



NeuroEpigenEthics

The Moral Implications of asking “What is autism?”: Going beyond the Catch-22 of autism research and diagnosis.

Jo Bervoets, Kent Inside Out 04/07/19

Autism between disorder and positive identity



Early Intervention In Babies May Eliminate Autism Symptoms By Toddlerhood



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Waiting until toddlerhood to “treat” the symptoms of autism may be too long, a [new study from UC Davis](#) suggests. Infants as young as six months old who

PETA campaign 2014

@NeuroRebel (originator #ActuallyAutistic)

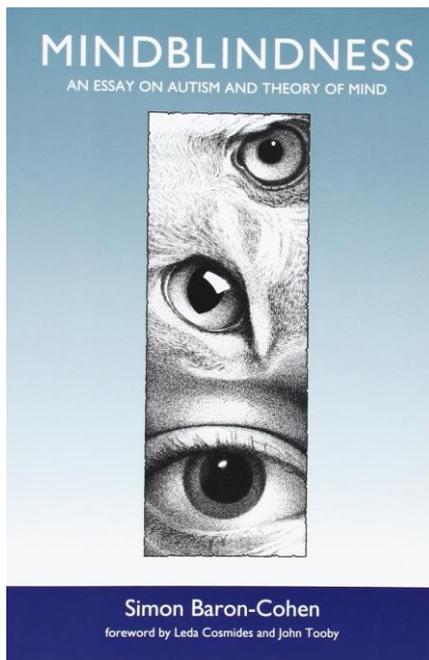
Forbes article on (Rogers & al, 2014) in JADD



Merchandising by

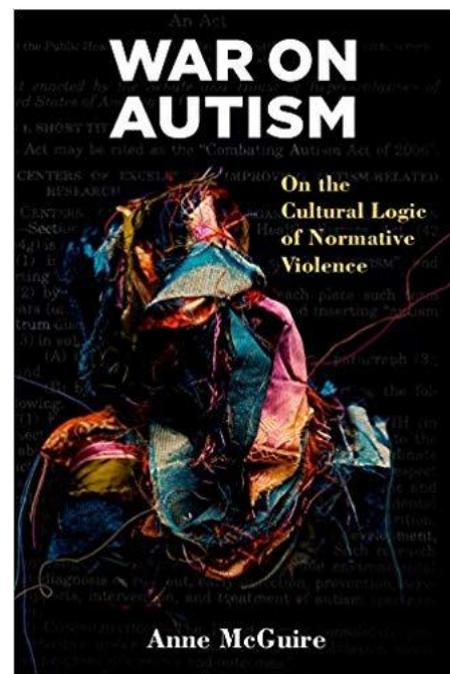
See also (Jaarsma & Welin, 2012) in HCA

Autism research: reality or social construction?



“In order to forestall tedious discussion on whether child abuse was socially constructed or real, I wrote that “it is a real evil, and it was so before the concept was constructed. It was nevertheless constructed. Neither reality nor construction should be in question” (Hacking 1995, 67f).

“What a terrible equivocation! What “it” is a real evil? The object, namely the behavior or practice of child abuse. What “it” is said to be socially constructed? The concept. (..) But not so fast. I thought, in retrospect that I had been guilty of careless confusion, yet a number of people reported how the very same passage has been very helpful to them. It gave some readers a way to see that there need be no clash between construction and reality. (..)” (Hacking, 1999, p. 29)



The Catch-22 of autism diagnosis

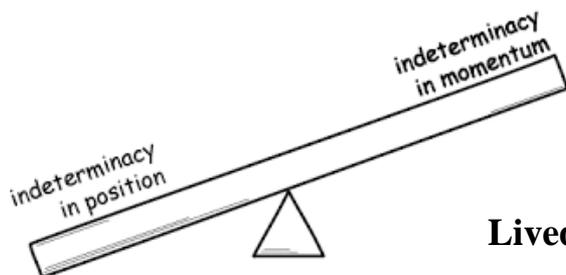
The tension seems built-in in the DSM-5 criteria (APA, 2013) for ASD, which couples a behavioral definition (clauses A/B) both to what is broadly considered as an innate learning disorder (clause C) and to problematic functioning (clause D). In everyday autistic life this means that, once diagnosed, we are retro- and proactively understood as problematic, causing practical issues for us e.g. for insurance.

