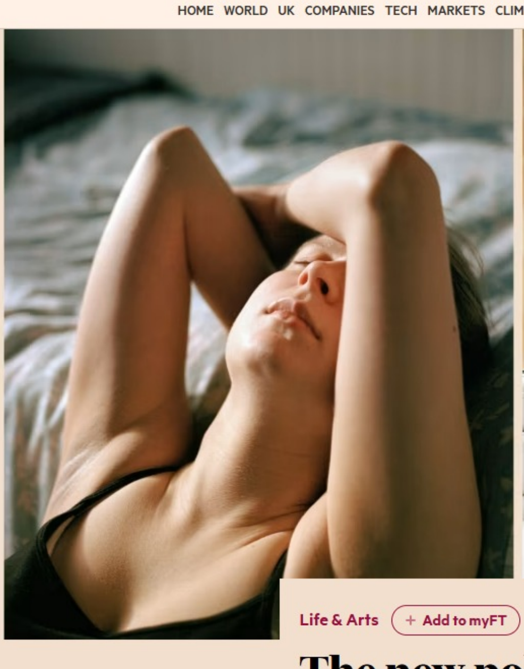

Emily June Smith's photographic project 'A Dissonant Past Unmasked'

The new politics of autism

As contentious claims over rising diagnoses get a presidential platform, Simon Baron-Cohen explains where talk of an 'epidemic' goes wrong — and why we need more recognition that autism comes in different forms

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Autism — a neurodevelopmental disability — has become a political issue. How did this happen?

There is a short answer, which begins with the press conference held two months ago by US President Donald Trump and his health secretary Robert F Kennedy Jr, in which they linked a rise in the prevalence of autism to increases in environmental toxins, such as women taking paracetamol during pregnancy, or the use of vaccines in early childhood. While the scientific community has dismissed these views as unsubstantiated, and pointed to evidence disproving them, the episode raised questions about why politicians should be entering into debates about the science of autism.

To understand the unlikely relationship between autism and politics, however, we must turn to the diagnosis of autism, since today this has become contentious. Before 1994, it was mostly diagnosed in people who also had an intellectual (or learning) disability, and in those who had language delays or difficulties. Clinicians back then called it classic autism, and we all referred to the paper published in 1943 by child psychiatrist Leo Kanner at Johns Hopkins University in Baltimore, and credited him with the first report of autism.

From then on, up until the 1990s, the scientific and clinical community achieved an agreement of what autism was, because the social and communication disabilities were strikingly apparent; the strong narrow interests, and the strong preference for routines and repetition, stood out like a "red thread", as Kanner said. Even your grandmother could spot the signs, not least because these were often accompanied by other striking features such as rocking, hand-flapping, tip-toe walking, exuberant whole-body spasms when excited, loud tantrums and distressing self-injury when stressed. And some of these individuals, despite their learning disability, had areas of remarkable talent, in music, drawing or memory, for example — so-called "savants".

Donald Trump and US health secretary Robert F Kennedy Jr during a press conference in September in which the president linked autism to the use in pregnancy of paracetamol, also known as acetaminophen © The Washington Post via Getty Images

Then, in 1994, the American Psychiatric Association (APA) published the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (called DSM-IV), which introduced the category of Asperger syndrome as a subgroup of autism, to diagnose a person who had the core "symptoms" of autism, but who did not have intellectual disability and/or language difficulties. In doing so, the APA credited the paediatrician Hans Asperger in Vienna as having described a form of autism even earlier than Kanner, in 1938.

Overnight, this meant that autism as a diagnosis became available to anyone in the population, whatever their IQ or language level. The floodgates had opened. The consequence of DSM-IV has been that between 1998 and 2018, the rates of autism (the total number of cases, combining classic autism and Asperger syndrome) in the UK have risen by an estimated 787 per cent. In the US, that combined number was 1 per 150 in the year 2000; today the prevalence is 1 in 31. Much of that increase is attributed to the huge number of people seeking a diagnosis of what was then called Asperger syndrome.

And it became apparent to clinicians and scientists that the presence of average or even above-average IQ changed how autism appeared. In some of these individuals with Asperger syndrome the autism was still clearly visible, as they made little eye-contact and were very socially isolated.

Yet other people with Asperger syndrome were able to learn how to hide their autism, so-called masking or camouflaging, so that their autism was invisible. The only way to know they were autistic was to ignore their superficially fluent social skills, the fact that they had taught themselves eye-contact and conversational turn-taking, for example.

