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## Science AMA Series: I'm Suzannah Iadarola, Ph.D., autism specialist at the University of Rochester Medical Center. April is Autism Awareness Month, so let's chat! AMA.

SUZANNAH\_IADAROLA [R/SCIENCE](#)

Good afternoon Reddit!

I'm Suzannah Iadarola, and I'm an Assistant Professor of Pediatrics at the University of Rochester Medical Center. I'm a clinical psychologist and board certified behavior analyst who specializes in working with children with autism spectrum disorder (ASD) and their families. I'm happy to be here today to answer questions about ASD and to hear about your experiences.

I've been working with children with ASD and their families for over 15 years. In addition to providing direct clinical services, I also am involved in various research studies. This includes projects related to family stress and to helping under-represented families access high-quality interventions. Much of this work is done in partnership with key community members and family members.

I'm looking forward to a lively discussion today! I will be back at 1 p.m. to start answering questions. In the meantime, here are some links in case you want to get started with some information.

-General information about [ASD from the CDC](#)

-Autism Speaks and the Autism Treatment Network created a variety of helpful [Toolkits for families and educators](#)

-The [Interactive Autism Network \(IAN\)](#) can connect you with potential research studies about ASD

**Thank you all for the lively conversation today! I am signing out, but I will try to check back in to read additional comments.**

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Recently I've seen articles about how ASD manifests differently in girls and women, which leads to incorrect diagnoses in childhood and late in life (adult) diagnoses that result in girls not receiving therapy as children. What have you found to be early signs of ASD in very young girls? What should parents and pediatricians look for?

[aethauia](#)

This is a great question, and a better understanding of girls with ASD is a high priority for researchers and clinicians. We already know that there are about 4.5 boys diagnosed with ASD for every girl. Emerging research suggests that girls who do not have an intellectual disability or high rates of problem behavior are less likely to fulfill ASD criteria than boys. Some research supports they are less likely to show restricted behaviors, repetitive behaviors, and intense interests, as compared to boys. There has been the suggestion that girls with ASD, especially those with average cognitive abilities, show more social interest and may be better at "camouflaging" among peer groups than boys with ASD. Interesting preliminary research also suggests that school-age girls with ASD show differential patterns of interacting with peer groups as compared to boys with ASD.

So what does this mean for early diagnosis? We do know that girls with ASD who also have an intellectual disability or high rates of repetitive behaviors tend to get diagnosed earlier. In the absence

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of these characteristics and when there are serious social concerns for girls, I would say a couple of things. First, take good care to assess the **quality** of interactions, such as how she approaches others and how she responds to and interacts with other, not just whether these skills are present or absent. Oftentimes girls with ASD can “camouflage” for a while but over time it becomes apparent that their social differences affect **how** they interact. Secondly, when assessing very young girls, it is important to continue to monitor over time. It might be important to be open to revising the possibility of ASD as girls age, particularly when they reach school age and the social demands might start to exceed their abilities. Your point about missing out on important therapies is very good too. For all children who present with social concerns – whether or not they end up with an ASD diagnosis – it is so critical to provide social supports early in life so that children can interact with their peers in a way that makes them happy. Social supports can be integrated into other forms of therapy, such as in speech therapy (through practicing greetings, conversation skills, asking another person to play, etc.).

What are your thoughts about the removal of Asperger's Syndrome with the publication of the DSM V? I'm a mental health therapist that has worked primarily with youth with co-occurring mental health disorders and developmental delays, usually Asperger's. I personally saw a worthwhile distinction between the two disorders. I felt the higher functioning Asperger's diagnosis was less stigmatizing for those without the more severe version of the disorder.

*edited: a typo was bothering me*

[Mail-Leinad](#)

This is certainly a topic that is discussed a lot. As many of you know, the official diagnosis of Asperger's was taken out in DSM-V (our current manual that we use to diagnose different conditions). I like to think about this a little differently and offer that Asperger's has not been “removed” per se, but is now captured under a broader definition of ASD that appreciates the full spectrum of abilities across many dimensions (social, behavioral, cognitive, language, etc.). One of the reasons for the restructuring of the ASD diagnosis is that even among clinicians with high levels of expertise, we were not very consistent at differentiating among individuals with Asperger's versus autism without intellectual disability versus PDD-NOS (another former diagnosis under the autism spectrum umbrella). Studies have shown that most individuals (including those with Asperger's) still meet criteria for ASD under DSM-V.

