

LIVE Election 2024 Results

▲ [Minnesota Now with Cathy Wurzer](#)

Cathy Wurzer and Gretchen Brown · October 10, 2024 11:42 AM

Research finds 1 in 16 Somali children diagnosed with autism, 3 times more than state average



ON AIR
MPR NEWS WITH ANGELA DAVIS

Listen Research finds 1 in 16 Somali children diagnosed with autism, 3 times more than state average

Save 

SHARE

One in 16 Somali-Minnesota 4-year-olds has autism. That's compared with one in 53 of their classmates.

The data comes from a 2023 Centers for Disease Control [autism survey](#), with help from two University of Minnesota researchers who are tracking the rise in overall diagnoses over the years.

Reporter Fred de Sam Lazaro recently spotlighted the increase in a [PBS Newshour report](#). Lazaro spoke to Amy Esler who is one of the researchers in this survey.

"I'm glad that we were able to provide some confirmation on what parents have been talking about for over 10 years now. And, hopefully, this helps influence policy," Esler told Lazaro.

For another perspective on this data, Dr. Deeqaifrah Hussein joined the program. She is the executive director of special education with Minneapolis Public Schools.

Use the audio player above to listen to the full conversation.

Subscribe to the Minnesota Now podcast on [Apple Podcasts](#), [Spotify](#) or wherever you get your podcasts.

We attempt to make transcripts for Minnesota Now available the next business day after a broadcast. When ready they will appear here.

Audio transcript

CATHY WURZER: One in 16 Somali Minnesota four-year-olds has autism. That's compared with one in 53 of their classmates. The data comes from a 2023 Centers for Disease Control autism survey from two University of Minnesota researchers tracking the rise in overall diagnoses over the years. Minnesota-based PBS reporter Fred de Sam Lazaro recently spotlighted the increase in a

parents have been talking about for over 10 years now. And hopefully, this helps influence policy.

CATHY WURZER: For another perspective on this data, we're joined by Dr. Deeqaifrah Hussein, who is the executive director of special education with the Minneapolis Public Schools. Dr. Hussein, thank you for taking the time.

DEEQAIFRAH HUSSEIN: Thank you for inviting me.

CATHY WURZER: The prevalence of autism, as you know, has risen significantly across all populations in this country. More common, though, among children of color. But the one group as we mentioned, Somali Americans, are seeing an alarming increase. Is this research consistent with what you're seeing in Minneapolis public schools?

DEEQAIFRAH HUSSEIN: Yes, definitely. We're seeing a rise within the Somali community. We're also seeing, because of the work that the University of Minnesota is also conducting, it's creating a prevalence awareness within the community. So parents are more savvy in navigating and asking for services.

CATHY WURZER: I'm wondering, from what you know, hundreds of genes have been identified that are linked to autism, and there might be an environmental component, too. What's the research saying when it comes to the Somali community? Anything?

DEEQAIFRAH HUSSEIN: The research is not saying much. If you look at the research, usually the literature says that there is three things. There's a social stigma within the community. There is lack of autism awareness. And one thing universal is the late diagnosis. I did my dissertation specifically in the experiences of Somali parents within autism diagnosis and navigating special education.

And my research was also consistent with the existing literature had found, which there was still a social stigma, lack of autism awareness, late diagnosis. In addition to that, there were lack of trust in the system, parents feeling grief and loss, shock of the disability label. And consistent among all those participants was the lack of knowledge about special education system and what supports are available to them in the school system.

advocates within the community. It's maangaar, which means unique mind. It is a positive spin, but also, it's timely because as the prevalence is going up, we have to find out a name because there is no name within the Somali community. Right now, the term that's being utilized is maangaar.

CATHY WURZER: And when people talk about maangaar, are there misconceptions about it itself within the community?

DEEQAIFRAH HUSSEIN: There is, depending on what journey the parent is at. If they have kids that are on the resource level, higher functioning autism, that can be addressed through social skills.