'Some Space Between' from 'A Dissonant Past Unmasked' by Emily June Smith

About the photography

Artist Emily June Smith was diagnosed in childhood with ADHD and autism. In her photographic series 'A Dissonant Past Unmasked', Smith stages herself alongside family members in re-enactments. As she writes, 'Private sufferings from the past are performed against the backdrop of suburban domesticity.' The lead photograph (mobile and tablet) is titled 'After 2:30pm'; on desktop, to the right of this are 'Back of the Classroom' and 'Meltdown'

Their kind of autism became apparent only during a clinical interview when they were willing to let the mask drop and explain to the doctor what it actually felt like underneath, how exhausting social masking was, how they struggled to keep even one friend, and how they felt like an outsider all their life.

Many of them only sought a diagnosis later in life, not in childhood when they could really have benefited. I called them the "lost generation" because they were born before the diagnosis of Asperger syndrome was available.

But then in 2013, the APA decided that the term "Asperger syndrome" was not helpful. It pointed to field trials that suggested that different clinicians couldn't always agree on whether a person seeking a diagnosis in adulthood had had single words before age two, since often there was no one to confirm this. Was it Asperger syndrome, or was it "high functioning" autism? That single question was enough for the APA to propose that Asperger syndrome should be deleted from the fifth edition of the DSM (or DSM-5).

Seeing the looming dangers of this, I had argued that it was premature to remove Asperger syndrome from the DSM. This is because this kind of autism might be both different biologically from classic autism — scientists had only had 15 years to study it, and the genetics and neuroscience was still incomplete. Furthermore, people with these two different forms of autism might need very different kinds of support services. People who fitted the profile of Asperger syndrome had had to wait since at least 1938 for the medical profession to finally officially recognise this disability, and yet after just 15 years, it was about to be taken away.

> **Elon Musk can call himself autistic, the same diagnostic label given to a child who will never leave home**

My arguments got a lot of support from those who had a diagnosis of Asperger syndrome, who sometimes called themselves "Aspies", as this new diagnosis had become part of their identity, and they didn't want it taken away.

But the APA ignored my plea, and in 2013 published DSM-5, reverting to the pre-DSM-IV days to use the umbrella term "Autism Spectrum Disorder" or ASD. In the UK we tend to avoid using the term ASD because the word "disorder" is quite stigmatising, so we just call it autism. But by removing Asperger syndrome and lumping all forms of autism together, we have ended up with a category that merges individuals who are markedly different to one another.

The result is that a person such as Elon Musk can call himself autistic and this is the same diagnostic label that is given to a child who will never leave home or live independently, who has significant intellectual and language disabilities, and may have a host of co-occurring conditions such as epilepsy and self-injury. Yet, in 2013, overnight, both major subgroups of autism were folded together.

Fast-forward to today, and many people are arguing that classic autism is just not the same autism that is diagnosed in the absence of intellectual and/or language disabilities. It is notable that it used to be that the majority (some 75 per cent) of autistic people had an intellectual disability, whereas today it is about 30 per cent.

Some parents or family members, such as Alison Singer, who co-founded the Autism Science Foundation in the US, are understandably upset by the merging of these two types of autism, and are calling for the autism spectrum to be split apart into two subgroups: profound autism (defined as having support needs that are 24/7 and where the person will never live independently) and non-profound autism. She argued in The New York Times last month that this is not just an academic debate, since it is blindingly obvious that people in these two groups have different support needs.

Indeed, we now know that those with profound autism have increased risk of reduced longevity because of co-occurring physical health conditions such as epilepsy, while those with what was called Asperger syndrome have increased risk of reduced longevity because of co-occurring mental health conditions, including suicide.

'Unattainable Hug' © Emily June Smith

Some autistic people who are vocal on social media, and who would probably meet the old criteria for Asperger syndrome, have been quick to attack the use of the term "profound", arguing that all forms of autism can have profound support needs. And they are right, since autistic people without intellectual disability turn out to be more at risk of poor mental health. So why call their needs less profound?

Given that the term "profound" autism is problematic for at least some autistic people, I suggested in Scientific American in 2018 that we should just move towards using Autism type 1 (with learning disability) and Autism type 2 (without), as these are neutral terms that simply enable both science and health and social care services to avoid mixing up apples and oranges.

