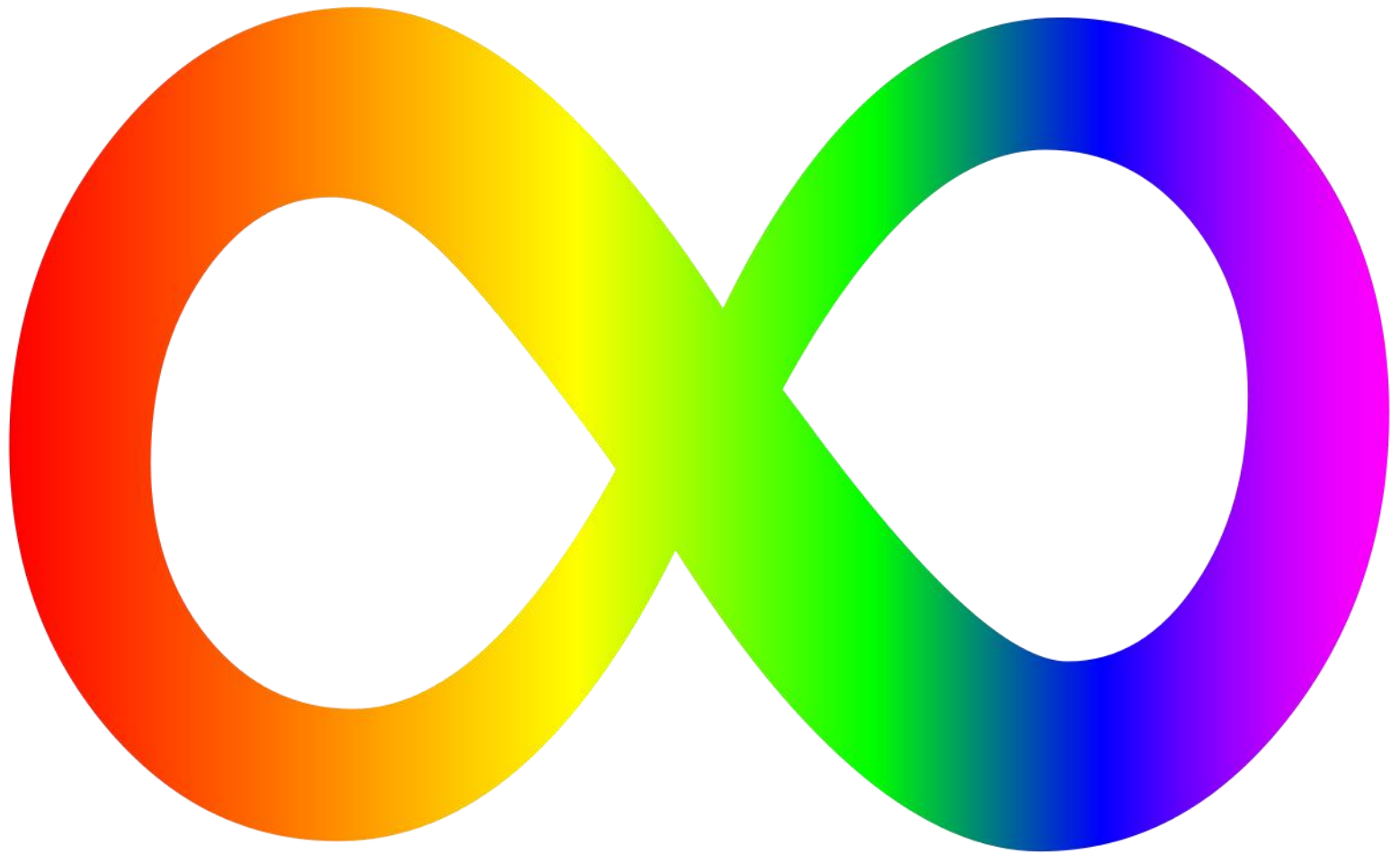
- Numerical
- Sensory
- Collectible
- Moral
- Natural
 - (Baron-Cohen, 2008)

Extreme male brain theory of autism

- Type S: systemizing better than empathizing
 - Extreme Type S: autistic persons
- Type E: empathizing better than systemizing
- Type B: empathizing is as good as systemizing
 - (Baron-Cohen, 2008)

Deficit in autistic persons

- researched
- classified
- modified



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Neurodiversity

- “In its broadest sense the concept of neurodiversity defines atypical neurological development as a normal human difference that should be tolerated and respected in the same way as other human differences” (Griffin, 2009).

Neurodiversity

- ASD
- ADHD
- developmental dyspraxia
- Dyslexia
- Tourette's syndrome

Neurodiversity claim

- Autism is not a disease to be treated and, if possible, cured, but rather a human specificity (like sex or race) that must be equally respected.
 - not a pathology or a handicap but a normal or natural variation.
 - rights and value to the neurodiverse condition of autism

Autism as a normal (natural) variation

- Normal variation:
 - Evaluative sense
 - Statistical sense
 - 1 in 59
 - » (U.S.A.)
 - 1 in 100
 - » (Worldwide)
 - Evolutionary explanation?

