

DEEP DIVE

# How one communication tool may fail some autistic people

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1 JULY 2020

*Illustration by Francesco Zorzi*

Aulton Grubbs sits in a chair against the wall of a small white room. A skinny teenager in athletic attire, he covers his eyes and ears with his hands while making a creaking noise with his vocal cords. The only word Aulton ever says, albeit sporadically, is “done.” Like roughly a quarter of people with autism, he struggles to communicate, which is why his mother has brought him to this two-story brick building in a leafy neighborhood in Austin, Texas.

It is late February and this is Aulton’s third day working with educator **Soma Mukhopadhyay**, who glides into the room wearing an oversized tan work shirt atop an elegant red sari. Her diminutive frame and hushed, lilting voice belie her intensity. She makes a beeline toward Aulton, ignoring the adults in the room. “Today, you decide what should we do,” she says to Aulton as she holds up a plastic board with the alphabet on it in front of him. “‘S’ for ‘science’ or ‘P’ for ‘poetry.’”

She peels Aulton’s right hand from his face. He gingerly extends his pointer finger toward the board, gazing in a different direction. His finger lands on the ‘Q’ first and then the ‘P.’ “P, that’s right,” Mukhopadhyay says. She shifts the letter board to the right to bring the ‘O’ closer to his finger. “You’re right, you’re right,” she says. Prompted by Mukhopadhyay, Aulton pokes at the board again. “E ... T ... keep going, keep going,” she says, moving the board slightly to meet his fingers. She pries his hand from his face a second time and stops it from moving away from the board before Aulton presses it to the ‘R.’ Then he taps the ‘Y.’ “We’re going to do poetry,” she says.

Mukhopadhyay invented this technique, known as the ‘rapid prompting method,’ in the 1990s to help her autistic son Tito communicate. In 2004, she came to Austin to work with other autistic children, many of whom are minimally verbal, meaning they speak few or no words. Eventually, she began training other teachers in the method. Mukhopadhyay says she will work with children of any age and will assess their knowledge to determine what they need to be taught. She recommends that parents of young children expose them to the written word and prompt them frequently with

questions, as she did with Tito starting at age 3.

Rapid prompting appears straightforward: A teacher holds up an alphabet board or a choice of two words on scraps of paper and then verbally or physically prompts an autistic person to point to individual letters or to words. The teacher might, for instance, tell the student that the sky is blue and then ask what color the sky is. Although teachers try to avoid moving the student's hand directly, they may nudge an elbow or tap a shoulder.

A central assumption behind the method is that a student's intellectual capacity rivals that of her neurotypical peers and that, despite her frequent lack of attention or response, she understands everything being communicated to her. In Mukhopadhyay's view, autistic children are limited only by poor motor skills and the distraction caused by a sensory system in overdrive. Even nonspeaking children can learn to read and communicate if they spend enough time interacting with letters, she says.

Many parents spend 30 minutes or more a day practicing the method, and some attend regular sessions with providers in the hope that it will enable their child to one day type independently on a keyboard, as appeared to happen with Tito. His story was recounted by the **BBC** and **60 Minutes**, and in the 2010 documentary "**A Mother's Courage: Talking Back to Autism**," narrated by actress Kate Winslet. Mukhopadhyay's alumni also include **Ido Kedar**, a self-published author in California, and **Michael Weinstein**, now in his 20s, who won first place in chemistry in the Austin Regional Science Fair when he was in high school. More than 4.4 million YouTube visitors have watched a video that Apple released in 2016 that shows an autistic teenager prompted by his therapist to use an iPad to communicate.

Despite rapid prompting's popularity, no rigorous scientific studies show that the method works. There is no empirical support for the idea that it spurs academic progress or that its students express their own thoughts. In a **2019 review** of the literature, researchers identified six descriptive studies, but none compared the method with a control group, a hallmark of any genuine trial. "You are not only not letting the person speak for themselves, but you are overlaying your own voice on theirs," says **Ralf Schlosser**, an expert in augmentative and alternative communication at Northeastern University in Boston, Massachusetts, who led the study. He makes his opinion clear: "That is a human rights violation."

