

Neurodiversity: The cases for and against

Presentation by ADAM FEINSTEIN at Exeter University

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SLIDE:

Johnny and Adam

I have been an autism researcher for many years but much of what I have learned from a personal point of view is from this young man, my autistic son, Johnny. And yes, he has taught me a lot. About how you can have a great sense of humour without language (like Charlie Chaplin and Buster Keaton) and an ability to understand a great deal without being able to express it.

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Judy Singer, an autistic woman, is believed to have coined the term ‘neurodiversity’ in Australia in 1988. The term was then 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.’

SLIDE:

The neurodiversity perspective basically boils down to these fundamental principles:

- 1) Neurodiversity is a natural and valuable form of human diversity.
- 2) 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.
- 3) 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.

Now, it is important to remember that the word neurodiversity was introduced at a time when conditions like autism, ADHD, dyslexia, and other cognitive variations were defined only, or mainly, in negative terms. In other words, people spoke of the deficits, not the strengths: they talked about what people could NOT do, rather than what they COULD. Advocates of this perspective believe that autism is a unique way of being that should be validated, supported and appreciated rather than shunned, discriminated against or eliminated. Those supporting the medical model of disability, on the contrary, identify the mental differences associated with these conditions as disorders, deficits, and dysfunctions, intrinsic differences in functioning which cause impairments in many areas of life. From this point of view, the mental states that are encompassed by neurodiversity are medical conditions that can and should be treated.

The case for neurodiversity in the workplace:

SLIDE OF HANS ASPERGER HERE

SLIDE OF ASPERGER'S QUOTE:

Not everyone thought in such negative terms, of course. As early as 1944, Hans Asperger, back in 1944, wrote: '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.'

Leo Kanner thought of his syndrome, early infantile autism, as a unique rare condition, whereas Hans Asperger, from very early on, recognised the broader spectrum and the originality and creativity of the children in his charge. Kanner, in contrast, while acknowledging their splinter, savant skills, did not observe, or mention, creativity,

As Uta Frith and Francesca Happé showed a few decades ago, weak central coherence (or, to employ the more positive terminology, local processing bias) is a common trait in people on the autism spectrum: they tend to see the parts rather than the whole. This can be a problem in some settings but a terrific attribute in others, especially in certain professions. For example, if you're looking for unique cells (as a lab technician), deep space anomalies (as an astronomer), differences

among species (as a biologist) or particular qualities of objects (as a gemologist, an antiques appraiser, an art historian).

Of course, certain jobs tend to make much less successful matches for people on the autism spectrum, including those that involve multi-tracking, high levels of socialising and sensory overload, such as cashier, airline ticket agent, waitress, receptionist or telephone operator. Yet even here, I know of specific exceptions: David Harris, a man with Asperger's syndrome, is an extremely successful employee on the information desk opposite Platform 1 on London's Paddington Station. I have seen him dealing calmly with some extremely angry passengers wanting to know why there was a delay on the train to Oxford. David simply remained calm and explained the facts. I also know of very successful waiters with autism. So these generalisations, while well-meaning, are like all generalisations: misleading and over-simplistic. The same applies to other overarching views of potential employees with Asperger's syndrome: that they are all great at IT and that they are all happy to do mundane repetitive tasks. This is a grossly distorted picture! I know many people with Asperger's who do not know one end of a computer from another. And while writing my book, I have made hundreds of autistic employees who have found loading and unloading lorries day after day horrendously tedious!

Steve Silberman's 2015 book, *NeuroTribes*, popularised the idea of neurodiversity, and has since been joined by a regular stream of articles and essays about neurodiversity employment in venues like the *Harvard Business Review*, *The New York Times* and elsewhere. An Autism at Work summit hosted by SAP and Microsoft in April 2017 attracted more companies, advocates and parents than in any previous year.

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SAP uses a metaphor to communicate this idea across the organisation: 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 firms need in order to innovate. “The corporate world has mostly missed out on this [benefit],” Anka Wittenberg observes.

This suggests that companies must embrace an alternative philosophy, one that calls on managers to do the hard work of fitting irregular puzzle pieces together—to treat people not as containers of fungible human resources but as unique individual assets. The work for managers will be harder. But the payoff for companies will be considerable: access to more of their employees'

talents along with diverse perspectives that may help them compete more effectively. “Innovation,” Wittenberg notes, “is most likely to come from parts of us that we don’t all share.”

Major firms, such as Airbnb, Salesforce, LinkedIn, and Facebook, are adding neurodiversity employment to their other diversity and inclusion efforts. Hewlett Packard Enterprise (HPE) in Australia has operated one of the leading autism employment initiatives since 2014, called the Dandelion programme, growing to 58 employees as of early 2017. It has sought to capture and quantify the benefits of hiring neurodiverse employees using economic and statistical metrics through partnerships with academic researchers at the Institute on Employment and Disability at Cornell University in New York and Latrobe University in Melbourne, Australia.