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 - Evolutionary explanation?
- Caused by:
 - (a) specific gene(s)?
 - environmental factors?
 - a combination of (a) gene(s) and environmental factors?

https://www.historyofvaccines.org/content/articles/do-vaccines-cause-autism

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- Vaccine-Preventable Diseases 
- Common Questions 
- Do Vaccines Cause Autism?**
- Have I Been Vaccinated?
- Misconceptions about

Do Vaccines Cause Autism?

Autism rates in developing countries have risen remarkably in the past 20 years. For children born in 1992, according to the U.S. CDC, about 1 in 150 would be diagnosed with an autism spectrum disorder (ASD). For children born in 2004, about 1 in 68 children would receive an



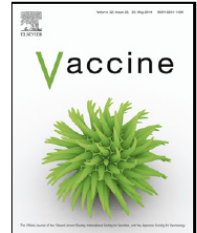


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Contents lists available at [ScienceDirect](#)

Vaccine

journal homepage: www.elsevier.com/locate/vaccine



Vaccines are not associated with autism: An evidence-based meta-analysis of case-control and cohort studies



Luke E. Taylor, Amy L. Swerdfeger, Guy D. Eslick*

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Autism as a normal (natural) variation

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Autism aetiology



Autism

Meng-Chuan Lai, Michael V Lombardo, Simon Baron-Cohen

Lancet 2014; 383: 896–910

Published Online

September 26, 2013

[http://dx.doi.org/10.1016/](http://dx.doi.org/10.1016/S0140-6736(13)61539-1)

S0140-6736(13)61539-1

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Department of Psychiatry,
College of Medicine, National
Taiwan University, Taipei,

Autism is a set of heterogeneous neurodevelopmental conditions, characterised by early-onset difficulties in social communication and unusually restricted, repetitive behaviour and interests. The worldwide population prevalence is about 1%. Autism affects more male than female individuals, and comorbidity is common (>70% have concurrent conditions). Individuals with autism have atypical cognitive profiles, such as impaired social cognition and social perception, executive dysfunction, and atypical perceptual and information processing. These profiles are underpinned by atypical neural development at the systems level. Genetics has a key role in the aetiology of autism, in conjunction with developmentally early environmental factors. Large-effect rare mutations and small-effect common variants contribute to risk. Assessment needs to be multidisciplinary and developmental, and early detection is essential for early intervention. Early comprehensive and targeted behavioural interventions can improve social communication and reduce anxiety and aggression. Drugs can reduce comorbid symptoms, but do not directly improve social communication. Creation of a supportive environment that accepts and respects that the individual is different is crucial.

Autism as a normal (natural) variation

- Normal variation:
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Psychiatric pathology?

- gay rights movement
- no longer a psychiatric disorder
- consequences
- not etiology



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AUTISM- PHOBIA

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Temple Grandin

- “When I was in high school being teased by the other kids, I was miserable. [...] High functioning teenagers on the spectrum often get bullied in high school”



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Premature mortality in autism spectrum disorder

Tatja Hirvikoski, Ellenor Mittendorfer-Rutz, Marcus Boman, Henrik Larsson, Paul Lichtenstein and Sven Bölte

Background

Mortality has been suggested to be increased in autism spectrum disorder (ASD).

Aims

To examine both all-cause and cause-specific mortality in ASD, as well as investigate moderating role of gender and intellectual ability.

Method

Odds ratios (ORs) were calculated for a population-based cohort of ASD probands ($n=27\,122$, diagnosed between 1987 and 2009) compared with gender-, age- and county of residence-matched controls ($n=2\,672\,185$).

Results

During the observed period, 24 358 (0.91%) individuals in the

general population died, whereas the corresponding figure for individuals with ASD was 706 (2.60%; OR=2.56; 95% CI 2.38–2.76). Cause-specific analyses showed elevated mortality in ASD for almost all analysed diagnostic categories. Mortality and patterns for cause-specific mortality were partly moderated by gender and general intellectual ability.

Conclusions

Premature mortality was markedly increased in ASD owing to a multitude of medical conditions.

Declaration of interest

None.

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Autism spectrum disorder (ASD) is a chronic childhood-onset neurodevelopmental condition with detrimental effects on adaptive functions throughout life.^{1–3} The number of people with ASD diagnoses has increased during the last decades although the underlying reasons for this increase are not fully understood.⁴ Both clinical^{5,6} and population-based studies^{1,7} have reported

and causes of death in ASD remain unclear, and it has not been possible to determine whether ASD *per se* carries an increased mortality.¹⁵

Gender is another possible moderator of excess mortality in ASD. Relative to males, females with ASD have been reported to have an elevated mortality risk.^{15–20} However, there has been