If the kid is verbal, they're not accepting of autism. But when the child is on the severe end of the spectrum, they can see it for themselves that the stereotypical symptoms that are identified with autism is prevalent within their child.

CATHY WURZER: Speaking of misconceptions, there are misconceptions in the community about vaccines causing autism. Are you having to battle that as well?

DEEQAIFRAH HUSSEIN: Yes. That's something that the community has been battling for a long time. There are still new parents who will be reluctant into vaccinating their children. The misconception is that vaccines do cause autism, and there is nothing in the medical literature that proves that point.

CATHY WURZER: Getting back to supports, you're with the Minneapolis Public Schools. What kinds of support help autistic kids thrive in school?

DEEQAIFRAH HUSSEIN: Early intervention. The earlier a student can get in our doors and get academic programming that addresses their academic, social, emotional supports, their related technical services, and functional communication, the better the student will thrive. Usually, other populations, they get early diagnoses and early childhood special education.

Our students sometimes come in after four or five years, and they're behind the minute they walk into our doors. They're already playing catch up, and early intervention has not been-- we get kids that sometimes don't even have an IEP in the system, and we have to work proactively in catching up the

the science?

DEEQAIFRAH HUSSEIN: They're not missing the science. It's multiple things. It's denial of the autism diagnosis itself. It is saying that it's a cultural misconception as well, where you will hear some families say that our uncles or our relatives spoke late, so it's a developmental delay. They like to hear the word developmental delay over autism anytime.

So if you look at the special education data using MDE, you would see that many of the Somali children or descents of Somali will stay on the developmental delay label all the way up to age 7, while other similar peers will get early childhood special education and then can get the autism services so that they can get the evidence-based practices that they need to be in the right programming. So it's still something that the community is struggling with.

CATHY WURZER: You mentioned denial. Part of denial sometimes comes as part of the grieving process. Do you think some parents are, in a sense, grieving?

DEEQAIFRAH HUSSEIN: I was one of them. When I got the diagnosis, and I got it from the University of Minnesota, I was in denial for a couple of months. I studied, went back to school, got my Masters in special education, and understood the relevance and the importance of early intervention.

The denial is two things. Denial of, you're shocked, and you're like, what this is? Is it something that you can cure through medication, medical services? Or is this a lifelong-- accepting diagnosis that this is going to be something that's going to be impacting the rest of your family and the rest of your life? Just getting to know, that's part of denial.

Another part of denial is the protection from the label. A lot within our community, there's a social stigma regarding the special education services and the label that comes with. Families see that kids are taken out of general education classrooms and into a smaller settings to get services.

I don't want my kid to be in a secluded area. I want them to be with their peers. So what sounds to be, sometimes, we're turning down services, is a form of protection from the label, advocating for the kid. So it's just a

but it would be this, I guess. There are supports in Minneapolis Public Schools, but what else needs to be done?

DEEQAIFRAH HUSSEIN: This is a community effort. Kids with autism have supports not only in the school system, but they also have it in the community. The medical community and the education community needs to do a wraparound service where we explain what services the schools provide through IEP.

And what services does the community provide through individual treatment plans? That's getting them ABA services. That's getting them other speech and OT services and getting the run around service for those students that are struggling with autism so that they can be and thrive to be their best selves.

CATHY WURZER: By the way, is it helpful to have mosques in the community also help in this effort?

DEEQAIFRAH HUSSEIN: Yes. I go to Friday prayers. And every opportunity I get-- the mosque is the heart of the community. And when mosques understand the struggles with autism within the community, it opens up the doors for families to seek additional resources and acceptance within the community. So it's very, very important.

CATHY WURZER: Well, I appreciate the conversation, Dr. Hussein. Thank you so very much.

DEEQAIFRAH HUSSEIN: Of course. Thanks for having me.

CATHY WURZER: Dr. Deeqaifrah Hussein is the executive director of special education in the Minneapolis Public Schools.

[Download transcript \(PDF\)](#)

Transcription services provided by [3Play Media](#).

News you can use in your inbox



ON AIR
MPR NEWS WITH ANGELA DAVIS