

Neurodiversity: The cases for and against

**Presentation by ADAM FEINSTEIN
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Johnny and Adam



‘Neurodiversity’

- **Term coined by Judy Singer in 1988.**
- **Popularised by Harvey Blume, writing in *The Atlantic* in 1998: ‘Neurodiversity may be every bit as crucial for the human race as biodiversity is for life in general. Who can say what form of wiring will prove best at any given moment? Cybernetics and computer culture, for example, may favour a somewhat autistic cast of mind.’**

Three fundamental principles:

- **Neurodiversity is a natural and valuable form of human diversity.**
- **The idea that there is one 'normal' or 'healthy' type of brain or mind, or one 'right' style of neurocognitive functioning, is a culturally constructed fiction, no more valid (and no more conducive to a healthy society or to the overall well-being of humanity) than the idea that there is one 'normal' or 'right' ethnicity, gender, or culture.**
- **The social dynamics that manifest themselves in relation to neurodiversity are similar to the social dynamics that manifest themselves in relation to other forms of human diversity (eg. diversity of ethnicity, gender, or culture). These dynamics include the dynamics of social power inequalities, and also the dynamics by which diversity, when embraced, acts as a source of creative potential.**

The case for neurodiversity in the workplace:



**Hans Asperger
(1906-1980)**

Hans Asperger (1944):

‘We can see in the autistic person, far more clearly than with any normal child, a predestination for a particular profession from earlier youth. A particular line of work often grows naturally out of his or her special abilities.’

SAP's 'puzzle piece' metaphor:

People are like puzzle pieces, irregularly shaped. Historically, companies have asked employees to trim away their irregularities, because it's easier to fit people together if they are all perfect rectangles. But that requires employees to leave their differences at home - differences which firms need in order to innovate.

Thorkil Sonne – and dandelion



Thorkil Sonne to Adam Feinstein:

'Kids love dandelions. But as you become an adult, this love turns to hate. The dandelion has become a weed. It destroys the order of your garden and you want to get rid of it. But the flower is the same. Something else has changed. Your own norms have been replaced by society's norms. But what is a weed? A weed is a flower in an unwanted place. If you put the dandelion in a wanted place, it turns into a herb. I know this because I visited a farmer who makes a living out of growing dandelions. He harvests them for nutritional purposes. They give you back so much if they are treated well. It's the same with people – if they're made to feel welcome, you have access to values. So what we're trying to do is make autistic people welcome in the workplace so that employers have access to all the values.'

The autistic spectrum

Wing, L & Gould, J. (1979) 'Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification'. *Journal of Autism and Developmental Disorders*, 9, 11-29



**Lorna Wing (right) and
Judith Gould**

In 1979, Lorna Wing and Judith Gould carried out their seminal study of 173 children in Camberwell, south London, leading to their introduction of the key concepts of the autistic spectrum and the Triad of Impairments

Caroline Hearst's autism constellation model



Jobs for non-verbal (or minimally verbal) individuals with autism:

- **Janitor, store re-stocker, library helper, factory assembly worker, warehouse helper, office helper, odd-job gardener**
- **Positive examples: the bottle bank worker in Belgium; Poetry in Wood (London)**

Jobs for visual learners:

Commercial artists, graphic designers, web designers, cartoonists, photographers

Jobs for verbal learners:

- **Public speaking**
- **Acting**

Positive examples: Dean Beadle (public speaker) and Julius Robertson (actor)



Derek Paravicini, blind autistic pianist



‘An investigation of Asperger Syndrome in the employment context’ by Anne Cockayne (Nottingham Business School) and Lara Warburton (Rolls-Royce Plc), a paper presented to CIPD Applied Research Conference, London, 2016

Found that managers identified employees with Asperger’s syndrome as having characteristics distinctive from neurotypical employees working in similar roles. A high work ethic and IQ were conceptualised by managers as strengths, whereas attention to detail, honesty and directness, flexibility and social interaction were conceptualised variously as strengths or as weaknesses, depending on the specific job role, working environment and the norms governing HR processes and ways of working.

Cockayne and Warburton (2016):

‘Employers should question if positive valuations of these “softer” skills are always appropriate or if they are based upon subjective and arbitrary notions as well as more precisely specify the attributes or skills that are actually required, for example: what attributes or ways of working count as team working? Is being empathetic and a “good” communicator always necessary?’

Neurodiverse or neurodivergent?

Jon Adams:

'I firmly believe it's the creatively divergent way of thinking that's enabling as an autistic artist, but this can't usefully exist in isolation. It needs an opportunity to be revealed and nurtured, and an understanding of neurodiversity is vital. We can see and reveal patterns, thoughts and ideas very differently, and when "compelled to make" can do so with great concentration and detail ...

... This is especially important in employment where ‘mistreatment’, deliberate or not, adds mental health issues and post-traumatic stress disorder (PTSD) to the weight of the rucksack you carry already. Without understanding on the employer’s part, all this adds to low self-esteem and becomes a self-imposed barrier, stealing focus away from what we can do and our talents. From recent experiences, I’ve unfortunately found that there are no grey areas – we are either enabled or “left” to struggle. Autism awareness and listening to what we say we need is key ... I’m confident with my neuro-difference. I wouldn’t change anything other than maybe people’s attitudes and their understanding but that’s something hopefully I can help to achieve with the work I make and show.’

