

# Neurodiversity in the post-factual society

2nd of March 2017 ESRC Autism research seminar series Autism and Society Seminar II: Autistic Wellbeing



### pre1: Facts and reason

- A fact, established correctly, is something verifiably true, based on reality, and independent of belief. Reason, applied correctly, draws verifiably valid conclusions from facts.
- Did I really need to say that? Yes! Disability rights activists
  "commonly assume that reality is constructed by social actors
  through their discourse and that there is no independent reality
  beyond this" (Dunn, 2005). This reduces facts to mere opinions,
  helping create the post-factual (a.k.a. "post-truth") society.
- Politics, belief, etc. have no place in establishing facts. Facts are inherently incapable of being political. Deciding what we want to do with them is where politics comes in.
- As an autistic social outsider, I find solace and reassurance in the existence of facts and reason that transcend belief and conformism.



### pre2: Autistic catatonia

- Aspect of my own neurodivergence: basic inability to do anything substantial out of my own volition, with disastrous effects on my sense of life fulfilment.
- Recent few years: deteriorating ability to initiate physical movement.
- A 17% prevalence of "catatonia-like deterioration" was found among people aged 15 years and over who were referred to a diagnostic service. (Wing & Shah, 2000)
- Most prevalent in the socially "passive" subgroup.
- In spite of that, in early 1996 something happened that propelled me into the forefront of the autistic community...



#### The start: 1990s

- Autistic people finding each other online
- ANI existed, but was not inclusive
- InLv: Run by hand, on dial-up
- First fully autistic-run, selfhosted Internet autism community
- Was venue for discussions that gave birth to "Neurodiversity" and "Face blindness" concepts





#### The start: 1990s

- InLv started by trying to help an autistic person being ostracised by other autistic people. I learned early on that autistics are not immune to *doing* the excluding. This experience shaped my involvement in the autistic community from the start.
- Yet, I still believed that autistics had an enhanced ability to reason logically and a reduced susceptibility to groupthink, making us well positioned to transcend some of the failings of human social group processes.



## Our early narrative

- Mutual emotional and practical support
- Self-advocacy
- Recognition of the reality of pervasive neurological differences
- Civil rights
- Appropriate services



## Neurodiversity

- Out of InLv discussions 1996-1998 grew the recognition of the fact that 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)
- By referring to "nature", Judy Singer coined "neurodiversity" as a fact, a phenomenon that physically exists, independent of belief.
- Referring to both the fact and the movement by the same name is problematic, because then by rejecting one, you reject the other.
   (Also, by accepting one you're expected to support the other.)



## Identity...

- The idea of *being* autistic, embedded in my identity, was key to:
  - 1. Understanding myself
  - 2. Sharing that understanding with others
  - 3.Belonging to a community of some description (for the first time in my life)
- Our identity was experienced as basically personal, though shared. We were a loose collection of individuals who happened to gravitate together because of something we had in common, something alienating us from mainstream society.
- Autistic culture (akin to Deaf culture), based on shared communication characteristics (Dekker, 1999)



# ...vs. identity politics

- Politicisation turns identity from personal into a new social norm, with ideology overriding facts and reason. Failure to conform results in being shunned and excluded (which, remember, increases the risk of suicide).
- Neurodiversity is now also a movement where you're expected to believe many different things, many of which have little or no bearing to the fact of neurodiversity.
- We copy this conformist and divisive behaviour from NT society, even though it's essentially anti-autistic.
- Research should study the process of social exclusion among, not just of autistics. How does it differ, how is it the same?



#### The limits of models

- A model is a limited description of one facet of reality. Like an analogy, it only goes so far.
   (If that weren't the case, models would be equal to reality and we wouldn't need them!)
- This implies a risk of overapplication. Both the social model (Dunn, 2005) and the medical model of disability are frequently taken to inappropriate extremes.
   (For example, my catatonia-like problems resist the social model.)
- Sometimes, all neurodivergent people need is for people to accept and accommodate them (social model). But some of us need (a lot) more than that. There's a wide neurodiversity even among the neurodivergent.



## Acceptance

- 'Autism is not an appendage' (Sinclair, 1993), meaning: it's inseparable from the person.
- But: experiences vary, because in fact, autism is not one thing. (Waterhouse, London & Gillberg, 2016)
- Putting the individual at the centre is essential to autistic wellbeing. The community should serve the good of the individual, not the other way around.
- Nearly everyone needs acceptance (especially those who wish for a cure).



#### Conclusion

- A fundamental aspect of autistic wellbeing is a social environment that has the (political) will and courage to take autistic people seriously as individuals.
- Resist social conformism, within our own ranks and outside.
- Facts, reason and the scientific method (as opposed to social norms) are essential tools to achieving autistic wellbeing.
   Autistics deserve and would benefit from high standards of science and ethics, but rarely get them (Dawson, 2004).
- If any social group or community should be actively resisting the post-factual/post-truth society, it's us autistics.



#### References

- Dawson, M. (2004): *The misbehaviour of behaviourists*.
- Dekker, M. (1999): *On our own terms: Emerging autistic culture*. Autism99 (online conference).
- Dunn, Y. (2005): Reclaiming the social model of disability for emancipatory research: a critical realist critique of disablism. Consult Yo Ltd.
- 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.
- Waterhouse, L., London, E. & Gillberg, C. (2016): <u>ASD Validity</u>. Rev J Autism Dev Disord. doi:10.1007/s40489-016-0085-x
- Wing, L & Shah, A.: *Catatonia in autistic spectrum disorders*. The British Journal of Psychiatry Apr 2000, 176 (4) 357-362; DOI: 10.1192/bjp. 176.4.357



# © 2017 Martijn Dekker martijn@inlv.org

