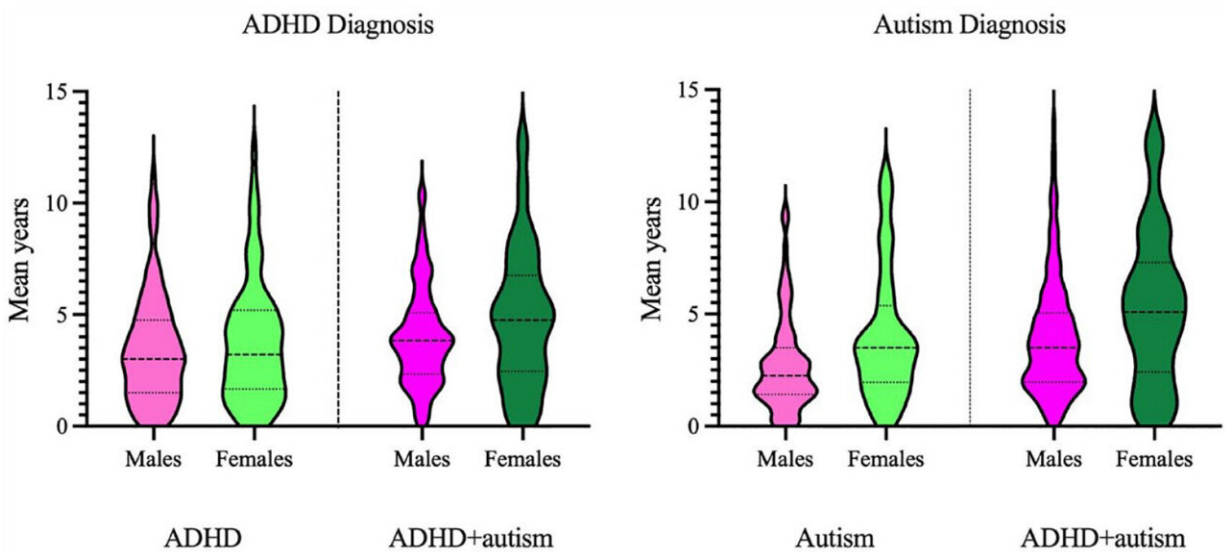


# Q&A: Identifying the barriers to earlier autism and ADHD diagnosis

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Delay to ADHD and autism diagnosis for males and females with ADHD, autism and ADHD + autism. Credit: *Australian & New Zealand Journal of Psychiatry* (2023). DOI: 10.1177/00048674231206997

Diagnostic delay is a major concern for children and young people with autism and attention deficit hyperactivity disorder (ADHD)—and also for their loved ones.

The delay is the gap between first concerns about a child's development, and their eventual diagnosis. In some cases this can be more than five

years.

Monash Ph.D. candidate Rachael Knott, from the School of Psychological Sciences and Turner Institute for Brain and Mental Health, has co-led [a new study](#) of nearly 700 Australian parents or caregivers that investigates the delay. The work is published in the *Australian & New Zealand Journal of Psychiatry*.

It's the first worldwide to directly compare age at diagnosis and diagnostic delay for males and females across ADHD, autism, and a combination of the two.

Knott explains the research to Lens.

## **First, what did you find out?**

We confirmed what we were expecting and what we were hearing from families, which is that it takes a really long time to get a diagnosis of ADHD or autism. The lowest estimate was three years, and up to four-and-a-half years.

The recent report from the Senate inquiry into the "assessment and support for people with ADHD" also highlighted long wait times for people seeking a diagnosis.

Another component we looked at was differences between males and females within each group, which also hasn't really been looked at, especially in the co-occurring group.

Females with autism and females with both autism and ADHD were waiting longer than males to get their [autism diagnosis](#), with females in the co-occurring autism and ADHD group having the longest delay. That was just over five years.

## **What needs to be done about this?**

It tells us we need more education and training for people involved in every stage of the process. Caregivers need more information on what to look for in the early stages. Maybe we need more specialist training for GPs, pediatricians and psychologists so more people can identify the early markers of the conditions, and hopefully or diagnose refer sooner.

We need more clinicians who are specialized in the area and know what to look for, especially when autism and ADHD occur together and how that might present.

Hopefully that would speed up the process of identifying and diagnosing.

## **GPs would seem to be crucial in this?**

Yes. GPs can be the initial gatekeeper, because parents come to them with a concern. They need to know more about what warrants referral.