SLIDE OF THORKIL SONNE AND DANDELION

SLIDE OF THORKIL’S QUOTE:

If you’re wondering why it’s called the Dandelion programme, it comes from an idea of Thorkil Sonne, father of an autistic boy, who founded the company Specialisterne – which has pledged to help one million people with autism into work by 2026. Here’s how Thorkil explained the dandelion analogy to me over breakfast in London not long ago:

‘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.’

SLIDE:

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

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

SLIDE:**Caroline Hearst's autism constellation model**

The autism constellation model

The autism constellation model was designed by AutAngel's founder Caroline Hearst and made by an autistic woodworker to demonstrate to participants in her autism awareness courses why autism is best described as a constellation.

Caroline does not like the concept of a spectrum or a neat, linear continuum. Her argument is that this concept does not match up to the far more complex reality. She points out that some people will find some tasks very easy some days and impossible to do at other times; individual profiles tend to be spiky and changeable. The constellation model offers a more comprehensive representation. (The spiky profile, of course, is what can also make life so difficult at times for autistic employees in the workplace. **MENTION MY BOOK HERE!**)

The autism constellation model is a wooden model representing the diversity of autistics and their spiky profiles:

SLIDE:**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)**

SLIDE:

Jobs for visual learners:

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

SLIDE:

Jobs for verbal learners:

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

SLIDE:

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

SLIDE:

Derek Paravicini, blind autistic pianist

We've seen a shift of thinking in recent years. While diversity hiring initiatives were once considered largely a form of corporate social responsibility and resourced accordingly, more recent diversity recruitment initiatives have emphasised the corporate economic value of employee diversity and the value of diversity to the bottom line. In this sense, the emphasis on demonstrating a measurable economic advantage to hiring autistic workers is part of a broader trend. With developments in data science, employers are increasingly eager to evaluate the performance of workers through scientific forms of measurement, rather than the subjective approval or disapproval of management.

SLIDE:

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

This interesting and important paper from last year 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.

I should point out that at the same time as creating strengths, these characteristics also place AS as a disability protected under the Equality Act (2010) on account of the very real impairments that AS people experience, for example being frequently troubled by loud noises and by feelings of being different from their peers. Autism, including Asperger’s syndrome (as well as dyslexia, dyspraxia, ADHD and Tourette’s) are all neurodiverse conditions protected under the 2010 Equality Act.

Every manager questioned by Cockayne and Warburton noted that their AS employees had some difficulties with interactions at work, whether these were with customers or colleagues, supporting the findings from clinical and employee-driven accounts. In describing what they noticed about the ways their AS employees worked in teams, managers indicated that sometimes colleagues could find these ‘ways’ strange, unusual, hard to warm to or work with. Almost all of the managers stated that their AS employees found it difficult to show empathy, citing difficulties in ‘reading body language or facial expressions’; ‘often interrupts me when I was talking to clients’; ‘approaches every situation the same way, not taking into account how the recipient will perceive the message’. Every AS employee strongly reinforced these observations, noting how hard it could be to recognise social cues and to avoid making points that others can see as disconnected from the specific topic of conversation.

BUT let me emphasise a positive aspect here: an employee working on a mental health ward had to deal with a patient who was self-harming. It was a situation which other staff members were walking away from. In fact, at one point a staff member walked in and walked back out again as he couldn’t deal with the situation. Whereas the employee walked straight in and dealt with the situation.

In this case, the ability to distance himself emotionally was a great help (compare the case of David Harris at the information desk at Paddington Station I mentioned earlier).

SLIDE:

In their 2016 paper, Cockayne and Warburton wrote:

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?’

Imagine you heard someone described as ‘being paralysed by shyness’. We are all capable of feeling shy in certain situations. But taken to excess, shyness can be ‘paralysing’. The person becomes disabled by an inbuilt disposition that cannot be seen or touched, exactly as it is for those with Asperger’s syndrome. That is where disability and diversity may overlap – especially in the workplace.

A person with Asperger’s syndrome doesn’t wear a badge telling colleagues to watch out for particular characteristics. Differences in outward behaviours may be highly visible, yet the disability itself remains unseen, making it hard for line managers and HR teams to understand completely why employees find such constraints disabling. So while it’s obvious to a company that a wheelchair user needs a ramp or a visually impaired person needs better lighting, someone who thinks differently, is hyper-sensitive to noise or other stimuli, finds team meetings a strain often doesn’t accord the same support. If line managers have a healthy curiosity and are able to find out what works for the individual, it is often the case that minor changes can make a major difference. People with Asperger’s syndrome find it very hard to concentrate in environments which are excessively noisy or brightly lit. They often find team meetings unnecessary and a distraction from the task in hand. Instead, employers could question the value of having all of the team present at all meetings, all of the time.

