Scientist, Professor, Mother

Margaret Kjelgaard is working to improve the lives of people with autism—including her son.

By Joanne Barker

The world was too loud for Walter. He could not stand everyday sounds like his mother doing dishes or his sister's cough. The noise of the shopping carts at Market Basket triggered tantrums; on other days, new store decorations might prove equally upsetting.

"You never knew when he would have a melt down," says Margaret Kjelgaard of her son, who has autism.

Dr. Kjelgaard, an associate professor in the Department of Communication Sciences and Disorders, had been researching autism for a decade before Walter was born. "He changed the direction of my research," she says. "When he was younger, life was really difficult for him. My question became, 'Why?' Why, for instance, was Walter so upset by sounds most of us barely noticed? Why would the sun at the beach overwhelm him when other kids could just have fun?"

Kjelgaard's research until then had centered on prosody, the inflections and rhythm of speech, and whether an inability to decode those signals could explain why communication was so difficult for many people with autism. For practical reasons, she studied children with mostly intact language skills because they could understand complex instructions and talk to her as she measured their judgment and reaction times. Not so with Walter.

Now 10 years old, Walter can understand much of what people say to him but he can only put together a few words of his own. About 30 percent of children with autism have minimal verbal skills, posing significant challenges for researchers. They often have behavior issues that thwart research protocols, and most measurement tools are designed for higher-functioning kids. So even as autism research proliferates, children like Walter remain understudied and poorly understood.

Much of Kjelgaard's autism research is informed by—and with—her son, Walter.

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"My son's issues made me increasingly interested in understanding lower-level sensory processes," says Kjelgaard, who is also a research scientist at MIT's Department of Brain and Cognitive Sciences and the McGovern Institute for Brain Research. She started to wonder whether the language problems associated with autism might stem from an underlying problem distilling sensory input such as sound, sight, and touch.

Kjelgaard shared her thoughts with a colleague, Professor John Gabrieli, an internationally renowned scientist who is the Grover Hermann Professor at the Harvard-MIT Division of Health Sciences and Technology, and is the director of the Athinoula A. Martinos Imaging Center at the McGovern Institute. He introduced her to Pawan Sinha, a professor of vision and computational neuroscience in the Department of Brain and Cognitive Sciences at MIT, who had arrived at some of the same questions through a very different route.

Sinha is internationally renowned for his work in vision, most notably as the founder of Project Prakash, a charity that provides treatment for curably blind children in India (which has more than 25 percent of the world's 45

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– *Margaret Kjelgaard*

Kjelgaard and Sinha believe their Predictive Impairment in Autism hypothesis will change the way researchers look at the condition.

million blind people). Through observing children as they first learned to see, he noticed some patterns that had been documented in children with autism. Both groups had trouble integrating individual pieces into a larger visual puzzle; they might recognize a tree but not be able to see it as part of a forest.

Over time, the Prakash children learned how to integrate visual elements; children with autism did not. "What we were finding was a difference in the ability to make use of dynamic information," says Sinha. When he met Kjelgaard, he had already started thinking that autism might stem from a problem integrating information as it changed with the environment.

Finding Common Ground

Despite their different backgrounds, Sinha and Kjelgaard found common ground almost immediately. "We quickly realized we shared many things," says Sinha. "Instead of labeling autism a social disorder, we wanted to explore whether there might be some underlying processing difficulties that contributed to its seemingly disconnected traits."

Sinha's lab was a treasure trove of research capabilities for Kjelgaard. "His lab is a great place to do this work because there are scientists from multiple disciplines such as those in computational cognitive neuroscience who are skilled at using machine learning, computer vision and signal-processing methodologies," she says. For Sinha, Kjelgaard brought a new level of wisdom to the lab. "She has a more intuitive, deeper understanding of the kind of challenges children with autism are facing." As a behavioral scientist with a mother's knowledge of autism, Kjelgaard could design experiments that work for children who easily panic.