At the moment we don't have guidelines on diagnosis for the co-occurring group. We do have diagnostic and treatment guidelines for autism only, and we've got the same for ADHD only, which have just come out in Australia, which is really exciting.

But what we don't have yet are guidelines specifically for this co-occurring group, and how they might be different. We don't have enough research yet to write those guidelines, but we're heading in that direction. Our paper is saying, "We need this, it's taking too long."

## **What's the process like now for a parent or caregiver?**

In Australia, when children get a diagnosis, that's a gateway for support

and funding. The faster we can identify and diagnose kids, the faster they have access to all of these things.

But the process is rarely linear and straightforward. There's a lag between when parents or teachers pick up some kind of neurodivergent development happening to when they go see their health care professional. And then, from that point, another lag on how long it takes the clinicians to disentangle what's going on with the child.

We've chosen to include this period of first concerns because parents and caregivers and teachers are important stakeholders in this discussion. That lag period can be about a year. If we don't include that, we're not really understanding the full picture.

## **Also, there's no biological markers for autism and ADHD, or both, so diagnosis is solely about behavior?**

Yes. Parents and teachers watch and compare and wait and see how it's all developing. When they get to the clinic, a similar thing happens.

The diagnostic categories for autism and ADHD are quite broad, so there's lots of variation in the symptoms and the combinations that children can have. Two children can look quite different and have the same diagnosis, which means it can take quite a while to disentangle what's going on with them.

And then, when you put the two diagnoses together, that adds more variation, so it takes even more time to get a diagnosis.

That's why it is important to look at not only children with just one diagnosis, but also this extra group which have both, as they are inherently more complicated in their presentation.

## **A lot of unknowns**

One of the challenges for the field at the moment is that when we measure delay, this period of initial concern is just general developmental concern, and we're not really sure what's going on yet.

And then, for the kids who have both conditions, we may not be able to differentiate or disentangle whether it might be an autism-related concern or an ADHD concern. We're just looking at general concerns at the beginning.

Development is very complicated, especially when you have two conditions. And so, in future, I think it would be great to be able to pick up what concerns are arising first. Maybe it's autism, maybe it's ADHD. What diagnosis do they get first? And then do different concerns arise once the first diagnosis is treated or not?

## **Why is it so complicated to separate the two conditions early?**

The first thing, I think, is the variability. So within each [diagnosis](#), there's all of these different types of presentations you might have for a child with autism. And then, in ADHD, there's all of these different presentations.

And then, if a child has both, you put them together, and it's this enormous kind of mess of behavior that you're trying to pick through and say where it belongs. There's a lot of overlap, and it can be very complicated.

I'll give you an example. So, social communication problems are pivotal to autism, but it can be difficult to tell when you're just observing

behavior if that social communication problem is because the child doesn't understand the social cues, which fits better in the autism category, or if they're maybe not paying attention to the social cues, which sits more in the ADHD category.

The origin of the behavior can be complicated to figure out when you're just watching them.

## **Can you explain that a bit more?**

Autism is perhaps going to be difficulties with social communication, problems with [social relationships](#), understanding [social cues](#), difficulty with appropriate gestures, or maintaining appropriate eye contact.

But maybe if they have ADHD, they're not looking at you because they're distracted, or they haven't been paying attention.

And then, probably more on the autism side, is the restricted repetitive behaviors, which is the other core diagnostic domain for autism. Then the hyperactive, impulsive component of ADHD is on the other side, even though that can come across as a bit socially inappropriate as well at times.

## **Why do girls with both autism and ADHD have a longer delay in diagnosis, do you think?**

The way that ADHD and autism can present in girls compared to boys can be different. The understanding of typical presentations of these conditions at the moment is probably more geared towards the male presentation rather than the female.

And so we thought that because of that, it might take longer to identify

the girls compared to the boys.

Sometimes, in ADHD, with a more inattentive profile rather than hyperactive or impulsive, it can take longer to pick up. It's very obvious if your child's climbing all over the table, but if they're just drifting off in class, it can take longer for that to be picked up by people around them.

And in [autism](#), there's a school of thought that females might be better at using compensatory or coping strategies that can sometimes mask some of their traits.

**More information:** Rachael Knott et al, Age at diagnosis and diagnostic delay across attention-deficit hyperactivity and autism spectrums, *Australian & New Zealand Journal of Psychiatry* (2023).

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