SLIDE:**Neurodiverse or neurodivergent?**

Jon Adams, a talented artist, musician and poet with Asperger's syndrome and synaesthesia who also collaborated with the celebrated theatre director, Sir Peter Brook, on the play *The Valley of Astonishment*, prefers the term neurodivergent. After all, he points out, we are *all* neurodiverse, in the sense that we all think differently. The term 'Neurodivergent' – coined by Kassiane Sibley - means having a brain that functions in ways that diverge significantly from the dominant societal standards of 'normal.' Neurodivergence can be largely or entirely genetic and innate, or it can be largely or entirely produced by brain-altering experience, or some combination of the two (autism and dyslexia are examples of innate forms of neurodivergence, while alterations in brain functioning caused by such things as trauma, long-term meditation practice, or heavy usage of psychedelic drugs are examples of forms of neurodivergence produced through experience).

In this way of looking at the issue, neurotypical is the opposite of neurodivergent, not the opposite of autistic. Autism is only one of many forms of neurodivergence, so there are many, many people who are neither neurotypical nor autistic. Using neurotypical to mean non-autistic is like using 'white' to mean 'not black.' There is no such thing as a 'neurodiverse individual.' The correct term is 'neurodivergent individual.' An individual can diverge, but an individual cannot be diverse. Diversity is a property of groups, not of individuals.

Jon Adams was diagnosed 'late in life' at the age of 52, although he says he felt 'different' from an early age. In Jon's words, 'I don't think there has been a day where creativity hasn't been the major part of my life. As a child, I was always assembling, collecting and drawing - never letting go of those desires or a pencil ever since. At 6 years old, when asked what I wanted, I said "to be an artist". It seemed the most honest, logical and heartfelt answer I could give.' He carved out a niche market for himself in the field of scientific illustration, although he says he's not sure whether he's a scientist who can draw or an artist who likes science.

SLIDE:**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.’

For Jon, the most people in his life are those who understand his different way of thinking, offering him acceptance and opportunity.

‘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 ...’

SLIDE:

The case against neurodiversity:

The concept of neurodiversity as applied to autism has been criticised for being biased towards the so-called ‘high-functioning’ individuals on the autism spectrum or those with milder forms of the condition. Because many of the so-called low-functioning individuals are unable to communicate effectively to express their opinions and wishes, controversy surrounds the issue of who are their advocates or can best represent their interests. So, for example, Sue Rubin, an autistic woman and author who was the subject of the fascinating 40-minute 2004 documentary, *Autism is a World*, favours a cure for the condition and asserts that while those with high-functioning autism tend to

support the neurodiversity anti-cure position, those who have low-functioning autism generally hold the opposite opinion.

Professor Manuel Casanova is a neurologist and currently Professor of Biomedical Sciences at the University of South Carolina. He is very much on the other side of the neurodiversity debate. In fact, he claims he has received threats from members of the neurodiversity movement because of his research which he says they have compared to genocide. He also, it is important to note, has a grandson with Rett's syndrome.

As you will see, Manny Casanova is one of the most vociferous opponents of the neurodiversity movement.

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In the latest article on his Cortical Chauvinism blog, Casanova wrote the following:

‘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 ...

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‘... 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.’

SLIDE:

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

I think there IS a middle ground:

SLIDE OF JOHNNY WITH LARA AND KATRIONA:

My son Johnny is unable to speak. Maybe he has an ‘unability’. But even if we accept that his lack of language is a disability, what is wrong with that? What is actually wrong with the word ‘disabled’? Why give it negative connotations? Why not accept that people have disabilities but also –in line with the neurodiversity campaigners – accept that they have potential, that they have a right to fulfil that potential and that they can have a valuable role to play in society?

A couple of days ago, I went to the joyous thirtieth birthday celebrations in south-east London of an organisation called Heart n Soul. One of the performers was a young and very talented autistic man, Dean Hedley, who founded his own rock Group, The Fish Police. Everyone at Heart n Sound is learning disabled and is happy to describe himself or herself as such. Yet they all say Heart n Sound has given them back their identify, their freedom to be who they want. Surely that’s what counts.

SLIDE OF DONNA:

Let me conclude with a telling quote from the late Donna Williams. Some of you may have read her books, which include *Nobody Nowhere*.

SLIDE:

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 varies 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” ...

SLIDE:

‘...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...’

SLIDE:

‘...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.’

SLIDE:

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, first published by Bloomsbury in 2004 to coincide with Neruda's centenary and re-issued in an updated edition in 2013.

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SLIDE:

THANK YOU FOR YOUR ATTENTION