

# 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</u>, 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 (<u>Dunn</u>, [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: <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!" ('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)

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