

Autism study is my life's work. The spectrum has lost all meaning

A professor who helped to shape our framing of the condition fears so many characteristics are linked to it that it's 'no longer a useful diagnosis'

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Dame Uta Frith is emeritus professor at the Institute of Cognitive Neuroscience, University College London

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When Dame Uta Frith began researching autism six decades ago, it was an extremely rare, little-understood condition which psychologists referred to as “childhood psychosis”. That was in 1966, and over the following decades she would play a central role in changing how the world sees the disorder.

She would expand what we understood autism to be, pioneering the leading “theory of mind” approach, which proposed that people with autism struggle to attribute beliefs to others, and arguing against the orthodoxy of the time which blamed autistic children’s unusual development on a lack of parental love. Along the way she argued that autism existed along a spectrum of

typical and “not-so-typical” presentations of the disorder. It is a concept which has been accepted and unquestioned for four decades. Until now. And it is Frith herself doing the questioning.

Now emeritus professor of cognitive development at the Institute of Cognitive Neuroscience at University College London, Frith, 84, is having second thoughts about the framework. “I think the spectrum has come to its collapse,” she says, over Zoom. Her cheerful and gentle manner feels incongruous with the gravity of the point she is making: Frith thinks that the autism spectrum is broken. That our approach is at best no longer relevant and at worst damaging. Not only that, she is also challenging a modern doctrine in science that values inclusivity as an end in itself.

It is this inclusivity, Frith says, that means “there is no longer a common denominator for all the individuals who are diagnosed as having ASD [autism spectrum disorder].”

“The spectrum has become so accommodating that I fear that it has now been stretched so far that it has become meaningless and is no longer useful as a medical diagnosis.”



ILLUSTRATION BY JAMES COWEN

In recent decades, rates of autism diagnoses have shot up dramatically. In 1998, 0.1 per cent of England’s population was diagnosed with autism. By 2024, that number had risen to 1.33 per cent (around 750,000 people), according to NHS data. The figures seem small, but it is a meaningful increase, and affects those on NHS waiting lists waiting for diagnosis and support.

The recent rise of cases “has not been equally distributed across the spectrum”, Frith says. “The group of children diagnosed in early childhood under the initial strict diagnostic criteria has remained relatively stable.” These criteria identify autism as a lifelong neurodevelopmental disorder which begins at birth (or maybe even before birth, Frith says) and involves impairments of speech and language and non-verbal communication that impact social skills, relationships and learning. It also affects IQ, and often involves an “extreme need for sameness” and repetitive behaviour.

But there is a second group, at the other end of the spectrum, people with milder problems, Frith argues: “These individuals have no intellectual impairment and are verbally fluent, but they typically feel highly anxious in social situations and are hypersensitive.”

There has been a dramatic rise in young people and adults in this group being diagnosed, especially women, says Frith. Studies in America and Sweden have shown that the rates of women with autism are rising faster than in other groups, and they are being diagnosed later in life. At the same time, autism has “become glamorised, and a diagnosis has become somewhat desirable”, as popular culture lionises fictional figures with autistic traits. “We don’t see schizophrenia being glamorised in the same way,” Frith says.

Frith, who began her academic career at Saarland University in Germany, is concerned about the consequences of this — “that the frightening rate of increase in later-diagnosed groups overshadows the needs of those with intellectual disabilities, who require much more intensive support”.

So how did we reach this point?

“Over the years, our basic definition of autism has remained the same, but it’s our interpretation of it that’s changed,” Frith explains. When she began researching autism, the diagnosis was narrow and confined to severely impaired non-verbal children. By the 1980s Frith was beginning to encounter children she felt did not neatly fit into the autism box but did present with some of its traits — the “not-so-typical” cases. These were children who had autistic traits but also fluent language and were highly intelligent. They were very similar to children described in the 1940s

by the Austrian physician Hans Asperger, another pioneer in the field, who lends his name to Asperger's syndrome. She argued that they too should be included in the study of autism.

This was part of the driving force behind the idea of autism as a disorder existing along a spectrum — credited to the British psychiatrist Lorna Wing — which has existed since the 1980s.

It was a way to include those children who were previously missing in their research, and at that time, better inclusivity was a good thing, Frith says.

Now, however, the milder end of spectrum has been expanded further, to include symptoms that once may have been considered to be personality traits, or individual sensitivities, such as an aversion to noise, or social awkwardness.

Part of the problem is that autism has no “biomarker”: there is no blood test, genetic screening or scan that shows someone is autistic. “If we had biomarkers, the diagnosis would be uncontroversial,” Frith says.

She is not trying to diminish those who experience these milder symptoms, or to suggest that there is nothing clinically wrong with those who fit into the bracket she loosely labels “hypersensitivity”. But she is, she jokes, a cold hard scientist: the clinical evidence simply is not present to include these people within the autism spectrum.

For Frith the widening of the autism spectrum also represents a troubling departure from the clinical rigour expected in a scientific field. She uses the example of young adults who have self-diagnosed with autism after reading about it online or on social media and coupled it with their extreme social anxiety, but who have excellent communication skills.

“Having a conversation with someone with autism is likely not to feel fluent, but to feel stilted or abrupt. So this fluency is a contra-indicator for the diagnosis of autism,” Frith says.

The clinical implications of this are particularly concerning, she says. Overdiagnosis dilutes research, Frith argues, because it mixes groups with potentially different biological causes and different cognitive dysfunctions. “This makes the data we obtain from large groups very noisy.”

She believes we should do away with the spectrum entirely. She would like to see it replaced with subcategories which separate those with childhood autism of the strict clinical kind, those with Asperger’s, and those with hypersensitivity.

“I hope that we may find meaningful subgroups, each with their own label,” she says.