But the lack of proof has not dissuaded many parents. Mukhopadhyay conducts up to 11 sessions a day and holds workshops around the world several times a year. In Austin, she sees her clients at the offices of a nonprofit called Helping Autism through Learning and Outreach (HALO), founded for her programs in 2002. Four-day HALO camps cost \$850, and training sessions for parents and providers are \$950. HALO sells Mukhopadhyay's books and a variety of letter boards. It also has lent its trademarked seal of approval to 10 independent providers in the United States, the United Kingdom and Mexico. Mukhopadhyay draws a salary of more than \$150,000 per year, according to tax filings. And HALO has competitors, such as the **Growing Kids Therapy Center** in Herndon,

Virginia, which provides training called Spelling to Communicate that also focuses on motor skills and encourages autistic people to use a letter board to communicate.

Parents have also tried to introduce the method into U.S. special-education classrooms. According to a 2018 study, 17 percent of 535 **special educators surveyed in Tennessee** used the rapid prompting method with their students every day — a frequency on par with their use of such evidence-based practices as **pivotal response treatment** and the **picture-exchange communication system**. Insurance does not cover the rapid prompting method, and school districts often reject its use in the classroom, so parents sometimes **raise thousands of dollars** through GoFundMe or other online campaigns to travel to training sessions run by Mukhopadhyay or other instructors.

For parents, rapid prompting has particular appeal. It holds out the promise that their children are far more intellectually capable than clinicians may have suggested. “The parents are just as much a victim,” says **Jennifer Hamrick**, a special-education expert at Texas Tech University in Lubbock.

Aulton and his mother have attended private rapid prompting method sessions with certified providers near their home in Tucson, Arizona, for three years. The two spend three hours a day working with the letter board at home, and at his private school, the Arizona Aspire Academy, teachers also use the method. Traveling to Austin for a HALO camp provided Aulton with his first chance to work directly with Mukhopadhyay. His mother, Nikki Grubbs, says, “It really doesn’t matter to me that it’s not evidence-based or scientific, because I see the evidence in him.”

## Boy wonder:

In the early 2000s, the media billed Tito as a miracle. Mukhopadhyay first brought him to the U.S. in July 2001 with the support of Cure Autism Now, a nonprofit that later became part of **Autism Speaks**. The organization’s co-founder, **Portia Iversen**, wanted Mukhopadhyay to work with her own son, Dov. Within months of her arrival in the U.S., Mukhopadhyay was working with other parents, and Iversen’s publicity machine attracted the interest of scientists. “Autism experts are studying him, amazed to discover, for what they say is the first time, a severely autistic person who can explain his disorder,” journalist Sandra Blakeslee wrote in a **2002 article about Tito** in *The New York Times*.

Raised in small apartments in Mysore and Bangalore in India, Tito found comfort staring at a ceiling fan as a child, according to one of his essays. Mukhopadhyay says she was a chemistry teacher with plans to become a professor, until Tito became her full-time job. She took him on walks, read to him the complete works of Shakespeare and Charles Dickens, and painstakingly taught him letters and their sounds through repetition. She taught him English because she thought it might be

easier than Indian dialects. She even tied a pencil to his hand and coaxed him to practice drawing letters himself.

After their arrival in the U.S., Tito, then 11 years old, visited six laboratories for neurological testing. The family settled in Los Angeles, California, where Mukhopadhyay began to share her methods with others. In 2004, Mukhopadhyay moved to Austin, where one of her clients had established HALO.

Tito was an inspiration, but also an anomaly. He was diagnosed as autistic and nonverbal as a young child, Mukhopadhyay says, but by age 12 he had developed a large speaking vocabulary, though his speech was garbled. “I need to write,” he scribbled on a yellow pad in front of Blakeslee. “I am waiting to get famous.” Most children learn to read and write by speaking — not the other way around. Language development in autistic people is often delayed because they lack social skills that foster communication: As infants, for example, they do not reliably follow a parent’s gaze toward another person or object — a behavior called joint attention that helps with learning words. These differences, which likely stem from changes in brain structure, are part of the reason so many people with autism are minimally verbal. This problem is unlikely to be correctable with a letter board, experts say.