That being said, I appreciate that there is a very large community of individuals who strongly identify with Asperger's, including those who self-identify with this diagnosis as well as their families. I strongly support this community in their choice to use a term that resonates with them. I also understand that identifying yourself or a family member as a person with Asperger's can help orient others to the individual's potential strengths and areas of need. For those who prefer the term for this or other reasons, it still makes sense to use it!

Is autism more prevalent now because of increased diagnosing techniques or is the disorder actually affecting more people?

[Schnawsberry](#)

Increased prevalence rates as compared to previous years (currently 1:68) (1:42 boys) (1:189 girls) are thought to reflect a combination of factors:

- Broader definition of ASD that includes individuals who might have been previously missed or diagnosed with something else
- Recommendations for screening for ASD at 18 and 24/30 months to make sure we identify children

early

- Greater awareness on behalf of educators, providers, and families
- Importance of documenting diagnosis to have access to important early interventions and school-based services

Rather than speaking to overdiagnosis of ASD or underdiagnosis of ASD, I'd rather think about it in terms of making sure that we have the correct diagnosis of ASD. The increased prevalence rate of recent years is in part due to "catch up" in the diagnosis of older children and youth who were not identified in early childhood. Because over half of individuals with ASD have typical cognitive abilities, many may not be identified in early school years. Some of these students would have benefited from social skills and other interventions. However, we do know that overdiagnosis is a problem for many behavioral disorders including ASD, ADHD, and bipolar disorder that do not have a specific biologic marker like physical disorders do. Importantly, the most recent data suggest that prevalence rates of ASD have actually stabilized over the past couple of years.

What is your opinion on the ongoing debate between cure vs acceptance? Do you think that both are important in supporting those with autism, or do you think that one is necessarily more important than the other? I don't know enough to form an opinion on either, but I am curious what an expert's opinion is.

Thanks for taking the time out of your busy schedule to make us more informed!

[st4n13l](#)

Thank you for raising this question. I will give my perspective and thank the others who have already replied as well. As humans, we are all on different spectrums – anxiety, ASD, mood, etc. The diagnostic manual that we use to provide a diagnosis focuses not on symptoms alone but on the extent to which they interfere with a person's ability to participate in society and do the things they want to do. The way I see it, interventions are therefore not designed to "cure" disorders but to address the aspects of a disorder that might cause distress to the individual or his/her family and to allow the individual to be more fully included in the life that they want. One other important side of neurodiversity involves celebrating differences and unique qualities of people with different abilities. Many individuals with ASD can speak to their own strengths and also identify strongly with their community of persons with ASD. Some of their voices are represented on this board today.

My son was diagnosed to be within the ASD displaying several symptoms around age 2. Since hitting puberty it's like his brain woke up and he has stopped having some of them. He can carry on meaningful conversations with eye contact now and no longer obsesses about his things. What happened?

[restless\\_and\\_bored](#)

That must have been a shift for all of you! Your story highlights how much we still have to learn regarding the biological and neurological underpinnings of developmental trajectories in ASD. Similar to what you see in all child development, individuals can show developmental bursts (like the one you described) that are accompanied by gains in certain skills. Unfortunately, we are generally not able to predict when these will happen, who they will happen to, or what gains to expect. Although I can't give a good scientific explanation for what you saw in your son, I do think his experience highlights how important it is that we continue to assess strengths and needs of a person in a dynamic way. This will allow us both to appropriately support individuals in meeting their goals and to appreciate their growth. Thank you to the teen who responded and gave us a personal account of their experience.

First, thanks for all the good work you do.

I have a family member who is profoundly autistic. He is essentially nonverbal, only quoting when he needs to communicate. He is approaching his adult years, and we are starting to grow concerned about how his care will be handled once he is done with school.

Early intervention, and great, dedicated educators have made a huge difference in his life, but after he is finished with school he'll still require care. Can you speak a little bit about what you and others have been working on to help those on the spectrum who need significant assistance into adulthood?