- JON ADAMS

The case against neurodiversity:

Professor Manuel Casanova (2017):

‘Neurodiversity proponents have a peculiar way of cherry picking characteristics of autism and hand-waving them into positive and somewhat appealing attributes. Repetitive movements, for example, are labelled as “personality traits” that can arguably be easily stopped at the whim of the individual. These behaviours are usually triggered by stress and may interfere with normal daily activities. Repetitive or stereotyped behaviours include flapping of the arms, rocking of the trunk and wriggling of the toes. Since these behaviours are part of their personality, ornaments as to what makes an individual unique, neurodiversity advocates argue against medical interventions that would curtail their expression. To readily agree with this proposal denotes lack of understanding and maybe empathy. As in many other instances, neurodiversity proponents ignore the concept of severity and isolate themselves in a diagnostic cocoon that excludes those more severely affected. Repetitive movements are chronic behaviours that can be momentarily suppressed. In some cases, self-stimulation (“stimming” behaviours) may serve to calm an individual who is confronting an overload of environmental stimulation...’

‘...These behaviours may also serve as a way of attracting the attention of caregivers when they are otherwise unable to properly express themselves through language ... [However], these behaviours, including head banging, head rubbing, eye gouging, self-biting, and picking at the skin, can be self-injurious and their severity is probably the greatest source of concern for the parents of those so affected ... There is nothing rosy about self-injurious behaviours. Calling them a personality trait does not preclude them from being a medical condition which, in many occasions, require treatment. Self-injurious behaviours are not a gift but a disability to those who have them. At the very least, repetitive behaviours should not be considered as part of someone’s personality ...’

‘... The fact that autistic individuals have an excitatory/inhibitory imbalance of the brain has been used as an explanation for sensory and cognitive abnormalities. Autistic individuals are tweaked towards this imbalance by risk genes that mediate the function of inhibitory neurotransmitters. Having this excitatory/inhibitory imbalance is at the core of autism; it is part of who they are. In a significant number of cases, this imbalance is expressed as seizures. This is not a comorbidity, this is not a different and unrelated condition, seizures and sensory problems are part and parcel of being autistic ... Seizures can affect your state of alertness, mood and memory. Falls during seizures can cause broken bones. Kids with intractable seizures have to wear protective helmets all of the time. The mortality rate is increased in persons with autism who also have epilepsy. Seizures are part of autism. Seeing autism through rosy-coloured glasses should not detract anybody from the fact that this is a medical disorder for which many individuals need treatment.’

- Professor MANUEL CASANOVA

The case for a middle ground:

Be positive about both difference and disability – focus on the strengths, *not* the deficits, on what people can do, *not* on what they can't do

Johnny with his sisters, Lara and Katriona



Donna Williams (1963-2017)



Donna Williams: 'Autism as a Fruit Salad'

'People in the autism pride movement have expressed their right to define autism as they see it. And, sure, we can culturally choose to take ownership of words, labels, shape them in our own image or cling only to those images or stereotypes that feel our own interests, social benefits or self-esteem. Clinically, however, those with autism not only fit a range of ticks on a DSM-5 checklist, but underneath that static, 2-D linear snapshot is a dynamic multi-layered 3-D reality of usually unidentified but nameable disabilities occurring in episodic (now and then) or chronic (daily) forms anywhere from subclinical (unproblematic quirks) to acute (disabling). The person who presents with autism will do so as the result of a wide range of underlying conditions. In other words, under the umbrella term for their presentation as "autistic", they will actually have a range of "autism fruit salad". This "autism fruit salad" will vary from person to person not just in combinations of strengths and severity of challenges but in the variety of combinations, and people may identify with all, with parts or with none of their own "autism fruit salad" ...'

‘...The components of that fruit salad most challenging a person (or benefiting them) at any one time/situation/stage of their life will keep varying. Some parts may become more obvious in some situations, activities or with specific people, and different components of their fruit salad may become more obvious in others. Some of these pieces of fruit salad are undoubtedly abilities (if you’re lucky enough to have those in your fruit salad). Other parts may be medical issues that need addressing. Other parts may be genetic neurological differences that need respecting or require advocacy skills or adaptations so the person can navigate and function in a world without their same issues. Other parts may be related to brain injury, degenerative conditions or impaired neurological connections or development and these may benefit to some degree from brain gym and adaptations but benefit from little else. What’s more, fixating over and over and over again on a disability the person can’t change only fails to develop all they still have intact and psychologically and emotionally reinforces their own low self-esteem and self-defeating sense of incapability...’

‘... We are a wonderfully diverse group, we contain some wonderfully talented human beings who are not scientists, engineers, techies and don't even have that orientation! We have some wonderfully moving people on the spectrum who are contributing to society just by allowing us to know them and move in their world and we don't need a planet that only worships intellect for we would lose all sight of emotional depth. I will never be an Einstein but given he is equally well known for the vibrant, social, womanising, rounded human being that he was, I recognise that a percentage of non-autistic people do speak late, do slacken off in early education and can have the conscientious-obsessive compulsive personality trait to a degree they may become great in a given scientific field and I struggle to label him any more autistic or stake a claim to him as representative of me. I don't need to be that superior. I'm quite happy among the extraordinary subtleties and extremes of so called ordinary people in whatever form they be.’

- DONNA WILLIAMS

ADAM FEINSTEIN

Adam Feinstein's book, *A History of Autism: Conversations with the Pioneers*, was published by Wiley-Blackwell in 2010 and has been translated into a number of languages. He is the founder and editor of the international autism magazine, *Looking Up* (www.lookingupautism.org). He has written on autism for many publications, including the *Guardian*, and has given talks on the condition around the world, including India, China, Argentina, Mexico, Spain, Italy, Germany, the Netherlands, Switzerland, Denmark, Russia and the United States. He has a son, Johnny, with autism. He is also the author of *Pablo Neruda: A Passion for Life*, the first authoritative biography of the Nobel Prize-winning Chilean poet, initially published by Bloomsbury in 2004 to coincide with Neruda's centenary and re-issued in an updated edition in 2013.

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Thank you for your attention.