And to such a neutral nomenclature we could add as many more "types" as are scientifically or clinically useful, such as autism with or without language difficulties, autism with or without ADHD, autism with or without epilepsy, or autism with or without gastrointestinal pain. More subgrouping is likely to help science and support service provision.

Note that DSM-5 does currently allow for three levels of autism (level 1 being people who need support, level 2 substantial support, and level 3 very substantial support). But this doesn't solve the problem, as autism is still a unitary diagnosis when it is obvious that there are lots of different types of autism.

Some people in the autism community are understandably resistant to any splitting of the spectrum, feeling that they are already a small minority — only 3 per cent of the population are autistic — and it may be better to stand together to support one another, rather than be "stratified", which could lead to one subgroup being discriminated against and the other not.

> **Waiting lists for an adult diagnosis in my part of East Anglia can now run to 10 years (no, that's not a typo)**

And we know the appalling history of disability, particularly learning disability and the extremes of discrimination to which such individuals were subjected. In the name of eugenics in the US and elsewhere in the 1920s, this led to people with such disabilities being compulsorily sterilised, and in Germany in the 1930s and 1940s it led to people with such disabilities being compulsorily "euthanised" in gas chambers, along with other minorities in the population who didn't fit the Aryan norm. Better, many autistic people argue, to stand together, since divided we can be segregated, controlled and even prevented or eradicated.

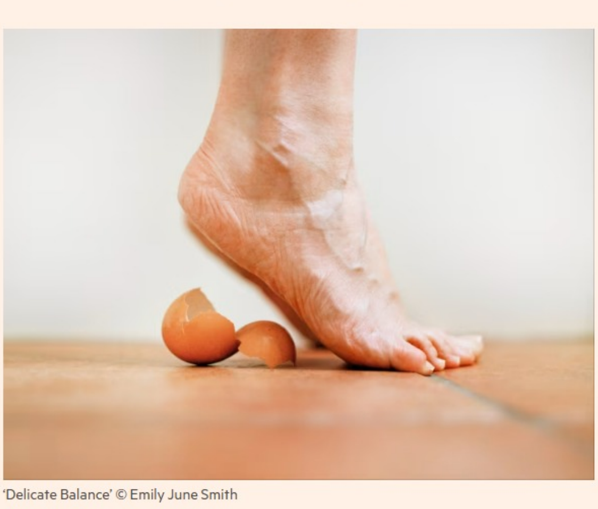
My own view is that the pendulum has swung too far in both directions, and that instead we should subgroup when it's helpful to do so, and unify when needed, perhaps when lobbying politicians for more funding for support services.

Some critics of this approach will argue that if we create a sharp delineation between subgroups, there will inevitably be some ambiguity about whether a given individual should fall in one category or another: some people fluctuate in their abilities based on situations or stress, and some people change over time, for example. London psychiatrist Dr Lorna Wing, who coined the term "autism spectrum", is attributed with saying: "Nature never draws a line without smudging it." It should however be possible to create a classification system that allows for change and that describes a person's type of autism as a snapshot in time.

My reason for arguing that we should use the nomenclature of type 1 and type 2, rather than just bringing back the old language of Asperger syndrome, is that in 2018 the journal Molecular Autism, of which I was co-editor-in-chief, published an article by a historian of medicine showing that Hans Asperger collaborated with the Nazis. He referred some autistic children to a hospital ward in Vienna that was known for compulsory euthanasia, to their death. No one wants a diagnosis named after a Nazi collaborator, so let's just go for the neutral and value-free nomenclature of type 1 and type 2.

Autism has become politicised in other ways. Back in 1998, sociology student Judy Singer coined the term "neurodiversity" in her undergraduate dissertation. Neurodiversity simply means there are many different types of brains in the world, just as the term "biodiversity" means there are many different types of flora and fauna. But Singer had a political motivation, as she wanted to kick-start a civil rights movement for autistic and other neurodivergent people, akin to women's rights, Black rights or gay rights. Consciously or otherwise, autism had become political.

Singer recognises she has a lot of autistic traits in herself, has an autistic daughter, and recognises her mother, a Holocaust survivor, was probably autistic. She could see how autistic people and those with ADHD or other kinds of brains had had their human rights overlooked, when other minorities were finally being accorded equal rights.



