

VIEWPOINT

A call to scientists to develop communication tools for autism

BY SHANNON DES ROCHES ROSA

20 DECEMBER 2016



My son, Leo, turned 16 in November. He's mostly thriving: He attends a school where he is surrounded by excellent teachers, speech-language pathologists and other special education experts, and he's the middle child in a family that adores him (the occasional sibling fireworks aside). Despite all our best efforts, though, Leo has difficulty communicating his most basic wants and needs. This is intensely frustrating for him — and for us, too.

Leo is what researchers call a **minimally verbal** autistic person. He has always used some words, such as Disneyland, pizza and 'Totoro' (a character from a Japanese animated film). Experts assumed this list would grow over time. And Leo has gained a few more spoken words with age, but his communication disability remains significant. His ability to understand far exceeds his ability

to express himself.

We have tried various evidence-backed methods to encourage Leo to develop more oral speech, to no avail. So we are floundering, wondering how best to help him share what he's thinking.

It is monstrously unfair that so many people like Leo have things to say but no reliable means to say it. I simply do not understand why there isn't more research to help him and guide us.

I have some theories on why this may be, and I've asked other parents and professionals to weigh in, too. Autistic people and their supporters who try alternative strategies for communication are sometimes labeled as being anti-research or pro-pseudoscience. In fact, most of us just want more and better research. And we want scientists to understand that they have the opportunity to change the lives of autistic people and their families.

Lost in translation:

It's not as though there are no evidence-based options to help people like Leo communicate. Most existing approaches are behavioral: They are designed to encourage communication by offering rewards for doing so. But not all autistic people can respond to these strategies. As Ruti Regan of Real Social Skills, a website that analyzes attitudes about autism, puts it, "Walking lessons do not replace wheelchairs."

Leo's speech therapists helped us understand that he needs communication options besides oral speech. They were also instrumental in helping Leo learn to use his symbol-to-speech device. The tablet-like machine has a rectangular touch-based grid of icons that he can tap to 'speak.' But he only uses it to reiterate what he already says orally.

Unfortunately, there are few other options out there that are backed by research. It's no wonder autistic people and their families feel compelled to try alternative approaches such as facilitated communication — a method that has been **widely debunked** by researchers (even though autistic users insist **researchers are asking the wrong questions**) — when available ones fail.

Please do not misunderstand me: I get why researchers dismiss alternative approaches that haven't been scrutinized in a carefully conducted study. I also understand why they're leery of investigating these approaches themselves. But where does this leave non-speaking autistic people?

I head a nonprofit group called **Thinking Person's Guide to Autism** that advocates for approaches that are firmly rooted in evidence. So it takes a lot for me to ask scientists to look beyond their skepticism.

At the same time, I see mounting evidence that approaches such as the **Rapid Prompting Method**

are helping people once considered incapable of communicating to open up. I wonder why some researchers scoff at the approach instead of investigating how it might help some individuals communicate.

Missed opportunities:

Jamie Pacton, whose young autistic son has been using the Rapid Prompting Method for years, says researchers are too quick to give up on some autistic people as being incapable of communication. “At the heart of this dismissal lies a deep strain of ableism,” she says. I agree. Like Jamie’s son, Leo appears to have **fewer abilities than he actually does**.

I don’t mean to imply that there is no research into communication support for minimally verbal autistic people. But autism is so heterogeneous that the limited number of studies can’t possibly address the needs of every individual. For instance, some autistic people have **motor issues**. There is no point in trying to motivate someone to speak if his body cannot comply.

We also need research addressing the best time to implement communication support strategies. Children with spoken language delays need evaluations and options as early as possible, in tandem with standard speech therapy. But we also need to know how best to support people like Leo when we realize, after early childhood, that they need alternative support strategies.

For people like me who are trying to make educated decisions based on scanty and often conflicting resources, it’s frustrating — sometimes infuriating — that professionals don’t have a framework for timing communication support.

Finally, we need research that addresses the real-world needs of minimally verbal autistic people. A method that works in a quiet clinic under the guidance of a therapist might not translate in the chaos of a home.

Communication challenge:

Our own family’s experience with communication support devices has been maddening. The user interface for Leo’s device is intuitive enough, and Leo learned it quickly. But setting up and troubleshooting the tool is a nightmare.

I once watched two experts debate for 10 minutes how to change a single icon on the screen. How are parents supposed to help our children get the most from their devices when even experts find the process challenging?

It also took more than a year of insurance and logistical battles to get Leo his current device, which costs upward of \$8,000. For far too many autistic people and families, these cost hurdles are unsurmountable and, in my opinion, unconscionable. We need better options.

So, researchers, I know most of you want to make a difference. This is how you can help: Get past the misconceptions about options for helping autistic people communicate. **Talk to autistic people** who need communication devices, and to their families. Break new ground. Be revolutionary.

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