



# Sink or Swim<sup>#</sup>

Sink or swim. That was Kiely Law's choice twenty years ago. From almost any angle, she seemed to have it all. A medical student happily married to another med student. Mom to a three-year-old son, Isaac -- a name that means "laughter." "Our lives had gone as planned ... both of us were very motivated, driven people. We had never talked about having a child with a disability. It wasn't on our radar," she remembers.

So when Isaac was diagnosed with autism spectrum disorder (ASD) at age 3, it both confirmed their suspicions and caught them by surprise.

At that point, Kiely had a choice to make. Would she continue with med school? Other parents of newly diagnosed kids on the spectrum were making drastic changes to their lifestyles, often curtailing a parent's career ambitions. Many parents also wrestled with the decision to avoid -- or continue -- having additional children.

Kiely decided to swim, and she ended up not only staying afloat but building a life raft that has carried countless other parents along the tide of uncertainty that is parenting a child with autism.

She and Paul, Isaac's father, decided that both would remain in medical school. And despite knowing that any future children had a 20% chance of having autism, they chose to expand their family. Three more children arrived healthy and without developmental concern. "We felt that if we changed our life plans at that point, then somehow autism had won," Kiely recalls.

Being a medical leader for the autism community was never Kiely's goal. Her priority was keeping her head above water -- educating herself about autism and what might lie ahead for her son and her family. For his first eight years, Isaac was able to float along with the flow of his parents' lives. After graduation, both Dr. Kiely Law and Dr. Paul Law became involved in overseas public health, treating children in underserved areas. By 2001, they knew it was time for a change. For Isaac to thrive, he needed to be in a more settled, stable environment, so the Law family returned to the U.S.

## **Building the Raft**

Over the next few years, Kiely became increasingly involved in the autism community through traditional means – volunteering, advocacy, fundraising. It was the kind of thing many parents did. In fact, as she met other parents struggling with the same challenges, a dream began to form. She knew that researchers often lacked volunteers for their autism-related research. Families of people with autism often searched unsuccessfully for reliable information on the disorder. Wouldn't it be great if the medical community could connect the families with autism researchers? The benefits would be mutual – more information for the families, and easier access to people with autism for the researchers.

At the same time, a new advocacy group known as Autism Speaks was emerging, and the first planks of Kiely's new life raft fell into place. Autism Speaks was looking for a sentinel project to fund in their early days. Dr. Gary Goldstein, president of Kennedy Krieger Institute, a children's research hospital in Baltimore that focuses on brain, spinal cord and musculoskeletal disorders, knew the group and knew Paul and Kiely from their medical school days. And since Isaac was diagnosed at Kennedy Krieger, Dr. Goldstein knew of their personal connection and growing interest in focusing their research careers on autism. Would they be interested in writing a proposal for a new program to be funded by Autism Speaks?

Paul and Kiely created that proposal, and Autism Speaks came through with three years of funding. The Interactive Autism Network (IAN) was born.

From the beginning, IAN addressed issues common to people with autism and their families. For example, one of IAN's most important studies considered the proclivity of children with autism to wander away from home or school. How big of a problem was it? Were the anecdotes that said more than half tended to wander actually true? (Yes, the study found.) Researchers studied family dynamics – if the siblings of people with ASD also wandered away, could it be a parenting problem? (Definitely not, the study confirmed.) What kind of dangerous situations were associated with wandering? Was age a factor?

The beauty of IAN was that researchers could find out the facts without extensive travel or inconvenience for the families. IAN is based on a technology-enabled process that questions participants via online surveys. If data-gathering were conducted in person, each researcher would be limited by access to those he could actually meet. Sample sizes would be relatively tiny. And since some studies focus on narrow aspects of autism or specific demographic groups, in-person or geographically limited research was difficult if not impossible.

But research conducted online allowed families and adults with autism to participate around their schedules. And they responded in droves, hungry to see scientific advances, thirsty to gain more understanding of this perplexing condition. More than 54,000 participants have climbed onto this life raft, providing a growing trove of data for researchers.

For the first time, families affected by autism had an audience eager for their input. And medical researchers could easily find those who fit whatever categories their work required. While the practice of connecting patients and researchers was not new, it hadn't happened previously on a large scale in the autism community.

Jean Brooks is the mother of a 16-year-old son with autism. As she remembers, “It was the Wild West of autism when he was diagnosed (in 2002). I was told ‘your kid will never be alright, and there’s nothing you can do.’” There were a million tiny outposts of information, she said, but no central gathering of medical, educational, and psychosocial data. Several years later, she found IAN and became an early participant (and now, an advisory board member).

At the time, she saw studies that seemed to ignore the practicalities that parents of children with autism knew. Gastrointestinal difficulties were common among kids on the spectrum, and sleep disorders were rampant, with some kids barely sleeping at night. Brooks’ son was hyposensitive to stimulus, and therefore, fearless in his search for sensation. She remembers him as a young child, hanging out of third floor windows seeking a thrill. She ended up nailing their home’s windows shut and placing alarms on their doors. But the medical community was not set up to synthesize these anecdotes, so there was little official acknowledgement that these were common situations with ASD patients.

