

Researchers develop new tool to help detect hidden signs of autism in adults

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Researchers have developed a potential new tool to help clinicians detect hidden signs of autism in adults.

Autism is usually diagnosed in childhood but a growing number of adults are being diagnosed with the condition, even in mid-to-late adulthood.

Many adults develop compensatory psychological strategies to hide their symptoms from clinicians, employers and even their own families.

These strategies make the developmental condition much harder to diagnose and "performing" to fit into society can place a huge mental strain on the autistic person.

Eloise Stark, 30, a postgraduate student at Oxford University diagnosed with autism three years ago, said the hardest part of being autistic was trying to "hide it," and likened it to wearing a "mask."

Researchers from Cardiff University, King's

College London and the University of Bath have now devised the first potential tool to help detect psychological strategies that disguise signs of autism.

In a new study, published today in *Molecular Autism*, the researchers outline a checklist of 31 compensatory strategies that doctors, psychiatrists and psychologists could look for or ask their clients about.

They developed the checklist by asking autistic people about their experiences of using psychological strategies in everyday social situations.

Dr. Lucy Livingston, who led the research, said: "This allowed us to come up with a checklist of the most frequently-reported 'social scripts,' including things like copying gestures and facial expressions of others, learning when to laugh at a joke without understanding why it is funny and deliberately making eye contact, even when it might be really uncomfortable."

Dr. Livingston, a psychology lecturer from Cardiff University's School of Psychology, who has worked with autistic people who received a first diagnosis in adulthood for many years, said the next step would be to test its clinical efficacy.

"At the moment, professionals know very little about these strategies and what to look for. The new tool, if found to be effective, could help clinicians assessing adults for autism who appear to be non-autistic or 'neurotypical' on the surface, particularly those who are highly intelligent," she said.

"Being aware of these strategies should help clinicians to understand how hard the individual could potentially be working to keep up this appearance.

"Ultimately, this could mean that autistic people

receive a more accurate and timely diagnosis."

Eloise said: "This work has the potential to help spot autism in people like myself, who have gone 'under the radar' up to now.

"If I had received my diagnosis earlier, I may have avoided years of inappropriate medical and psychological interventions, and I would also have been able to build the positive autistic identity that I enjoy today much earlier."

Dr. Livingston said it might also help clinicians to identify and support those autistic people with additional mental health difficulties experienced as a consequence of "pretending to be normal."

It could also be used by adults who think they might be autistic or are seeking a diagnosis to help them understand their own behaviour, she added.

About 700,000 people in the UK are living with autism and it is under-diagnosed in females; three times as many males as females are diagnosed.

Senior author Francesca Happé, who is Professor of Cognitive Neuroscience at King's College London, said "Our work is one step towards helping to recognise compensating behaviours that autistic people use, often to avoid bullying and negative responses from neurotypical peers.

"We hope it will aid diagnosis and improve understanding of just how hard many autistic people work to fit in to an often hostile world."

Eloise's story

"I am learning to be more authentically autistic and authentically Eloise, even if that means that I sometimes stand out"

The most common response when I tell people that I am autistic tends to be something along the lines of "well you don't come across as autistic." This is precisely the point, and often the most burdensome part of living as an autistic woman in 2020; I often try to hide it.

I did not receive my diagnosis until the age of 27,

following an arduous battle with anxiety and depression that left me eager for answers as to why I had always felt "different" but had tried desperately to fit in throughout my life.

This process of fitting in often revolved around a complex set of rules and algorithms that enabled me to compensate for my inherent lack of a social instinct. Socialising is a bit like being among a crowd of people, and all of a sudden you forget how to walk.

Everyone around you is walking around nonchalantly and you have to think through every aspect of how to put the motor sequence together to stay upright and transition from one foot to the other. That's what it is often like to be autistic but trying to fit in. It takes energy, thought, and even though you might appear to walk just like everyone else, it takes a lot more effort to stay upright and appear normal.

Some things are easy to hide—I learnt implicitly from an early age that you are expected to make eye contact with people. As I grew older, I created algorithms to help scaffold my social behaviour, such as looking away for two seconds at a time for every four sentences of a conversation. I know that if someone makes a joke, I am expected to laugh whether I find it funny or not.

I recently learnt how to code and it struck me that my social brain works a bit like the code itself—input, rule, output. Observe others, see what they do, however odd it seems, and act as they do.

I am learning, however, to be more authentically autistic and authentically Eloise, even if that means that I sometimes stand out. Growing up in a neurotypical world can be hard and I spent much of my teens and twenties trying to fit in and compensate for my autistic quirks, but as I hit my 30th year, it dawned on me that it doesn't really matter whether I do "fit in" and actually, as long as I am flourishing in my own individual way, I can drop the compensation, camouflaging and my 'mask,' and that is okay.

Eloise, 30, from Oxfordshire, is currently studying for a DPhil in psychiatry at Oxford University.

Checklist

Provided by Cardiff University

Using the checklist, the researchers summed up compensatory strategies in 117 adults (58 with autism, 59 without autism) to create numerical compensation scores. They found that participants with an autism diagnosis or those self-reporting higher autistic traits (for example difficulties in reading other people's minds) had higher compensation scores.

Individuals would score 1 (presence of strategy) or 0 (absence of strategy) on each item on the checklist:

- Predict, plan out and rehearse conversations before they happen, out loud or in your head
- Mimic phrases, gestures, facial expressions, tone of voice picked up from other people and/or TV/film/book characters
- Rely on props (e.g., dog, children, interesting object) to structure and guide conversation
- Make appropriate eye contact, even if it is not useful for communication and/or is aversive OR avoid eye contact but give the impression of social interest (e.g., look at bridge of nose, stand at a 90° angle to interaction partner).

The checklist could offer a first step for clinicians to help measure compensatory strategies during autism assessments. It could also help improve awareness of more invisible features of [autism](#) to GPs, who are the first port of call for individuals seeking a diagnosis.

The study used a sample that was predominantly comprised of intellectually-able females so the researchers said further work would be needed to establish whether the findings were true of the wider autistic population.

More information: Lucy Anne Livingston et al. Quantifying compensatory strategies in adults with and without diagnosed autism, *Molecular Autism* (2020). [DOI: 10.1186/s13229-019-0308-y](https://doi.org/10.1186/s13229-019-0308-y)

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