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 ([Dekker, 1999](#))
- 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” (Sinclair, 1993), 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
  • ...

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 ([Dunn, [year?]])

• 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: a, b, c)
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!”
  (‘windsweptchildonashootingstar’, 2016)
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.
References
(note: underlined titles are clickable links)

- Baggs, A.M. (2016): “The stranglehold of self fulfilling autism stereotypes” (followup 1, followup 2). As small as a world and as large as alone (blog).
- Dunn, Y. (year?): “Reclaiming the social model of disability for emancipatory research: a critical realist critique of disablism”. Consult Yo Ltd.