Leczenie, czy akceptacja
Cure versus acceptance

Autyzm bez przemocy
Autism without violence
10-11 June 2017
My background
90s: Finding each other

- 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
Before ‘autism’

❖ 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 an 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.

Ref.: Waltz, 2013; Silberman, 2015
Rise of parent narratives (1960/70s)

- 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.

Ref.: Waltz, 2013; Silberman, 2015
Autism: permanent war of narratives

❖ 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?
1992: Parents vs autistics on Internet


- 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)
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’).
What is autistic space?

- **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?

- What we wanted most was:
  - Mutual emotional and practical support
  - Self-advocacy
  - Civil rights
  - Appropriate services
  - Recognition of neurodiversity ⇒

Neurodiversity

- 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’.)
“Emerging autistic culture”

- 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

- 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)
Every coin has two sides

- Communication impairments ⇔ Enhanced directness
- Social impairments ⇔ Enhanced honesty, independence
- Rigidity ⇔ Enhanced detail perception
- Monotropic attention span ⇔ Enhanced concentration
- Sensory issues ⇔ Enhanced sensitivity
Yes, but what is autism really?

- 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 ⇒
Disability

- 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)
Accessibility

❖ 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
Cure

- 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
Acceptance

❖ ‘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
Conclusion (1/3)

❖ 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).
Conclusion (2/3)

❖ 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.
Conclusion (3/3)

❖ Everyone needs acceptance, especially those who don’t accept themselves.

❖ Autistic community is essential, even for autistic kids!
References / Further reading

Underlined text = clickable link

❖ Dunn, Yo (2005): “Reclaiming the social model of disability for emancipatory research: a critical realist critique of disablism”. Consult Yo Ltd.
❖ Sinclair, Jim (1994): *Re: Autobiographies*. St John’s AUTISM list. (First online use of term ‘self-narrating zoo exhibit’)