Most methods for teaching minimally verbal autistic children to communicate begin with pictures and not letters; children can use pictures printed on cards or on a tablet device to express needs or create simple sentences. But parents who hope for an intellectual connection with their children can find that approach frustrating. “They want them to have normal or near-normal skills,” says **Howard Shane**, director of the Autism Language Program at Boston Children’s Hospital. So those parents seek out alternatives, such as rapid prompting.

It really doesn’t matter to me that it’s not evidence-based, because I see the evidence in him.” Nikki Grubbs

As rapid prompting’s profile has grown over the past two decades, veteran researchers in speech pathology say they have experienced an unpleasant sense of déjà vu. They say that, in some ways, the method resembles one called facilitated communication, or supported typing, developed in the 1970s by an Australian educator named **Rosemary Crossley**. Like Mukhopadhyay, she believed in presuming competence in her students. Crossley used her own hand to guide a minimally verbal person’s hand across a letter board or keyboard placed on a table or a stand. Proponents reported that some people who had never said more than a word or two and were not known to read would then spell out abstract thoughts and even express sarcasm.

The method came under attack when, in more than a dozen cases, minimally verbal autistic people, through facilitated messages, accused parents and caregivers of **sexual abuse**. Children were removed from their homes and parents were **sometimes jailed**, even though many of these accusations were **never corroborated** with physical evidence or other testimony.

Time and again, both researchers and expert witnesses involved in legal cases were unable to validate facilitated communication. (Crossley was the facilitator in at least one case involving sexual abuse allegations later determined to be false.) In a typical test, a minimally verbal autistic person could not answer a question if it were not also posed to the facilitator. In 19 studies conducted in the 1990s, researchers found the same: Minimally verbal people could respond to questions correctly only if the facilitator **knew the answer**. Their conclusion was that facilitators — unwittingly or not — probably somehow cue the people they are working with to produce a specific answer.

Supporters of rapid prompting point out that it differs from facilitated communication in that the facilitator does not typically touch the autistic person's hand after the initial stages of training. The facilitator may, however, move the letter board or prompt the person verbally or physically.

“You manipulate the output device or you manipulate the person, but that doesn't mean that the output is valid,” says **James Todd**, a psychology professor at Eastern Michigan University. In a study of nine children working with Mukhopadhyay and her colleagues at HALO, all nine provided more correct responses to questions when they were **not looking directly** at the letter board than when they seemed to be paying attention, suggesting the facilitator was responsible for their successes.

## Elephant walk:

For more than a decade, researchers have wanted to vet rapid prompting using the same methods used to test facilitated communication, but Mukhopadhyay and her supporters have repeatedly stymied them.

In the early 2000s, **Richard Kubina** set out to conduct a small trial, funded by a man whose daughter was attending rapid prompting method sessions. Kubina, a special-education researcher at Pennsylvania State University, says he reached out to discuss the study with Mukhopadhyay. Instead of responding, he says, she posted a message to mailing lists she manages, telling parents and teachers not to cooperate with him, he says. “I got these emails from parents telling me what an awful person I was and how I hate kids,” Kubina recalls, claiming, “She blackballed me.” Mukhopadhyay says she does not remember Kubina but says she does “caution parents” against participating in certain research projects.

School districts in Texas, Connecticut and Pennsylvania have also tried to investigate methods that resemble rapid prompting, such as Spelling to Communicate. In 2017, for instance, the parents of an autistic child in Pennsylvania asked their school district to fund training for staff in Spelling to Communicate and to allow it to be used in the classroom. Other parents fronted the funds, and school staff agreed to conduct a validation trial, which failed. In a 33-page decision, a special-education hearing officer wrote that the facilitator “was using excessive prompts and cuing to obtain correct responses from the student” to questions a teacher posed. The student answered questions correctly only when “the teacher gave the adult communication partner the answer key.”