[astrobeen](#)

As you highlighted, this is such an important topic. Many individuals with ASD will require assistance throughout their lifespan. With respect to research, funders have recognized that this area is understudied, and have supported specific research opportunities for those interested in ASD in adulthood. In terms of our research program, we have an excellent group here that is working on a health literacy program, to assist individuals with ASD make the transition to caring for their own medical needs. Nationally, there are also efforts to promote successful transitions into adulthood for individuals with developmental differences, such as those offered through [Project SEARCH](#). An increasing number of colleges are also offering specific programming to support the academic, daily living, and social experiences of students on the spectrum. At the policy level, there are groups dedicated to advocacy and development of services for individuals with disabilities who might require long-term support. I invite you to explore the [National Council on Disability](#) and the [Health and Human Services Office of Disability](#) to learn more about these efforts.

Any thoughts or theories of how ASD and anxiety are related? With the high comorbidity, I'm often wondering if it's some aspects of ASD (black and white thinking, fixating on ideas) that leads to the anxiety or if these two conditions are both directly caused by the same underlying brain differences.

[malica77](#)

There is so much to be said on this topic! Like you said, these conditions are highly comorbid, with around 40% of individuals with ASD (and up to 70% by some estimates) also demonstrating anxiety. It is quite possible that some of this may be socially constructed (as suggested below), such that it is stressful to meet the demands of integrating into society. There are questions about whether there are physiological characteristics of those with ASD that might relate to high levels of anxiety. Unfortunately we don't have definitive evidence to support this yet.

From a clinical perspective, it is extremely important to be aware of this comorbidity and explicitly assess for anxiety. An increasing body of research is suggesting that anxiety may present differently in ASD and that it is critical to make sure we are assessing for anxiety in a way that is developmentally and linguistically appropriate for individuals with ASD.

Would there be any benefit to an adult who may have high functioning autism getting diagnosed?

Could someone 20+ who has already had to learn to emulate others realistically expect any further quality of life improvements?

[himthatis](#)

I think it largely depends upon you and what your goals are. As suggested earlier, some people who are diagnosed as adults may qualify for supportive services to which they would not otherwise have

had access. Others may seek a diagnosis in adulthood just to better understand themselves or their experience. If you are a person who might have struggled in some ways when you were younger and never felt that you knew why, an ASD evaluation could provide at least some answers. It sounds as though you have already done a lot on your own to help yourself be successful.

We do have good diagnostic instruments that can be used in adults, such as the Autism Diagnostic Observation Schedule, 2nd edition (ADOS-2). If you choose to seek an evaluation, I would recommend finding someone who has expertise in adult ASD assessment.

I see you do a fair bit of work with ABA therapy and I'm wondering, as an ABA therapist myself, is there any single suggestion you could give me/fellow ABA therapists that would make a difference in the effectiveness of our work? I work with kids of all ages and abilities. I'm curious if you've seen something over the years that sticks out.

Edit: I'll append my question with a second. I have seen a good bit of negative sentiment in response to ABA therapy in the online community. What would your response be to that?

[imapadawan](#)

All the responses so far have highlighted the charged debate around ABA really well. Generally (and as others have suggested), I think there is a widespread misunderstanding of what ABA is. Often it is equated with the running of repeated, massed, "table-top" trials to teach a child a specific skill. Rather than a therapy however, ABA refers to a set of behavioral principles that govern behavior for all of us. This acknowledges that behavior can be influenced by what comes before it (antecedents) and what comes after it (consequences). To some extent we all operate under these principles. How many of us would show up to work tomorrow if we knew we were no longer getting paid? (In this example, the paycheck is the consequence.) In practice, ABA-driven interventions for children can be quite flexible when they are done right. Such interventions may occur at a table, but they can also occur at circle time or in a park or in a dance class. These interventions can meet the needs of the child, some of whom might require repeated trials to learn something new, but the emphasis should always be on generalizing skills to real-world settings. There is also an increasing number of treatments represented in research that can be considered "blended" interventions, which incorporate ABA-driven, adult-led strategies with more developmental, child-led strategies. These have been successful in promoting language and social interaction skills. I hope this response sufficiently answers your question and also highlights the true flexibility and naturalistic nature of ABA-based interventions.

My brother is severely autistic and his only way of communicating with us is basic sign language (ex: bathroom, he wants something, he wants to go somewhere). He's in love with Disney movies, and would repeat the Pinocchio theme song all day. Is there a reason for autistic people to be so repetitive?

[Someyoungchild](#)

That's a great question! There is preliminary exploration into brain differences in individuals with repetitive behavior, but I don't think we're at a point where we can definitively say why individuals with ASD engage in repetitive behavior. Repetitive behavior may serve a self-calming function for some individuals. It may be enjoyable for them either because the repetitive action itself is enjoyable or because the behavior is related to a favorite topic. Repetitive language and play may also be a way for individuals with language or social difficulties to communicate with others in a manner that is comfortable to them (as suggested by the person below).

