NEWS

‘A catalyst for change’: NIH makes first call for research supporting minimally verbal autistic people

BY **LAURA DATTARO**

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In January, Kristina Johnson participated in a **two-day workshop** on promoting communication in minimally verbal and nonspeaking autistic people, hosted by the National Institute on Deafness and Other Communication Disorders (NIDCD), a member of the U.S. National Institutes of Health (NIH). Just a few months later, on 3 April, the NIDCD posted its first-ever **Notice of Special Interest** (NOSI) encouraging researchers to submit grant proposals on the topic.

Johnson is a postdoctoral fellow at the Rosamund Stone Zander Translational Neuroscience Center at Boston Children's Hospital in Massachusetts, working with **Mustafa Sahin** and **Carol Wilkinson**. She had long felt her work was on the outskirts of the NIH’s funding interests, she says, and the posting thrilled her. “I’m so excited to see it. I do think that it will be a catalyst for change.”

The NIH created NOSIs (pronounced “no-see”) in 2019 to encourage researchers to study a particular topic via its existing funding mechanisms. They replace the more general program announcements that offered funds in a scientific area. Until recently, the NIH’s only funding announcement for work with minimally verbal autistic people was a **2010 call** for researchers with active grants to extend their projects to include the “characterization and/or treatment” of nonverbal autistic children. The April NOSI is the first to specifically address autism since the category’s inception four years ago.

For Johnson, the post set off a flurry of activity. The NOSI will enable her to pursue what she sees as “immediately answerable” questions, she says, about improving communication for autistic people who largely don’t use spoken words. Johnson has plans to join the faculty at Northeastern University in Boston in September, and her future coworkers have already begun strategizing about how Johnson can join collaborators in the field to submit a proposal that will likely aim to develop improvements to augmentative and alternative communication (AAC) devices.

That kind of research requires teamwork and money, which can be a “barrier,” Johnson says. “A NOSI like this allows you to say, ‘Hey, I’m going to get all the right people in the room, we’re going to give them some money and some dedicated time, and we’re gonna do the thing.’”

Applications under the NOSI opened on 5 June and will close 6 June 2026. The NIH does not share the number of applications it receives, but Johnson is not alone in her enthusiasm. Other researchers *Spectrum* spoke with are hopeful that the NOSI will motivate investigators in adjacent fields to consider how their expertise could benefit minimally verbal autistic people and help grow the collective knowledge. **Helen Tager-Flusberg**, director of the Center for Autism Research Excellence at Boston University, says the NOSI was needed. “We still know so little” about nonverbal autistic people, she says.

The NIDCD’s first explicit public interest in this area came in 2010, when the agency hosted a **webinar on nonspeaking autistic children**. That stimulated interest and funding opportunities, says Tager-Flusberg; in 2013, she received a **five-year, $10 million grant** from the NIDCD to explore ways for minimally verbal autistic children to learn communication skills — the first federal grant to study that population.

But across the field, research lagged because of its challenges and high costs. Most assessments used in autism studies are not designed for people with little or no language. For example, an assessment that takes one hour with a verbally fluent autistic person might take four with someone without spoken language, Tager-Flusberg says.

> ”A NOSI like this allows you to say, ‘Hey, I’m going to get all the right people in the room, we’re going to give them some money and some dedicated time, and we’re gonna do the thing.’” Kristina Johnson

What’s more, federal funding for autism research has historically favored basic science rather than the kinds of studies that might, say, create a new assessment for minimally verbal people — an imbalance many researchers, families and autistic self-advocates have long pushed to change. In 2018, the most recent year for which data are available, 67 percent of the nearly $274 million that the NIH devoted to autism research supported work on biology and risk factors, whereas just 14 percent went to work on supports, treatments and interventions, according to **data from the Interagency Autism Coordinating Committee**. Those dollars covered 64 percent and 14 percent,

respectively, of the autism projects the agency funded.

Johnson knows this funding disparity well. While in the thick of working on a doctoral degree in physics, examining nonlinear dynamics of superfluid helium, she gave birth to her first child. As a baby, her son was diagnosed with MEF2C haploinsufficiency syndrome, an extremely rare neurodevelopmental condition.

Johnson left her degree program and later started trying to fill what she saw as vast gaps in knowledge about children like her son. She found that most studies' skill requirement — such as a handful of words — excluded her son.

And because nonverbal children are so little studied, and their progress is often so incremental, it's hard for research to demonstrate measurable results, Johnson says. That makes it difficult to attract grant money; the NOSI should make it easier. The effect, Johnson says, is that the NIH has said to the research community, "This is meaningful; we see you; we want you."

On 10 July the NIDCD took another step by **asking the public** for input on which avenues of research would best support minimally verbal people. **Karen Chenausky**, director of the Speech in Autism and Neurodevelopmental Disorders Lab at the MGH Institute of Health Professions in Boston, says this call, together with the NOSI and the workshop, mark a shift in the agency's autism priorities.

Chenausky is applying for a New Innovator Award for early-career researchers. Just three **such grants** have gone to autism projects to date: one for gut-brain neural circuits, one for genetic contributions to autism, and one for modeling autism using pluripotent stem cells. Chenausky's proposal, on the other hand, involves identifying and supporting children who may not develop spoken language.

Until April's NOSI focusing on nonverbal autistic people, such work has been a difficult sell, Chenausky says, because it's "hard to convey" to NIH reviewers that rigorous work is possible with this group.

But now, she adds, she can show her grant reviewers that the NIH is explicitly interested in her work. She wrote the NOSI's notice number into the first page of her proposal.

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