Suicide

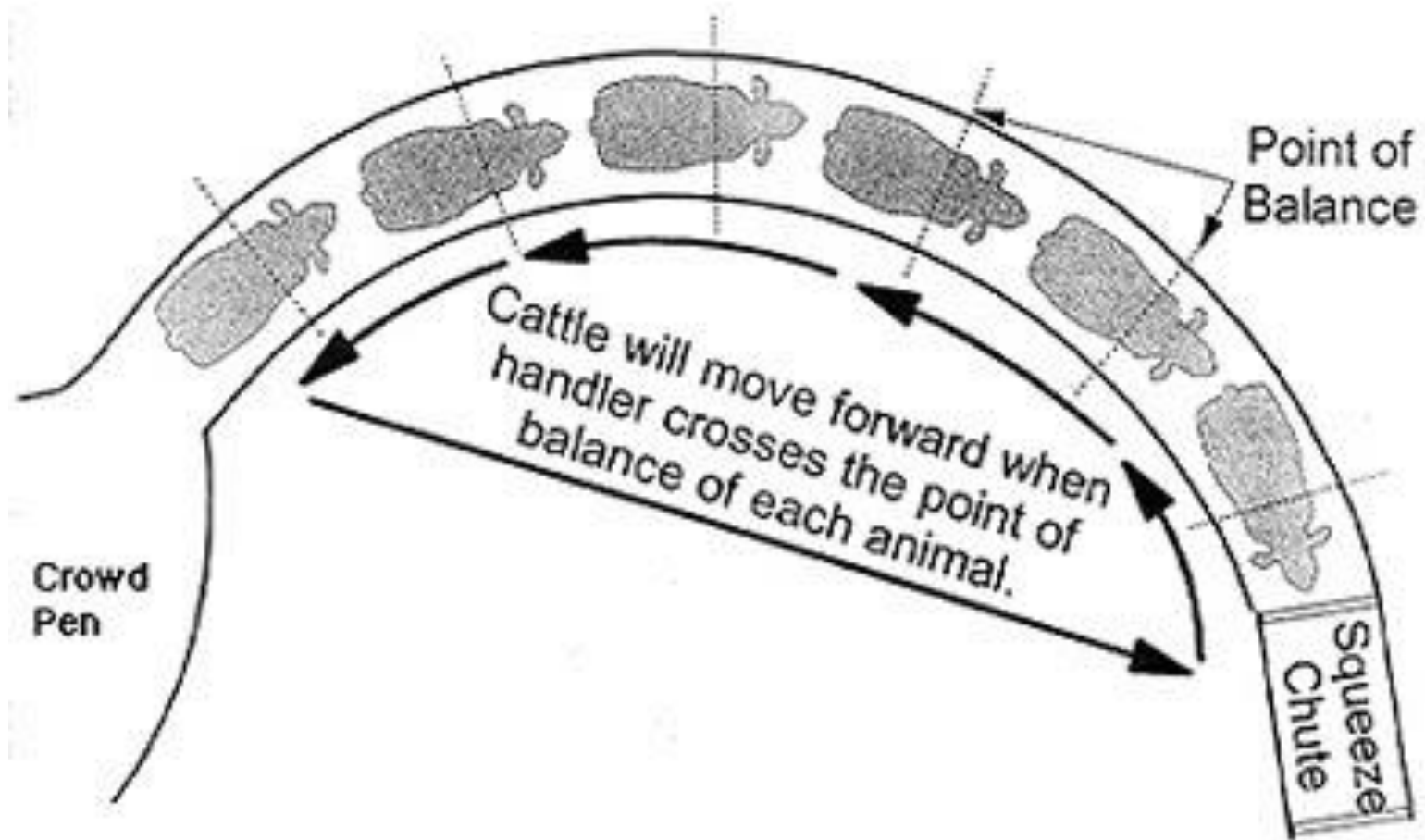
- Suicide
 - higher risk in high-functioning ASD compared with low-functioning ASD
- Psychological vulnerability: increases the risk of suicide
 - (Hirvikoski et al, 2016, p 236/237).”

Temple Grandin

- “In some ways, I credit my autism for enabling me to understand cattle. [...] I have been lucky, because my understanding of animals and visual thinking led me to a satisfying career in which my autistic traits don’t impede my progress.”



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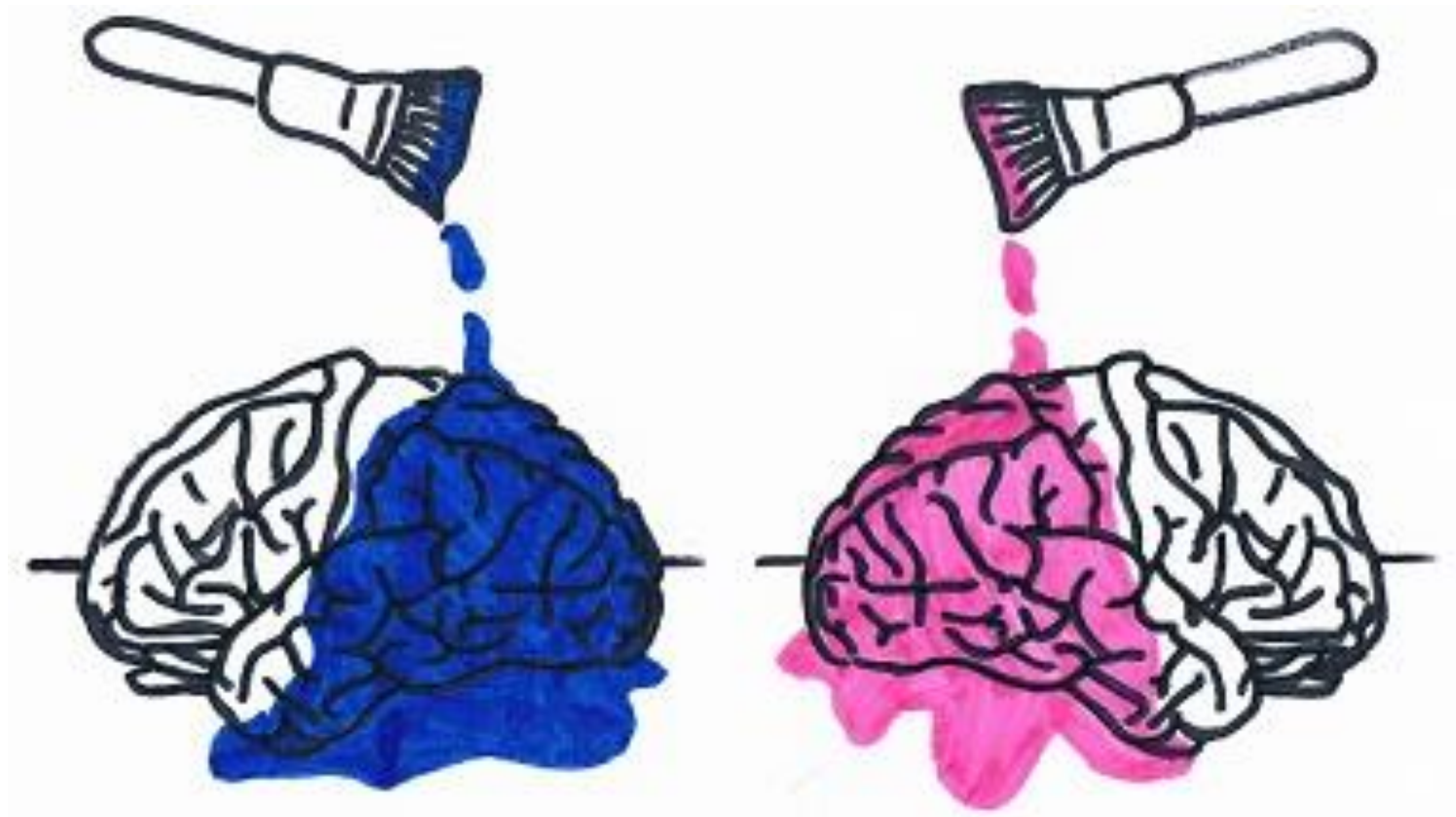


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“Those diagnosed with AS say they are happy with who they are and that any suffering they may have undergone has been the result of society and not inherent in their condition.”

Clarke, Juarne and Van Amerom, Gudrun(2008) 'Asperger's Syndrome', *Social Work in Health Care*, 46: 3, 85 — 106.

∨ EXTREME MALE BRAINS



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Simon Baron-Cohen

- “the empathy deficit of persons with mild autism can still be valued in a positive way because of the presence of a hypersystemizing ability in these persons”



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Compensating capabilities

- attending to *details*
- finding patterns
- not only intact systemizing but also accelerated or superior development in this domain
- scientific, especially mathematical skills
- creativity
 - perseverance, drive for perfection, disregard of social conventions and others' opinions

Worst case scenario: a world rid of autism



"It seems that for success in
science or art a dash of autism is essential."

Hans Asperger



Everybody has a right to a good life

**NFH Nordiskt möte
29-30 augusti 2019 på Marstrands Havshotell**

Alla har rätt till ett gott liv

Quality of life

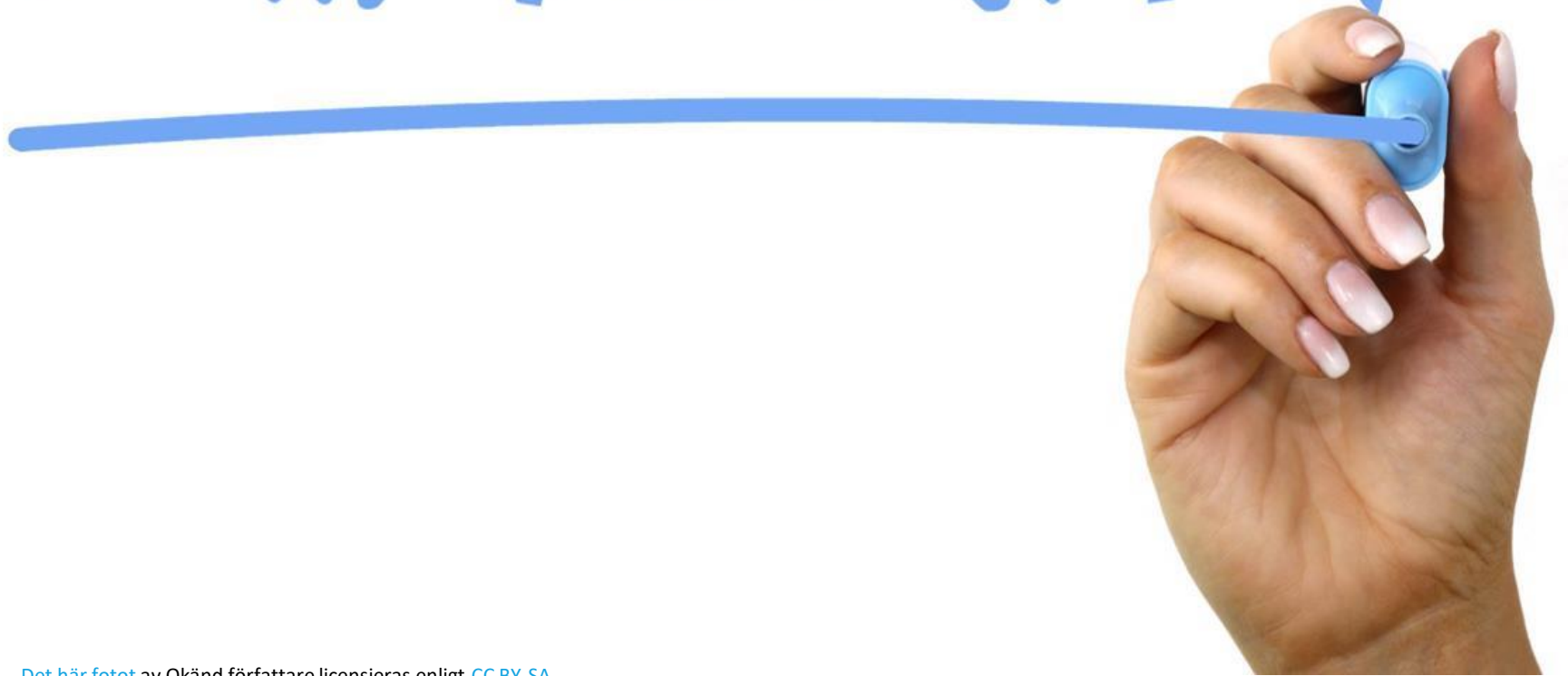
- ‘an individual’s perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns’ (WHO, 2011)

Quality of life

- ‘an individual’s perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns’ (WHO, 2011)
- ‘a concept that reflects a person’s desired conditions of living related to eight core dimensions of one’s life: emotional well-being, interpersonal relationships, well-being, personal development, physical well-being, self-determination, social inclusion, and rights’ (Graetz, 2010, p. 34).

- supportive social environment
- no socially constructed barriers
- autism-friendly set of social circumstances

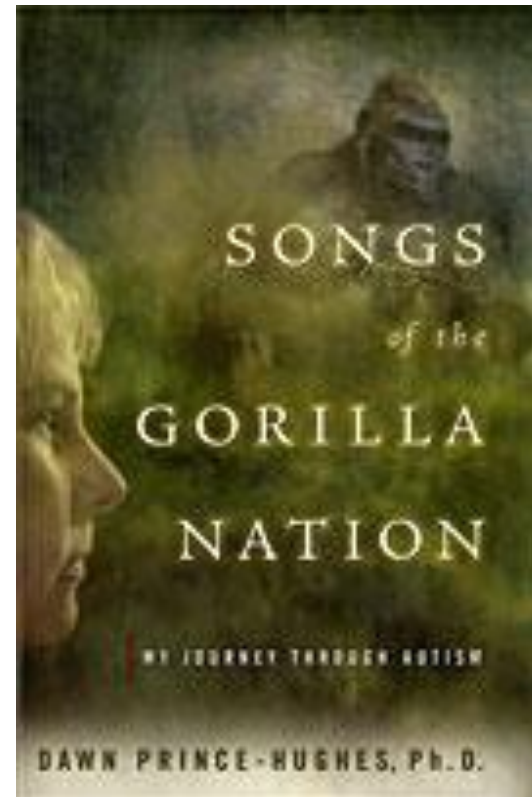
MINORITY



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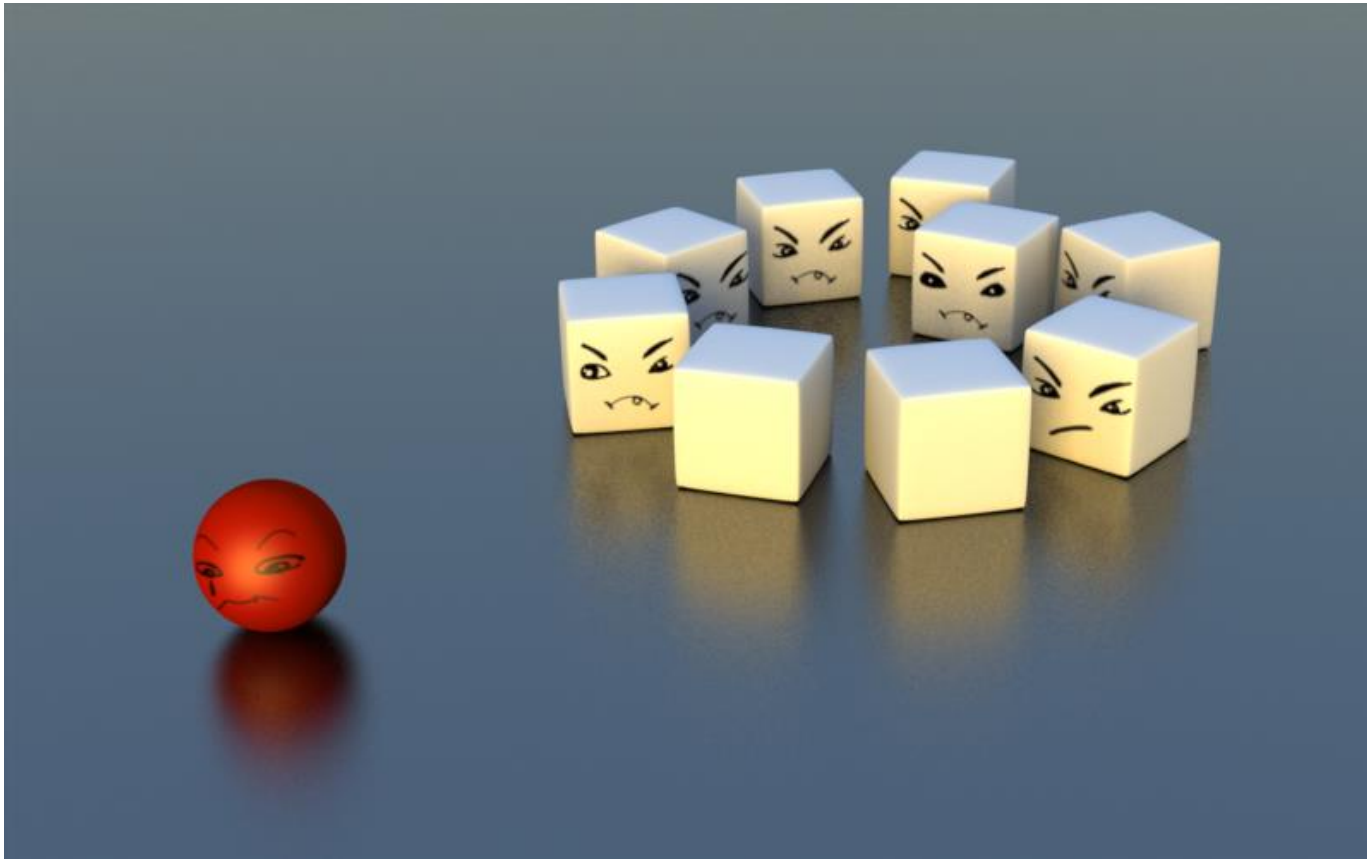
Dawn Prince-Hughes

- “much like the deaf community we autists are building an emergent culture. We individuals, with our cultures of one, are building a culture of many”.



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Discrimination, exclusion and social isolation



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Young adults with ASD

- less likely to live independently
- more likely to coreside parent or guardian
- often restricted lives
- difficulty with employment
- isolated from peers [...]”
 - Marsack and Perry (2018) *Research on Aging* 2018, Vol. 40(6) 535–557

Children with ASD

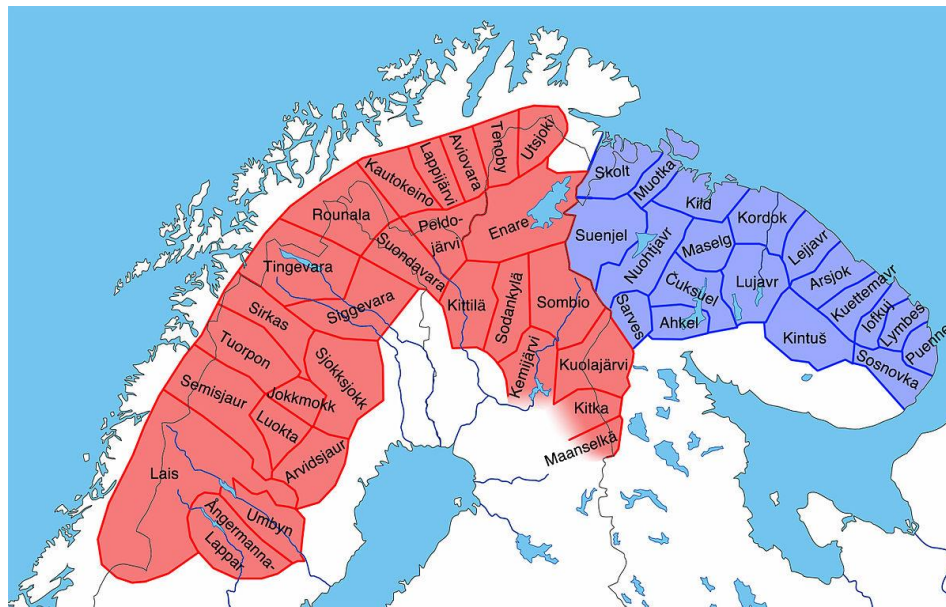
- more likely to be rejected
- less likely to be accepted
- greater levels of bullying
- lower levels of social support
- depression rates significantly higher
 - Trimmer et al (2017) *J Autism Dev Disord* 47:2326–2335, p. 2327

Social exclusion of autistic individuals

- increased experience of ostracism in this population
- both recognized and deeply felt by those with ASD
 - Trimmer et al (2017) *J Autism Dev Disord* 47:2326–2335, p. 2333

Group-specific rights

- “Group-specific rights for minorities are needed to ensure that all citizens are treated with genuine equality.”
- Kymlicka, W (1996) *Multicultural Citizenship - A Liberal Theory of Minority Rights*. Oxford: Oxford University Press.



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The Charter of Rights for Persons with Autism

Source: <https://www.disabled-world.com/health/neurology/autism/charter.php>

- The right of people with autism to live independent and full lives to the limit of their potential
- **The right of people with autism to an accessible, unbiased and accurate clinical diagnosis and assessment**
- The right of people with autism to accessible and appropriate education
- The right of people with autism (and their representatives) to be involved in all decisions affecting their future; the wishes of the individual must be, as far as possible, ascertained and respected
- The right of people with autism to accessible and suitable housing
- The right of people with autism to the equipment, assistance and support services necessary to live a fully productive life with dignity and independence
- The right of people with autism to an income or wage sufficient to provide adequate food, clothing, accommodation and the other necessities of life
- The right of people with autism to participate, as far as possible, in the development and management of services provided for their wellbeing
- **The right of people with autism to appropriate counseling and care for their physical, mental and spiritual health; this includes the provision of appropriate treatment and medication administered in the best interest of the individual with all protective measures taken**

The Charter of Rights for Persons with Autism (continued)

Source: <https://www.disabled-world.com/health/neurology/autism/charter.php>

- The right of people with autism to meaningful employment and vocational training without discrimination or stereotype; training and employment should have regard to the ability and choice of the individual
- The right of people with autism to accessible transport and freedom of movement
- The right of people with autism to participate in and benefit from culture, entertainment, recreation and sport
- The right of people with autism of equal access to and use of all facilities, services and activities in the community
- The right of people with autism to sexual and other relationships, including marriage, without exploitation or coercion
- The right of people with autism (and their representatives) to legal representation and assistance and to the full protection of all legal rights
- The right of people with autism to freedom from fear or threat of unwarranted incarceration in psychiatric hospitals or any other restrictive institution
- The right of people with autism to freedom from abusive physical treatment or neglect
- The right of people with autism to freedom from pharmacological abuse or misuse
- The right of access of people with autism (and their representatives) to all information contained in their personal, medical, psychological, psychiatric and educational records

Acceptance of neurodiversity by society

- High functioning autists
 - freed from the stigma of having a deficit
- Low functioning autists
 - may not get the care they need



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A natural and vulnerable human variation

- Vulnerability is something we all experience
- Vulnerabilities are grounds for moral responsibilities
- Moral responsibility to care for autistic persons based on autistic vulnerability

Conclusion

- Autism is not a disease to be treated, but rather a natural though vulnerable human variation that must be equally respected.

The logo features the words "Autistic" and "Proud" in large, colorful, 3D block letters. "Autistic" is in red, orange, yellow, green, blue, and purple. "Proud" is in blue, green, yellow, and orange. The word "and" is written in a smaller, black, cursive font between the two words.

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Oral health status of children and young adults with autism spectrum disorders: systematic review and meta-analysis

SILVANA NUNES DA SILVA¹, THAIS GIMENEZ^{1,2}, RAFAEL CELESTINO SOUZA³, ANNA CAROLINA VOLPI MELLO-MOURA¹, DANIELA PRÓCIDA RAGGIO², SUSANA MORIMOTO¹, JUAN SEBASTIAN LARA⁴, GIOVANA CORREIA SOARES¹ & TAMARA KERBER TEDESCO^{1,2}

¹Graduation Program, School of Dentistry, Ibirapuera University, Sao Paulo, Brazil, ²University of São Paulo, Sao Paulo, Brazil, ³Pediatric Dentistry for Special Need Patients Course, São Leolpodo Mandic College, Sao Paulo, Brazil, and ⁴Dental Health Unit, The University of Manchester, Manchester, UK

International Journal of Paediatric Dentistry 2017; 27: 388–398

evaluate the oral health status of individuals with ASD; to be an observational study; and to assess

Journal section: Medically compromised patients in Dentistry
Publication Types: Review

doi:10.4317/medoral.19084
<http://dx.doi.org/doi:10.4317/medoral.19084>

Management of children with autism spectrum disorder in the dental setting: Concerns, behavioural approaches and recommendations

Konstantina Delli ¹, Peter A. Reichart ², Michael M. Bornstein ³, Christos Livas ⁴

- Knowledge and in-depth understanding of basic behavioural patterns
- Therapeutic approach according to individual patient needs

Autism and primary care dentistry: parents' experiences of taking children with autism or working diagnosis of autism for dental examinations

NICOLE THOMAS ^{1,2}, SHARON BLAKE², CHRISTOPHER MORRIS² & DAVID R. MOLES¹

¹Plymouth University Peninsula School of Dentistry, Plymouth, UK, and ²Peninsula Cerebra Research Unit (PenCRU), University of Exeter Medical School, Exeter, UK

International Journal of Paediatric Dentistry 2018; 28:
226–238

Results. Key themes identified were flexibility of the dental team and environment, confidence of the parents to advocate for their children's needs

- “Accessing and receiving preventative dental treatment can be difficult for children with autism due to sensory processing disorders and/or challenging behaviours coupled with a reported reluctance by dentists to treat these children.”



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In this issue (6 articles)

Original Paper

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[Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement](#)

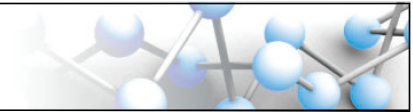
Pier Jaarsma, Stellan Welin

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ACCOMMODATING AUTISTICS AND TREATING AUTISM: CAN WE HAVE BOTH?

CHONG-MING LIM

Keywords

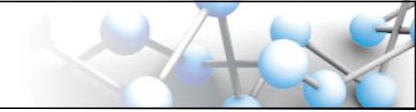
autism,
neurodiversity,
accommodation,
treatment,
P. Jaarsma,
S. Welin

ABSTRACT

One of the central claims of the neurodiversity movement is that society should accommodate the needs of autistics, rather than try to treat autism. People have variously tried to reject this accommodation thesis as applicable to all autistics. One instance is *Pier Jaarsma and Stellan Welin*, who argue that the thesis should apply to some but not all autistics. They do so via separating autistics into high- and low-functioning, on the basis of IQ and social effectiveness or functionings. I reject their grounds for separating

Accommodation thesis

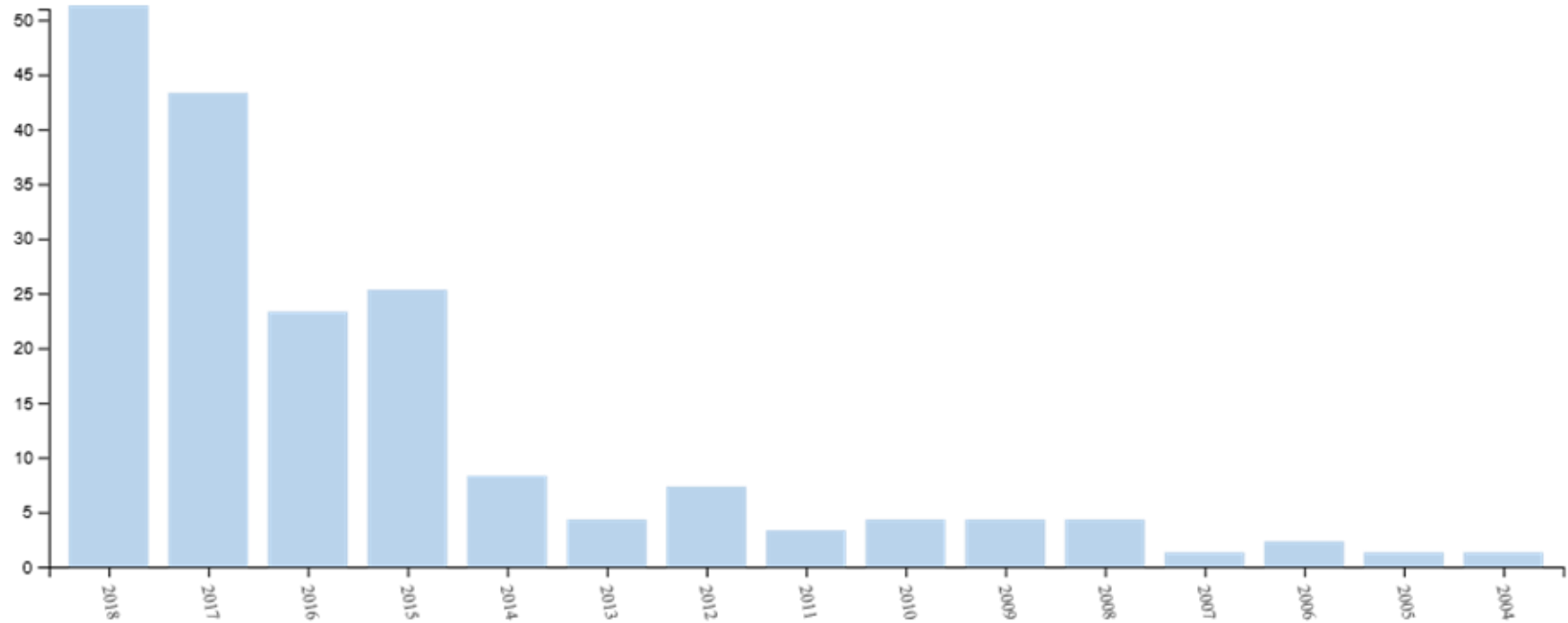
- we should accommodate autistic individuals rather than treat autism
 - Lim (2015)



AUTISM, ACCOMMODATION AND TREATMENT: A REJOINDER TO CHONG-MING LIM'S CRITIQUE

PIER JAARSMA AND STELLAN WELIN

Academic interest in neurodiversity (2004-2018)



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THIS

Opinions