What can be done to combat the myth that vaccines cause autism?

[PhyrePhoxe](#)

To be honest with you, I have personally struggled with how to best address this myth. The scientist side of me shares the facts. I cite the myriad research debunking the link between ASD and vaccines. I tell the story of Andrew Wakefield's personal conflicts of interests when it came to the vaccine companies. I tell people that as a professional who has worked in the field of ASD for over 15 years, I did not hesitate to vaccinate my own children. But I also make space for people to share their own stories, so I can better understand the concerns of those who still struggle with this issue. The more awareness we (as clinicians, advocates, family members, etc.) have of both sides of the argument, the better prepared we are to discuss this in a way that can resonate with those who don't share our beliefs.

Is the rise in autism diagnoses due to a decrease in intellectually disabled (mentally handicapped or "challenged") diagnoses? It seems like the spectrum is becoming so broad that it's just a reclassification of previously existing conditions that were viewed in a more negative light, i.e someone who is a non-verbal autistic may be given more opportunities than someone classified as "mute".

<https://www.sciencedaily.com/releases/2015/07/150722130412.htm>

[flamaxblanca](#)

I think you are correct. The broadening of the ASD criteria has included more individuals with high cognitive abilities, but it also captures:

- Those who are minimally verbal (without intellectual disability) who might have previously been given a different diagnosis
- Those with an intellectual disability **and** ASD who would previously been giving a diagnosis of just intellectual disability

I am glad you linked to that graphic; I think it shows this pattern very well!

After reading many sites and the "signs" associated with Autism, how would an adult 18-30 year old be screened to know if they are autistic, or if they just have some tendencies?

[oathkeeper2013](#)

I'll repeat some of the information from a previous post, because this is a good question. There are what we would consider to be gold-standard assessments for ASD in adults, namely the Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2). There are ASD screeners, such as the Gilliam Autism Rating Scale (GARS-3), that can also be used in young adults. An evaluation should focus on DSM-V symptoms and would likely also cover possible other mental health conditions that might results in similar "signs" in adulthood. If you seek this evaluation, I would encourage you to connect with a provider who has expertise in ASD evaluation in adults.

As someone who is actually autistic, I feel the need to point out that Autism Speaks is generally HATED by the autistic community for how they treat us and how little support we receive from them. I would strongly recommend you look into their history and interactions with autistic people and question your connection to them!



That being said, what autistic support/advocacy groups have you been involved with and who (among charities) do you see as actively contributing to research in the field at this time?

[Kell\\_NaraneK](#)

Thank you for letting us hear your voice on this. To your point, Autism Speaks no longer emphasizes a "cure" as part of their mission. There is a very active community of people who self-identify as having ASD who **should be heard** regarding their own experiences, particularly in the culture of increasing acceptance of neurodiversity. This can also be balanced with experiences of families and individuals with ASD who have significantly benefited from the resources offered and developed by organizations such as Autism Speaks. For the larger community, I believe it is possible to hold awareness of both of these perspectives and continue to have conversations so we can better understand all sides of the issue.

To the question about other organizations – most of my experience with our excellent local agencies and not-for-profit organizations, which are quite extensive in Rochester. Nationally, the [Association for Science in Autism Treatment](#) offers excellent information and updates regarding research findings on interventions designed to help support individuals with ASD. More broadly, the [Association of University Centers on Disabilities](#) fosters interdisciplinary collaboration around research, services, advocacy, and policy for individuals with disabilities. I highlight them here because their truly inclusive board represents neurodiversity, among other types of diversity. I often find that local organizations can be extremely helpful to those looking to support and promote acceptance of individuals with ASD. For those who are not already involved, I would recommend researching what is available in your area and becoming active with a group whose mission aligns with your values.

My son turns two in a few days, but only says 5 words. He engages with others, uses sign language and is perfectly normal in every other way. Medical professionals want to label him autistic, even though he doesn't really have any other behaviors (their words). 1) Is there a rush to label? 2) how many false positive diagnoses are there?