“With IAN,” Brooks says, “the testimony of the people who are living with this 24 hours a day became meaningful to the researchers. From our point of view (as parents), it was miraculous.” She and her son have completed more than 2 dozen research surveys since 2006, and Brooks’ two older sons without ASD have also been included. “The more people from diverse geographic locations participate, the more powerful the data becomes,” she added.

Autism research blossomed in this new setting. As IAN grew and matured, practical applications of the studies enhanced the world of autism. Because IAN features a massive, searchable collection of autism data as well as extensive publications on virtually any issue affected by autism, it is essentially a one-stop shop for people affected by the disorder, as well as for researchers.

Dr. Carla Mazefsky is one of those researchers. A clinical psychologist and associate professor in the department of psychiatry at the University of Pittsburgh School of Medicine, she has been studying emotional dysregulation in those with autism for much of the past ten years. Initially, she recalls, typical studies might have sample sizes of 20 or 30 individuals, with researchers largely unable to sift through participants to find a particular subgroup of patients to study. Within the past year, 700 individuals have signed up for a study Dr. Mazefsky is conducting, thanks to IAN. Within days of beginning, she had hundreds of responses. Because autism spectrum disorder varies greatly from person to person, it had previously been difficult to project results or observations over the whole spectrum from a limited sample size. With the large number of participants in IAN, that’s no longer a problem.

In her work, Dr. Mazefsky is also connecting ASD patients being treated in inpatient psychological units with IAN, further broadening the database for all researchers. “The majority of ASD patients meet the criteria for emotional or behavioral disorders,” she said, although most do not receive inpatient treatment.

### **Sailing that raft into the future**

Twenty years ago when her son was first diagnosed, Kiely found that autism awareness, information, research, and advocacy were all but nonexistent. Now that autism is widely recognized, she is also on

the forefront of another wave: that of young people moving toward adulthood with a diagnosis on the autism spectrum. What lies ahead for them? For Isaac?

Those young adults (and their families) will need to consider the level of independence they can attain, as well as employment. How will they manage their healthcare? Many people with ASD have co-occurring diagnoses as they get older, from depression and anxiety to bipolar disorder and physical problems. Will first responders and society be ready to welcome them and treat them with respect? How will we, as a nation, continue to provide support services for these fellow citizens?

Dr. Katherine Gotham, assistant professor in the Department of Psychiatry & Behavioral Sciences at Vanderbilt University Medical Center, specializes in research involving adults with autism spectrum disorder. “IAN is an unparalleled resource to gain a large sample size of a specific disorder,” she said. People with autism who were diagnosed as adults, as well as adult females with autism, are examples of those “hidden” demographic groups. She also pointed to IAN as a way to support the research of young medical professionals. At an early stage in their careers, many do not have the resources or time to conduct extensive research, but with IAN, they can participate in a less intense way.

Her research has included a study asking adults with ASD for their opinions in several areas. How were they spending their days, and what did they want researchers to focus on? “It was my first chance to find out what they wanted,” Dr. Gotham remembers. She included both adults with verbal fluency who could self-report their opinions, and family members of minimally verbal adults.

Both groups expressed very similar feelings. They wanted more research done on learning life skills, on co-occurring conditions, and on vocational and educational opportunities. What both groups deeply yearned for, however, was public acceptance of adults with autism spectrum disorder.

The “aging out” of people with autism who leave school-age-based services is a big concern to the ASD community, and to society in general. People with autism are not fully able to adapt to the mainstream community, so the mainstream community will need to adapt to them, welcoming these individuals into everyday life. It’s something that Kiely deals with in her work as well as in her home.

“It’s still a daily struggle, even though I work in this field,” Kiely admits. Isaac is verbal and moderate to high-functioning, but he is very different from his siblings and others without autism, she says. Unlike most people, those with autism have difficulty learning just by observation – everything has to be taught. “At a restaurant, he wouldn’t know how to leave a tip, although my other kids know by watching. It’s that way in everything, like calling and setting up a doctor’s appointment or buying groceries at the store.”

As the legendary Temple Grandin, herself a Ph.D., consultant, author, and autistic person, puts it, “Working with a person with autism, you’ve got to just coach them, like coaching somebody in a foreign country, how to behave in different situations.”

And so, perhaps the life raft that Kiely began building is not yet complete. Because adults with ASD need help and support just as much as the children do. Just like all of us do.

*IAN is a partnership of the Simons Foundation and Kennedy Krieger Institute. IAN is also partially funded through a Patient Centered Outcomes Research Institute (PCORI) Award for the development of the National Patient-Centered Research Network, known as PCORnet. For more information about IAN, see [www.iancommunity.org](http://www.iancommunity.org).*

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