David Schneiderman is autistic.

Until almost a year ago, Herb and Hillery Schneiderman believed their youngest son was also retarded. Last spring, the Schneidermans heard about a new method that helps autistic people reveal their thoughts, something those with autism have never been able to do. This method, facilitated communication, works with a student, like David, sitting at a computer keyboard or letter display and typing with hand or arm support from another person. Facilitated communication finally allows autistic people to express themselves, to unlock their thoughts.

“We now have access to what he’s thinking,” says Herb Schneiderman. “I had no idea he had so much locked up in him.”

Thanks to facilitated communication, the past year has brought moments such as these:

- Herb Schneiderman and his wife were going on a trip. Schneiderman met with David to say goodbye. David typed, “I will be lonely.” Schneiderman was stunned—and moved.
- “Once David said that he had a rash and that it stings,” recalls Schneiderman. Knowing nothing about it, he asked David where it was. David slapped his knee and, sure enough, when they rolled up his pant leg, there was a rash.
- During one long afternoon of communicating with his mother, David was physically aggressive, often thrashing about and even slapping those around him (behavior that is not atypical for someone with autism). He later calmed down a bit, apologized, and typed, “Thank you for caring about me.”

A new approach to communication, championed by Syracuse professor Douglas Biklen, has unlocked the “hidden intelligence” of people with autism.
David and many of his counterparts want very much for people to know that their handicap is not reflective of their intelligence. “David has repeatedly told us that he’s not unintelligent,” says Herb Schneiderman.

• In regard to his high school graduation, David typed, “I’m not getting a regular diploma. I’m special. I have special needs. I’m autistic.” Then he stressed, “I’m not retarded. I’m intelligent.”

Aside from demonstrating his intellect, David was also expressing emotion. Until very recently, it was thought that people with autism were incapable of expressing sentiment.

Through facilitated communication, autistic and nonverbal individuals are now conveying such thoughts and feelings.

The assistance from the “facilitator” establishes a calm, stabilizing effect, enabling the student to point to or type on a keyboard or alphabet display.

The facilitator often asks a question. This is sometimes specific, such as, “What did you do this weekend?” Other times it’s more general, such as, “Is there anything you want to tell me?”

Left alone, the autistic student would be virtually helpless at a keyboard. Some people have the tendency to hit the same key continually, and they need help remaining steady. But with the gentle guidance of a facilitator, she or he becomes capable of articulating thoughts and ideas.

Before the advent of facilitated communication, no one even knew these children had thoughts and ideas to convey. Facilitated communication has unlocked the door for those with autism, revealing that they have unexpected literacy.

Douglas Biklen, director of the division of special education and rehabilitation at Syracuse University, has introduced this method not only to Syracuse, but to North America in general. His work at SU has become widely recognized, drawing daily inquiries, either from parents of nonverbal children looking for help, or teachers and speech therapists wanting to learn the technique. The day after Biklen appeared on ABC’s Prime Time Live in January, his office received approximately 600 calls for information.

To understand the facilitated communication technique, it helps to understand autism.

Autism is a physical, not psychological, disorder. Its common characteristics have been thought to include an inability to feel love or form social attachments, a lack of self awareness, mental retardation, difficulty understanding speech, and an inability to grasp abstract concepts or symbols.

Some autistic people can speak, but not in a typical manner. They often repeat words, or simply echo what they’ve heard. Most cannot form sentences or ask questions.

Until the mid-sixties, experts viewed autism as a social, psychological disease. In 1964, Bernard Rimland, director of the Autism Research Institute, discovered that the cause of autism is actually neurological.

What causes autism is still not precisely known. There are two main theories that those with autism have excessive levels of the neurotransmitter serotonin, or they have an underdeveloped cerebellum and limbic system.

The accepted wisdom has been that the disorder is a social cognitive one, i.e. that those with autism are socially dysfunctional, unable and unwilling to communicate with the outside world.

Due to the intelligence revealed through facilitated communication, Biklen believes the definition of autism must be re-examined.

“We’re finding now that [autistic] people are quite interested in social interaction,” he says. “It’s just that they have problems expressing themselves.

“Our main hypothesis is that people have difficulty getting their bodies to do what they want them to do in terms of speaking and in terms of physical action.”

As it turns out, the simple activity of typing with assistance is the key, allowing those with autism to open up their personalities.

Biklen is quick to point out that facilitated communication is by no means a cure for autism.

The physical characteristics of autism persist. That may never change. But at least the years of silence are behind those with the disorder. They can now communicate with the world.

Biklen has worked in special education for more than two decades. He received his Ph.D. from SU in 1973 and has been on the University’s faculty ever since.

Biklen first encountered facilitated communication in 1985 in Australia. At the time, the method was successfully being implemented with a person with cerebral palsy.

Rosemary Crossley, an educator at the Dignity Through Education and Language Communication Center in Melbourne, used facilitation with Anne McDonald. McDonald, who was born
with cerebral palsy, spent her first 14 years in a hospital, where she was believed to be severely handicapped, both mentally and physically. Two years later, Crossley, with the use of facilitated communication, had McDonald reading and performing math skills.

Biklen was impressed when he witnessed this, but not surprised that such a method could succeed with people with cerebral palsy.

He was skeptical, though, when told the method might be successful with an autistic child. As part of his work in special education, Biklen had spent many years working with autistic children—to him such a possibility seemed improbable.

Not everyone believes in facilitated communication. Skeptics of the method liken it to that of the Ouija board. They question whether the facilitators are prodding the students, putting words in their mouths.

Biklen decided to find out for himself.

With assistance from the World Rehabilitation Fund, Biklen returned to Australia. He studied the method, working with and observing children, then applying the technique himself.

What he learned dispelled any “Ouija board” reservations Biklen may have had. “The students use creative spelling,” he says, adding that they “make typographical errors that are unique to the individual, and convey information not known to the facilitator and reveal quite different personalities.”

Seeing was believing. In August 1990 Biklen published his findings in the Harvard Educational Review. He then brought facilitated communication to Syracuse, training others in the method and advocating its use to the rest of the world.

“It was important for me not only that I could in some way prove what I had seen,” Biklen says, “but I also felt a moral obligation to get it in place in the United States.”

Today, autistic children in Syracuse represent the pilot program for facilitated communication in the entire country.

A long-time advocate of integration of the developmentally disabled into public school systems, