



Martijn Dekker <martijn@inlv.org>, Groningen, Netherlands

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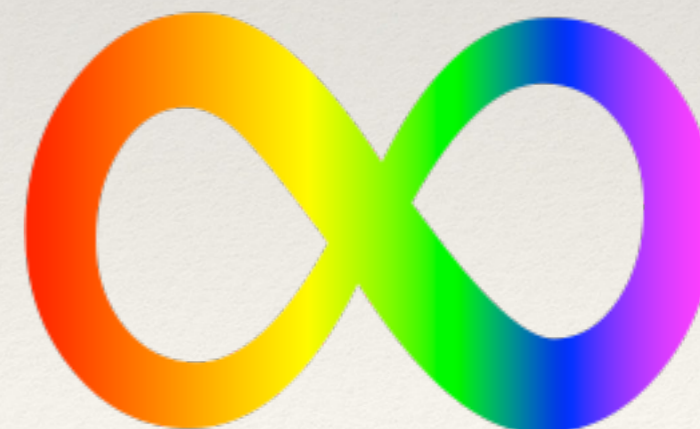
# Leczenie, czy akceptacja

## *Cure versus acceptance*

Autyzm bez przemocy  
Autism without violence

10-11 June 2017

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# My background



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# 90s: Finding each other

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- ❖ Autistic people finding each other online
- ❖ “Autism” became my key for belonging to a community of some description (for the first time in my life)
- ❖ Online participants discovered their autistic identity through a shared, yet deeply personal, exploration of a different way of being



# A brief (?) history lesson



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# Before 'autism'

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Ref.: Waltz, 2013; Silberman, 2015

- ❖ Survival for severely disabled was low. However, autistic traits such as superior pattern recognition would have had advantages in prehistoric societies (which were relatively uncomplicated and predictable).
- ❖ Folk beliefs, such as changelings, leading to torture and murder of children with disabilities, were pervasive for millennia.
- ❖ Late 19th / early 20th century: Psychology / psychiatry turned folk beliefs into 'science'. 'Degenerates' / 'defectives' were now made to 'disappear'.
- ❖ Term 'autism' first used by Eugene Bleuler in 1911 to describe one aspect of 'schizophrenia': *deliberate* escape from reality as a coping skill.
- ❖ Autism and 'hospitalism' (trauma): enduring confusion due to similar outward characteristics, reinforcing belief that autism is deliberate escape.



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# Rise of parent narratives (1960/70s)

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Ref.: Waltz, 2013; Silberman, 2015

- ❖ 1940s: Leo Kanner, Hans Asperger described autism in terms of case studies: one form of narrative. *It's been all about the narrative ever since.* Perspective of subjects being studied completely absent from narrative.
- ❖ Psychoanalysts (led by Melanie Klein) blamed 'refrigerator' mothers – a narrative that endured for decades (in France even now).
- ❖ As a reaction, parents started autism organisations (e.g. NAS in 1962) and developed an enduring mistrust of mainstream science, while still adopting a medical and pity / charity model of autism.
- ❖ Behaviourism / ABA: promise for people the psychoanalysts had written off as hopeless. But if child failed to be cured, parents were still blamed.



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# Autism: permanent war of narratives

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- ❖ Kanner & Asperger: original pair of competing narratives
- ❖ Psychoanalytical vs. behaviourist narrative
- ❖ Parent narratives introduce new science (neurobiological causes) as well as lots of nonsense (anti-vaccine, etc.)
- ❖ Abysmally low standards of ethics and science (ref.: Dawson, 2004)
- ❖ *Where is the autistic narrative?*



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# 1992: Parents vs autistics on Internet

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- ❖ Parents took to internet: St John's University AUTISM mailing list (founded by Ray Kopp in 1992). Parent- and treatment-oriented.
- ❖ Some autistics started to insert themselves into the discussion, but parents mostly used them as resources ('self-narrating zoo exhibits'). Communication between autistics was considered an annoying waste of bandwidth. (Sinclair, 1994)





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# Reaction: autistic space

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- ❖ Fed up with being patronised, Autism Network International (Sinclair et al) started ANI-L in 1994, with hosting provided by Syracuse University. First online autistic space.
- ❖ In 1996, building on internet community, ANI organised *Autreat*, the first conference for and by autistics. Took idea of autistic space to 3D realm (a.k.a. 'real life').



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# What is autistic space?

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- ❖ **Shared** by several autistic people
- ❖ Designed or **adapted** for autistic processing; values autistic ways of functioning
- ❖ Autistic people are **in charge**: *we* determine our own needs and how to meet them
- ❖ Being and acting autistic is **acceptable** and **accepted**
- ❖ Can be online or “in real life”
- ❖ Better chance to meet similar and / or **compatible** people
- ❖ Non-autistics tend to be rather socially disabled here!



# So what was *our* narrative?

Ref.: Singer (1998), Dekker (1999)

- ❖ InLv (1996-2012-ish): First entirely self-run, self-hosted online autistic community.
- ❖ What we wanted most was:
  - ❖ Mutual emotional and practical support
  - ❖ Self-advocacy
  - ❖ Civil rights
  - ❖ Appropriate services
  - ❖ Recognition of *neurodiversity* ⇒



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# Neurodiversity

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- ❖ Recognition of the reality of pervasive neurological differences: humans vary in neurology as they do in every other characteristic
- ❖ ‘We are beginning to divide ourselves [...] according to something new: differences in “kinds of minds” [...] swinging the “Nature-Nurture” pendulum back towards “Nature”.’ (Singer, 1998)
- ❖ (Peeve: one person cannot ‘be neurodiverse’ or ‘have neurodiversity’; neurodiversity is a collective feature. The appropriate adjective for an individual is ‘neurodivergent’.)



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# “Emerging autistic culture”

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- ❖ Autistic culture (akin to Deaf culture), based on shared communication characteristics (Dekker, 1999)
- ❖ These shared communication characteristics usually include:
  - ❖ Focus on content rather than social hierarchy
  - ❖ Literal interpretation, direct expression
  - ❖ Honesty
  - ❖ Cooperative monologuing
  - ❖ Silence OK



# What is autism?



# Common stereotypes

- ❖ 'Missing'
- ❖ 'Locked up'
- ❖ 'Puzzle'
- ❖ 'Unfeeling'
- ❖ 'Violent'
- ❖ Not fully human
- ❖ ...



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# Pathologisation

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- ❖ Diagnostic criteria are purely negative and fail to recognise that autistic traits can also be beneficial.
- ❖ Let's turn this on its head: 'Social dependency disorder'
  - ❖ Severe impairments in social independence (e.g. groupthink and collective destructiveness)
  - ❖ Severe lack of exactness in social communication (e.g. a loose relationship with the truth)
  - ❖ Severe impairments in rigour of thought (base rate neglect, confirmation bias, prejudice, superstition, ...)
- ❖ ref.: Institute for the Study of the Neurologically Typical (1998)





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# Every coin has two sides

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- ❖ Communication impairments  $\iff$  Enhanced directness
- ❖ Social impairments  $\iff$  Enhanced honesty, independence
- ❖ Rigidity  $\iff$  Enhanced detail perception
- ❖ Monotropic attention span  $\iff$  Enhanced concentration
- ❖ Sensory issues  $\iff$  Enhanced sensitivity



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# Yes, but what is autism *really*?

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- ❖ We only really know that **autism is not one single thing**.  
“The ASD diagnosis lacks biological and construct validity” (Waterhouse, London & Gillberg, 2016)
- ❖ Most autistic people do seem to have something important and fundamental in common; the label is clearly needed
- ❖ “All models are wrong, but some are useful” (Box, 1978)
- ❖ Autism is not a disease
- ❖ Autism is a disability ⇒



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# Disability

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- ❖ Social model vs. medical model
- ❖ In the social model, disability is caused by society's failure to adapt to someone's impairments. So there is always a social factor.
- ❖ However, by definition (!), all models have limited validity. This means there is always a risk of over-applying a model. The adherents of each model tend to take it to an extreme. (Dunn, 2005)



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# Accessibility

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- ❖ Prominent concept with other disabilities (e.g. making public buildings accessible to wheelchair users)
- ❖ Applying this to autism is new, but equally valid
- ❖ What kinds of accessibility do autistic people need?
  - ❖ Communication
  - ❖ Sensory
  - ❖ Organisational
  - ❖ Social



# Cure versus acceptance



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# Cure

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- ❖ Cure = removing a “disease” (whereas treatment = merely managing / improving it)
- ❖ Difficult to define. Where do you draw the line?
- ❖ ABA / IBI goal: ‘indistinguishable from their peers’
- ❖ In autism, it’s fundamentally a fear-based idea: people fear that which is not “normal” and want to normalise it
- ❖ Parents: When someone tries to sell you fear, *don't buy it*



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# Acceptance

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- ❖ ‘Autism is not an appendage’ (Sinclair, 1993), meaning: it’s inseparable from the person
- ❖ But: experiences vary (autism is not one thing)
- ❖ Lack of respect for personal choice
- ❖ Everyone needs acceptance (even those who wish for a cure)



# Conclusion





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# Conclusion (1/3)

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- ❖ As long as there is no one well-defined condition called 'autism', the idea of curing it is a fallacy. Even if it weren't, it's morally wrong.
- ❖ If needed, concentrate on remedying specific problems and impairments (treatment) rather than forcibly normalising the whole person (cure).



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# Conclusion (2/3)

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- ❖ Autism is not the real enemy; the real enemy is the invisible barrier of non-understanding between you and your child. (Damian Milton's "double empathy problem")
- ❖ Don't forget the social model; often better to change environment, not the child (or adult).
- ❖ **Autistic children are people.** Respect personal choice, even in children.



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# Conclusion (3/3)

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- ❖ Everyone needs acceptance, especially those who don't accept themselves.
- ❖ Autistic community is essential, even for autistic kids!



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# References / Further reading

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Underlined text = clickable link

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[martijn@inlv.org](mailto:martijn@inlv.org)  
[www.inlv.org](http://www.inlv.org)

