Autistic identity and the limits of inclusion

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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)
- The idea of *being* autistic became embedded in my sense of identity

"Emerging autistic culture"

- Autistic culture (akin to Deaf culture), based on shared communication characteristics (<u>Dekker, 1999</u>)
- Self-advocacy (US et al)

- Empowerment (Scandinavia)
- "Expert by experience" (NL)

Identity

- Online participants discovered their autistic identity through a shared, yet deeply personal, exploration of a different way of being
- Autism is "not an appendage" (<u>Sinclair</u>, <u>1993</u>), meaning: it's inseparable from the person

Neurodiversity

- '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"; the word is neurodivergent)

"Identity politics"

- Turns shared personal exploration into a social movement, enforcing conformism
- "Self-advocacy" abandoned in favour of polarising identity-based political activism
- "Listen to autistic people" (but only those who agree with us)
- "I like you, so you must be autistic"

Inclusion

- Differences are recognised
- People with them are accepted as belonging
- Factors that limit or damage inclusiveness:
 - social norms
 - political agendas
 - mutual and external stereotyping
 - a history of being considered special
 - incompatibilities between different access needs
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Disability

• Social model vs medical model

- By definition, all models have limited validity.
 Risk of overapplication
- The social model is usually taken to an extreme (<u>Dunn, [year?]</u>)
- Is it possible to be autistic without being disabled? (Note: disabled ≠ "no abilities")

What is autism anyway?

- There is no one thing called autism "The ASD diagnosis lacks biological and construct validity" (Waterhouse, London & Gillberg, 2016)
- Most of us do seem to have something important and fundamental in common
- Self-defined or community-defined?
- Autism is a stereotype!

Stereotyping

- Social pressure to conform to autistic role (including "immunity from social pressure")
- Not just by outside society but also mutual
- This can even be necessary for survival, e.g. during assessments for benefits or services
- "All autistic people fake autism": The stranglehold of self-fulfilling autism stereotypes (Baggs, 2016: <u>a</u>, <u>b</u>, <u>c</u>)

Choice vs "hard-wiring"

- One common stereotype: everything we are is hard-wired
- Problem: takes agency out of the individual
- Is anything truly accepted if it's not acceptable to choose it?
- "Yes, I've changed! I'm learning to be me!" (<u>'windsweptchildonashootingstar', 2016</u>)

Conclusions

- Autism politics have become far too polarising, dogmatic, and black & white
- Should be more democratic and pluralist, representing diverse views and experiences
- Neurological "wiring" is fundamental but not the be all & end all. Even accepting that you have a certain kind of wiring, there is a lot of room for choice and growth.



- Baggs, A.M. (2016): "<u>The stranglehold of self fulfilling autism stereotypes</u>" (followup <u>1</u>, followup <u>2</u>). As small as a world and as large as alone (blog).
- Dekker, M. (1999): "On our own terms: Emerging autistic culture". Autism99 (online conference).
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- Sinclair, J. (1993): <u>"Don't mourn for us"</u>. *Our Voice*: vol. 1, no. 3. Autism Network International.
- Singer, J. (1998; republished 2016): "<u>NeuroDiversity: The Birth of an Idea</u>". Faculty of Humanities and Social Science, University of Technology, Sydney.
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- 'windsweptchildonashootingstar' (2016): "Open letter from an autistic human".
 Diary of female autism trying to understand themselves and the world (blog).