'Delicate Balance' © Emily June Smith

'Self-Defeating Thoughts' © Emily June Smith

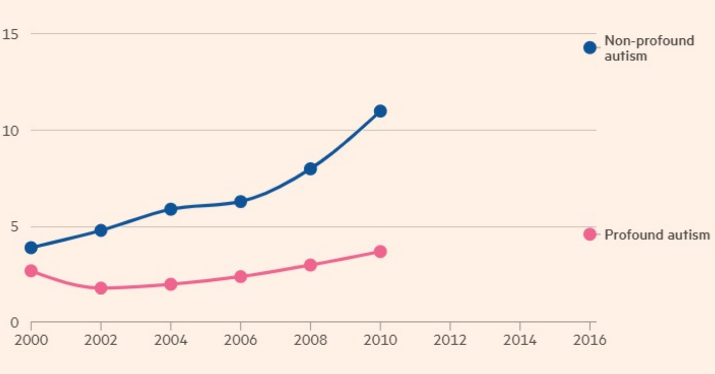
But for autistic people, nothing much changed — so much so that, 20 years later, in my keynote speech in the United Nations in New York on Autism Awareness Day 2017, I drew attention to the fact that autistic people were still falling outside of many human rights, such as the right to education, employment, protection under the law, health, dignity and leisure. Autistic people were at increased risk of dropping out of school, ending up unemployed, developing poor physical and mental health, experiencing social isolation, being arrested, and being the victim of abuse, bullying and hate crimes.

Back to Trump and Kennedy linking autism to environmental toxins: it is important to see how such speculations risk pathologising autistic people. Their view is antithetical to seeing autism in terms of the revolutionary concept of neurodiversity, as just one or several of the varieties of brains in the world that arise for largely genetic reasons, and which should be accepted and respected as differences and disabilities.

It is vital to speak out against the attempt to portray autism as something bad, something that should be cured or prevented. At the same time, we need to acknowledge that some forms of autism are accompanied by co-occurring medical conditions that do cause suffering and distress — conditions such as epilepsy and gastrointestinal pain — where cures would be welcome.

Prevalence of profound and non-profound autism among children

Per 1,000 children aged 8 years



Source: Centers for Disease Control and Prevention • Analysis based on data from 15 US sites in the Autism and Developmental Disabilities Monitoring Network. Data from 2012 and 2014 were unavailable and were excluded from analyses

Kennedy cites increases in diagnosis as evidence that there is an autism "epidemic". Leaving aside that the use of this term implies autism is a disease spreading in the population, which it is not, we should recognise that the huge rise is largely due to type 2 (Asperger syndrome) rather than type 1 (classic autism), since the rates of the latter have remained fairly stable over the decades.

Type 2 has not only increased because of folding Asperger syndrome into autism, but also because of social media and a huge growth in awareness of autism. And the growth of private diagnosis clinics for type 2 has undoubtedly contributed to the rising numbers. The small increase that can be seen in classic autism is likely due to "diagnostic overshadowing" of learning disability.

Politicians need to use language carefully since autism itself need not cause suffering and may not be in need of treatment or cure, even if some of the co-occurring conditions do cause suffering and are therefore valid "targets" for treatment. And we all need to recognise that while some aspects of autism lead to disability that needs support, other aspects of autism are just differences — some of which are even strengths or talents. Examples of the latter include a strong interest in pattern recognition, which in my book *The Pattern Seekers* I argued has driven human invention during the past 70,000-100,000 years.

So where does this all leave us? Today, we find ourselves in the depths of a crisis in the autism community. Waiting lists for a diagnosis of autism in adults in my part of East Anglia can now run to 10 years (no, that's not a typo): the NHS clinic I set up in 1999 for the "lost generation" of adults seeking a diagnosis of Asperger syndrome (type 2 autism) is now offering a diagnostic appointment in 2035.

And we are witnessing a crisis in rates of poor mental health in autistic people. When we looked at the patients coming to our clinic, we found two-thirds had felt suicidal and, shockingly, that one-third had planned or attempted suicide. We published that in 2014 as a wake-up call to governments around the world, but it took until 2023 for autism to be recognised as a high-risk group for suicide by the UK suicide prevention strategy, during which time we lost countless numbers of autistic people. They are feeling suicidal because of a history of bullying, discrimination, exclusion and high rates of unemployment and educational underachievement.

It's time to split the spectrum into type 1 and type 2, and to ensure there is high-quality support for all autistic people.

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