“When you start to just use ‘magic’ instead of science, you stop searching for the truth.”  
Kevin Ayres

In 2015, many researchers in the special-education community hoped a new study might finally fill the void of published data. That December, **Kevin Ayres**, co-director of the University of Georgia Center for Autism and Behavioral Education Research, sought approval from an ethics board to recruit participants for a trial of rapid prompting, according to emails and other documents obtained through a Georgia public-records request filed by *Spectrum*. After two years, in late 2017, Ayres got a single taker: A Georgia woman named Bretta Milner inquired about participating with her minimally verbal autistic son, whose condition she described on Facebook. After learning about **Spelling to Communicate**, Milner had begun using a letter board with her son, then 17, and soon reported on Facebook that he **was working on a blog** titled “Don’t Give Up.” “If this method works as well as we hear, other families and researchers need to know,” Ayres wrote Milner in an email on 26 September 2017. “It has the potential to change lives.”

In fact, Ayres’ investigation ultimately failed to confirm that Milner’s son was the author of the messages she prompted. Ayres submitted his findings and conclusion as a case study to the *Journal of Autism and Developmental Disorders*. After it passed peer review, it was uploaded to the preprint server PsyArXiv on 30 July 2018, and about a week later, the American Speech-Language-Hearing Association (ASHA), published the final version of a **position statement on rapid prompting**. It said that the words produced using the method “should not be assumed to be the communication of the person with a disability.” The organization said that potential harms of the method include lost time and money, and keeping people from pursuing effective interventions. The organization based its statement partly on Ayres’ pending study, which, it stated, had “found evidence for instructor influence over the messages using this technique and no evidence that [the rapid prompting method] is a valid form of communication.”

ASHA’s statement created a kerfuffle in the rapid prompting community. A newly formed

organization called **United for Communication Choice**, which does not disclose its leadership, released a letter **expressing concern** that the statement hurt the chances that the method might be accepted in public schools. Milner became one of the group's 2,300 supporters on Facebook, 'liking' its page and sharing its posts. On 1 August, she filed an ethics complaint with the University of Georgia demanding that the university "immediately revoke consent for my participation and my son's participation in this study." Among other allegations, Milner said her identity had been compromised because she had told others in the rapid prompting community that she was participating, and her son turned out to be the study's sole participant. "I was lied to and deceived by these researchers," she stated in the complaint.

Three weeks later, the university's institutional review board withdrew its ethical approval for the research, ending any future work and calling past work into question. Ayres took the paper off PsyArXiv. The board did not find that the researchers had lied to Milner. Instead, it cited various minor lapses, including an expired ethics certification for one of the study's researchers. Because Milner had also compromised her own identity, the board recommended that the researchers comply with her withdrawal request and destroy all video and data. After the researchers pulled the study from the preprint server and withdrew it from the journal, Milner wrote again to the university demanding that references to it be scrubbed from the statement from ASHA. "Mention of this paper in this document gives it legitimacy and inflicts continued emotional distress on my family," she wrote. ASHA stood by its position statement but deleted references to the now-withdrawn study. (Neither Milner nor her husband responded to *Spectrum's* multiple requests — via Facebook, email and phone — for comment.)

On 6 September 2018, United for Communication Choice posted a statement saying that the researchers committed "**serious ethical violations**," a characterization that a university official disputes in a draft statement obtained by *Spectrum*. Ayres has been advised by the university not to answer questions related to the allegations or to the study's specifics, but he did tell *Spectrum* his opinion on rapid prompting: "I am all in favor of speaking for someone who cannot speak for themselves, but you should not make up words for them," he says. "When you start to just use 'magic' instead of science, you stop searching for the truth."

On Facebook, Mukhopadhyay has said that researchers' attempts to study rapid prompting are "foolish" and that they are criticizing it because they are intimidated by the method's growing stature. "Back in India there is a saying: When an elephant walks, street dogs bark," she wrote. "That doesn't affect the elephant." She says testing is stressful and demeaning to her students. When asked to estimate, in her experience, how effective rapid prompting is, her response is unequivocal. "I don't think I ever failed," she says.