Using seed grants from the MIT Simons Center for the Social Brain, she and Sinha began considering the common features of autism: challenges with language and communication, social interactions, and sensory processing, to name a few. From there, they hypothesized that an impaired ability to predict what will happen next might be at the root of many of autism's symptoms, a collective condition they call Predictive Impairment in Autism.

"Researchers and clinicians have traditionally looked at autism as a laundry list of unrelated symptoms, but we believe they need to be studied as the outcomes of a single, unifying problem," Kjelgaard says. "The brain is designed to make predictions in all aspects of life. If one can't predict how things are going to work out, as we think is happening in autism, it's going to prevent them from navigating in a world that's constantly changing."

In 2014, along with six other scientists from Sinha's lab, they published "Autism as a Disorder of Prediction" in *Proceedings of the National Academy of Sciences*, published by the independent nonprofit that provides expert science advice. Their hypothesis includes testing habituation, which is a brain's natural tendency to gradually become accustomed to and

eventually ignore repetitive noises like a ticking clock or baby crying, and whether people with autism lack this filter. Without it, the world becomes a barrage of chaotic, unpredictable stimuli. "Imagine how overwhelming it would be if everything was seen, heard, and felt as if it were fresh and new," Kjelgaard says. "You would be overloaded quickly and unable to focus. It would affect a person's ability to learn and interact with others."

Walter shows hypersensitivities to sounds and other sensations, as well as an inability to determine the path of a thrown ball or a moving automobile—another symptom they are studying. "Children with autism have many close calls with cars, and sometimes are even hit because, we think, they can't determine how fast it is going or where it is headed," she says, grateful this did not happen with Walter when he would periodically run away during his early childhood.

It wasn't long after the paper was published that other autism researchers reached out, asking to become part of testing the theory. Collaborations were formed with Dagmar Sternad at Northeastern University's Action Lab and with Massachusetts General Hospital, while a new partnership with Yale University is expected to begin soon. It's too early to know the outcome of their research, but whether or not the theory is eventually proven, they believe it will have changed the way researchers look at autism.

A Professor With Many Hats

When Kjelgaard walks into a classroom at the Institute, she brings her experience as a scientist and mother with her. She intersperses lectures about symptomology and interventions with guest lectures by people

SLP student Leila Denna has worked with Kjelgaard for the past two years.

with autism, parents, and advocates. Her goal is to give her speech-language pathology students as complete an understanding of autism as possible.

"My favorite thing about working with Margaret is that she lets you explore," says Leila Denna, who is completing her Master of Science in Speech-Language Pathology and has been one of Kjelgaard's three SLP research assistants for the past two years. "She gives you a piece of information and helps you explore the implications and evidence so you can develop your own critical analysis."

One of the many things Kjelgaard tries to impress upon her students is that the children they work with during their clinical placements have full lives outside of the clinical setting. She teaches students to think in terms of family dynamics and opportunities to make their clients' and their families' lives easier. "If a child is having tantrums every time a certain event occurs, let's give them words or other means by which to communicate in these contexts. Our job is to help them find another way to communicate that this event is upsetting to them."

As a parent, Kjelgaard knows how confusing it can be for families when new, and often contradictory, interventions for autism are publicized. She has seen parents, desperate to help their child, spend thousands of dollars for dubious programs claiming to cure autism. And so she teaches her students to look at such programs with a critical eye. "I want them to know about the interventions that are evidence based, and also ones that are not."

"She has such a wealth of information: how to conduct research, how to understand research, how to apply research," says Denna, who had been teaching children with autism for several years before coming to the Institute. "She can put on her mom hat, she can put on her researcher hat. The ability to go back and forth—it's an important perspective."

At home with Walter, Kjelgaard wears only one hat. Contrary to the assumptions of those who expect her to administer extra therapies to her son after school, she sticks with the typical activities of parenting—preparing his food, making sure he bathes, reading to him before bed.

"My philosophy is that my son is who he is," she says. "I definitely want to alleviate as much unhappiness for him as I can, I want him to reach his full potential, but I think the most important thing to do is to love him."

Because while she may be a researcher and teacher professionally, at the end of the day, Margaret Kjelgaard is a mom first. ■