Helping autistic kids read, write and communicate

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Three-year-old Max learns how to read with the guidance of Jessica Caron, graduate student in communication sciences and disorders, as part of Penn State's Literacy Program. Credit: Patrick Mansell

The boy is delighted. You can see it in his eyes—his enthusiasm for the task, his pride in his ability. Indeed, Max has good reason to be proud: At age three, he is reading. And at this precise moment, he is reading a

story about the Disney character Elsa with his speech-language pathologist, Jessica Caron, a Penn State graduate student in communication sciences and disorders.

As I sit watching the scene from the other side of the one-way mirror, my heart wells with affection for this petite, brown-headed boy who is so eager to learn. But another part of me is confused. I can't reconcile Max's sweet-natured and agreeable behavior with my own biased and inexperienced ideas of how a child with autism should act.

It isn't until his mother, Gina, joins me in the observation room that I learn of the difficulties she faces on a daily basis. Gina, who also has two daughters, says that Max often has tantrums; becomes obsessed with things like numbers, which he'll repeat over and over; and has difficulty expressing himself verbally, only recently being able to ask for something as simple as a drink of water.

But the hardest part about being a parent to Max, Gina says, is anticipating all the challenges he will face in his life.

"It's my job to prepare him for school, for life," says Gina. "They say early intervention is the best. That's why we're here."

Overcoming challenges

Max is a participant in the Literacy Program (Maximizing Outcomes for Individuals with Autism, Cerebral Palsy, Down Syndrome, and Other Disabilities) at Penn State. Directed by Janice Light, the Hintz Family Chair in Children's Communicative Competence, the program helps kids with complex communication challenges—such as those with autism, Down syndrome, and cerebral palsy—develop literacy skills including reading, writing, typing, and speaking.

"Literacy skills are critical to all of our lives," says Light. "They are fundamental to education, employment, social networking, access to technology, and the activities of daily living."

The purpose of the literacy program is threefold. First, as a research initiative, it enables Light to gather the data she uses to develop, implement, and evaluate the effectiveness of such tailored interventions. The program also provides a public service through the Penn State Speech, Language, and Hearing Clinic, and offers training and research opportunities to graduate students and other professionals.

For kids who have limited or no speech, the program makes use of augmentative and alternative communication (AAC) techniques—forms of communication other than oral speech—to help them begin to express their thoughts, needs, and desires. "Most kids are not able to speak when they first come to us," Light explains. "So they are very limited in terms of their communication with other people."

As she begins to describe the mobile devices and other technologies they use to help kids with complex communication needs, it becomes immediately apparent that she has spent many years—decades even—working with people who have trouble communicating. Her own speech is slow and deliberate. As she speaks, she looks me straight in the eye and refers to me frequently by name: a model communicator.

Light created the literacy component of her program—the one in which Max is participating—in collaboration with David McNaughton, professor of special education, based on the National Reading Panel standards aimed at at-risk children. The team adapted the program for learners with limited or no speech.

"Most literacy intervention programs require participants to use spoken responses," says McNaughton. "They are not appropriate for individuals

with complex communication needs who are not able to rely on speech to communicate."

Teaching kids to read

A, B, C. Say those letters out loud and you'll hear a long A, the word for a buzzing insect, and a synonym for vision. But the sounds the letters actually make within words can be very different. As children, we were all taught to recite the letters first, but this tactic can confuse early readers—even those who are typically developing—and slow them down, Light says.

In her literacy program, she teaches children the sounds letters make instead of their names. She teaches lower-case letters before capitals, because the former are what kids see most when they read. She teaches the most common letter sounds first, instead of going in alphabetical order. "We want to get the kids up and reading as quickly as possible," she says.

Another skill Light teaches is phonological awareness, the relationship between individual sounds and whole words. "If I hear someone going 'mmm…aahh…mmm,' can I blend that together and know it's 'mom?' Kids have to be able to make the sounds of the letters and then blend them together into words. We also teach phoneme segmentation, which is the opposite; it is taking a word and breaking it into sounds, which is needed when you write or type."

From there, the program moves into reading, starting with sentences in which the child is responsible for reading certain words and the teacher helps to fill in the gaps. Each child receives one-on-one instruction once or twice a week for 30 to 45 minutes. According to Light, it can take as little as 10 hours of intervention for a child to begin reading.

To date, Light has evaluated the literacy intervention with a wide range of individuals, including preschoolers, school-aged children, and adolescents. So far, all of the participants successfully acquired basic literacy skills and learned to apply them during meaningful reading activities. The Penn State program, Light notes, is the biggest and highest-ranked program of its type in the United States.

"We have had a 100 percent success rate; all of our kids have transitioned from being non-literate to being readers," she says. The research is still in progress, but several publications are currently in preparation to share the outcomes.

"Ultimately, our goal is to have the children start kindergarten as readers and writers because it provides evidence that these kids are learners, which can make a tremendous difference for their educational process," she says. "They end up being included in regular education programs rather than shuffled aside into special education classrooms."

The next step, she says, is to help kids use their reading and writing to support more effective communication skills that they will need in school and work. According to Light, spoken language is difficult for many children with autism because it is transient—there one moment and gone the next. "For many, that type of auditory processing is really challenging," she says. "For these kids, visual support really helps."

One of her grants, from the National Institute on Disability and Rehabilitation Research, is enabling her to develop new software for mobile platforms—Android, iPad, and others—that will allow kids who are using picture-based communication, such as communication boards and speech-generating assistive technologies, to seamlessly transition into using typing and words.

Training professionals

In addition to research and public service, Light also focuses on teaching both graduate students at Penn State and teachers and speech-language pathologists in schools.

Jessica Caron, the graduate student who is Max's designated speech-language pathologist, worries particularly about the teenagers who may have been passed over. "People often think if you can't talk, how are you going to be able to sound out a word, so parents and teachers often don't work on literacy skills with their children with communication disabilities," she says. "There are often low or inappropriate expectations of these kids, and that isn't fair because it doesn't give the kids full access to the world."

This fall, Caron will begin a project with teens aimed at achieving some of the same great advances the younger children in the program have made.

"It's such a text-based world," she says. "Teens are texting and on Facebook and that requires knowledge of text and reading. It's a huge part of their lives. If you can't read you get left out."

With grants from the U.S. Department of Education, Light is training 21 master's students and 12 doctoral students. She also provides training to schoolteachers and speech-language pathologists via both direct instruction and a comprehensive website that is accessible to all.

"It is amazing to see the huge impact our work has on kids' lives," she says. "And it is rewarding to be able to help parents to see what their kids are capable of doing."

For Gina, seeing her son Max succeed as a reader and learner has helped her to feel at peace.

"When we received Max's diagnosis of autism, I was so afraid for his future," she says. "This program has helped me to see that Max will be alright, that he will be successful in life. And that gives me immense comfort."

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