Communication breakdown:

After spelling out words from a Robert Frost poem, Aulton Grubbs and his mother take a break. They return an hour later for a free-form session. Mukhopadhyay asks Aulton to tell a story, and he taps out a few sentences about a journalist traveling to China to investigate the coronavirus. Aulton requires significant prompting, but Mukhopadhyay is not noticeably moving the letter board. Another student comes in for a session and proves even more persuasive. Owen Winber, a 12-year-old boy on his second pilgrimage here from Chicago, Illinois, holds the letter board himself and enunciates several vowels as he touches them.

The final client of the day pulls up in the parking lot. Mukhopadhyay hops up to greet Cheryl, a bubbly mother with a gray bob of hair walking with her adult son. He's a tall redhead in his 20s; his head is tilted backward and pressed against his right shoulder. A baby-blue chew toy dangles from his mouth. Mother and son are both wearing T-shirts decrying gun violence, which she explains has become his pet cause. (*Spectrum* is withholding the woman's last name and her son's name to protect their privacy.)

Inside the classroom, Mukhopadhyay uses the back of her chair to box Cheryl's son in at his desk and keep him focused on the letter board as she recounts Aesop's fable about a farmer and his donkey. The student is contorting his head and stimming with the chew toy. He kicks the desk away repeatedly and rocks forward as if to get up. He must be twice Mukhopadhyay's size, but she skillfully wrangles him back to the task, which is answering the question: Who has the donkey?

There seems to be an interruption with every letter: At one point, his left hand snakes its way into his pants. Mukhopadhyay hops up and runs to the cabinet for antiseptic gel, chanting, "Germs! Germs! Germs!" Later, she uses her own hand to force him to touch the letter 'r' in 'Farmer.' When the buzzer rings after 25 minutes, the young man bolts from his chair and vanishes down the hall, where he clangs around in empty offices.

Cheryl is beaming as she explains that she and her son have been coming to Mukhopadhyay for the past 15 years. "It's completely changed his life," she says. She pulls out her phone to share poems she says he has written with the letter board. One is called "At What Cost," about the horrors of climate change and gun violence. Another is about the impeachment hearings:

*Truth is in the transcript*

*Why can't they see?*

*It's not rocket science*

*It must be Fox TV*

Her son is now circling the waiting room. Cheryl pulls out her own letter board and is trying to get him to express his feelings about gun violence. She taps the board against his two outstretched

fingers, rigid as a mannequin's. "My gun ... sense ... is ... so ... negative," she says, ostensibly channeling her son's thoughts, though the letter board is moving far more than his contorted fingers are. Mukhopadhyay ducks into the back office.

For 10 minutes, Cheryl trails her son as he walks in and out of the building, using the letter board to craft sentences. His finger just hangs in the air, his mother moving the letter board to meet it. She translates each hard-won tap into an entire word. Five or six taps become a sentence. "I ... want ... you ... to ... k ... n ... o ... I want you to know my work is my own. ... Do ... you ... believe ... me?" she says for him.

Mukhopadhyay frequently says that the letter board is an education method — not a communication method. She admits that some of her families get ahead of themselves, asking their children complex, open-ended questions and moving the letter board to obtain answers. She says she tells the parents that it is best if the letter board is on the table, not in a facilitator's hand. And she offers to review videos of them spelling so she can provide pointers. They rarely take her up on it, she says. "There's a point where people don't listen."

Some children do not make as much progress as Tito did, although she makes no judgment regarding their intellect, she says. Her job is to focus on their motor skills — and let their parents believe what they want to believe. When "a parent is parenting," she says, there's almost nothing you can do to stop them. "Emotions are very high with autistic people, but especially the parents," she says.

Mukhopadhyay steps outside and locks the door to the building under a deep blue Texas sky. It's been a long day — but her work is not finished. Back home, Tito is waiting. Maybe he has something to say.