The current model for diagnosing ASD leads to a moral dilemma, a Catch-22:

- The autistic version: **“I’d be disordered if I accepted to be autistic but, if I’m in good mental health, I have to accept I’m not autistic.”**
- The living-with-autistics version: **“If they’re not autistic, they have to behave. But if they do not behave, being autistic may be their excuse for not behaving.”**

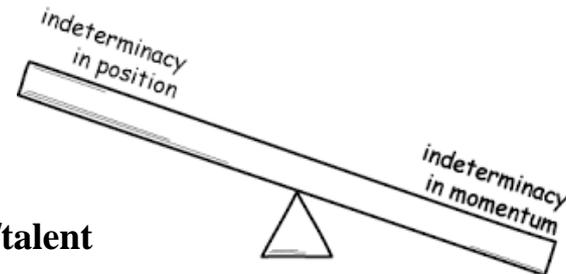
A quantum mechanical metaphor

- Trying to scientifically pin down “What is autism?”:
 - Exact sciences: particle aspect of autism (autistic nature)
 - Human sciences: wave aspect of autism (autistic behavior)
- Catch-22 of autism research: disregarding indeterminacy inherent in autistic lived experience

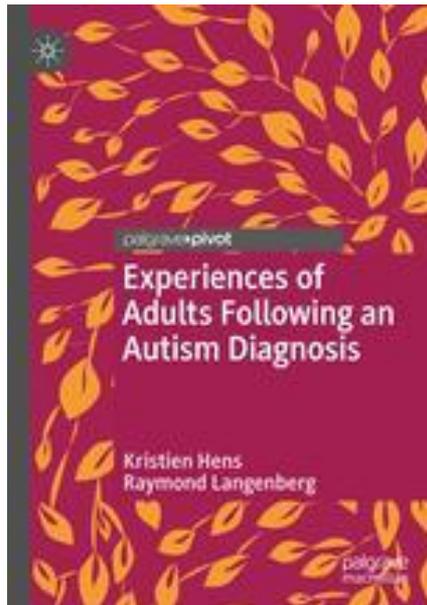


Position: autistic nature
Momentum: autistic behavior

Lived experience: coping/compensation/talent



Beyond the Catch-22: listen to actual autistics



“Dieser Weg von den Ausdruckserscheinungen zum Wesen verzichtet bewusst auf ein von vornherein gegebenes System. (...) so verzichten wir auch bewusst darauf, ihn in eine künstlich herbeigeführte Testsituation zu bringen, in eine stereotype Testmaschinerie einzuspannen, (...)” (Asperger 1944, p.7)

The binary choice implicit in a psychiatric diagnosis is linked to the inescapable moral dilemma of either accepting an innate psychiatric problem or denying a crucial feature of personal identity. This explains the ambivalence felt about such a diagnosis (e.g. Russell & Norwich, 2012).

Beyond the Catch-22: proposal to rename ASD to ARD (Autism Related Disorder)

Recognizes one can be autistic without being problematic.

Recognizes challenges commonly faced by autistics without splitting the autistic community (e.g. in high- and low-functioning).

Recognizes some of us *may* require support *some (or all of the)* time, based on the needs we (depending on our environment) experience.

Focuses on prevention (of problems) i.s.o. on treatment (of deficits).

Highlights the need for moral imagination: we are first of all human beings, not just patients (Arpaly 2005).

How it is not "just like diabetes": Mental disorders and the moral psychologist

Nomy Arpaly

Philosophical Issues 15 (1):282–298 (2005)

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Abstract

Many psychiatrists tell their clients that any mental disorder is “a disease, just like diabetes”. This slogan appears to suggest that mental states and behavior that are classified “mental disorders” are somehow radically different from other mental states and behaviors—both when it comes to simply understanding people and when it comes to moral assessments of mental states and of actions. After all, mental illness is just like diabetes, while other human conditions are not. That sounds like a huge difference. I think this suggestion is misleading

Questions and (maybe) Answers

- mail: joberv@gmail.com, twitter: @JoBervoets
- Detailed argumentation: The Moral Implications of asking “What is Autism?”. Going beyond the Catch-22 of autism research and diagnosis, available from my (Jo Bervoets) academia.edu page
- Autism Ethics Network home page: <https://autismethics.com/>
- AEN mission statement: *“The Autism Ethics Network is an international platform that unites researchers and individuals inspired by a desire to understand autism and to promote sharing of knowledge and collaboration. We believe that a transdisciplinary and inclusive approach is necessary for an ethical approach to autism and autistic individuals, and strive to surpass reductionist frames of thinking. We welcome researchers from different fields, such as sociology, philosophy, psychology, psychiatry, the arts, anthropology, but this list is non-exhaustive. Of course, people living on the autism spectrum are very welcome to contribute.”*