[surgesilk](#)

We know that early identification and intervention of ASD are associated with the best outcomes. For that reason, there is often a push for early diagnosis when concerns first arise. Primary care providers can provide multiple levels of surveillance and screening. They can provide ASD-specific screeners at specific timepoints (18, and 24/30 months) or if a parent expresses concern. For a 2-year-old, the Modified Checklist for Autism in Toddlers, Revised (MCHAT-R) is most commonly used. It is available online at (<https://www.m-chat.org/mchat.php>). The results of the MCHAT can help suggest whether a referral to an ASD specialist is indicated. Typically, an ASD evaluation would be done by a psychologist, developmental pediatrician, psychiatrist, or other provider who has specialized training in diagnostic assessment in ASD. At the same time, if there are concerns for other delays (such as speech or motor skills), the child may also be referred for another evaluation (such as through early intervention) to see if related services are recommended.

High functioning autism (24m) here.

If I have children, what are the chances of my offspring also being autistic?

[Droidehz](#)

The poster below gave a good reference to the JAMA psychiatry article. I'll add to this by also saying that if you have a child with ASD, there is a 1 in 5 chance that a second child will also have ASD, with the likelihood being slightly higher for a male versus a female child.

My son was diagnosed initially with Autism and later changed to Social Communication Disorder. I have found that when stating his diagnosis that I am often met with comments like "oh all kids have some communication issues" or don't think it is that big of a deal. When I state that it is similar to Autism without the repetitive behaviors the light bulb goes on and there is much more understanding of his abilities.

Do you feel that the addition of Social Communication Disorder has improved the ability to treat and diagnosis children? Or that it has hindered the ability of these children to receive the services that they need? Or that their just needs to be more awareness of the diagnosis?

[SilverLillyFarms](#)

Your answer is spot on! Social Communication Disorder (SCD) captures those who experience the social symptoms associated with ASD but do not show restricted or repetitive behaviors. With the changing criteria of ASD, SCD importantly identified those who require social support who might otherwise not have qualified for services. Your point about awareness is excellent as well. Because it is relatively new, SCD has not garnered the same attention and understanding as a diagnosis like ASD. You've experienced this in your efforts to explain what it is. Clinicians, school teams, and families should continue to have these conversations to help others understand the needs of children with SCD.

I have aspergers and have more than a passing interest in the sociological effects of being autistic.

What makes me unable to sleep at night is how little talk there is of the sociological problems/benefits facing people with Aspergers.

What makes the problem so severe is that there are so very few people who take the issue on.

Most experts regarding autism tend to be directly concerned with autism as a neurological condition.

It's sorta like being a woman where the feminist talk exclusively about the physiological aspects of gender and stare blankly when you mention income inequalities etc.

***\*My question is directly do you have any thoughts on the subject are you aware of the concern for the topic etc.\****

I know i have a natural tendency to obsess over things, and to be oblivious on how others might feel on the topic.

But I simply can't get over the feeling that I'm one of the most studied persons on the planet on the issue.

Not because I'm some high iq genius but simply because I have an autistic obsession in sociology/economics/humans systems.

If one is gonna acknowledge how severe the socioeconomic disparities are for people on the spectrum it seems there's a dire need for some serious strategies to fight this disadvantage.

[CommanderStarkiller](#)

I want to make sure I'm not misunderstanding your intent here, but I think you are referring to the concern regarding the systematic disparities that neurodiverse individuals face? If so, then I am aware of this critical issue, and in my experience I think others are as well. There are several research articles published on economic and service disparities in ASD (and this number is quickly growing). To some



extent I think your question aligns also with policy issues for those with varying abilities. Some of this work is being done by groups that I mentioned in earlier threads, including the [National Council on Disability](#) and the [Association of University Centers on Disabilities](#), to name a couple. I suspect that we are in a current social climate that will require us as a collective to confront various forms of "isms," including ableism. Awareness is a precursor to acceptance, so strong, passionate voices such as yours are critical to reducing various forms of disparities for neurodiverse individuals. Please keep raising your voice.

My little brother (age 4) is autistic (mild so far but only time will tell). My father had him in his second marriage at the age of 43. I was wondering if your research has found any correlation in genetics.

For example, are my chances of having autistic offspring increased since I have a sibling who has it? And does having children later in life (although my father's wife was 25 when she had him) increase your chances of having a child with autism?

[nyav-qs](#)

This is an important question, which is why it's being raised by multiple posters! I will refer you to my response to an earlier comment that covers your question. I hope it helps.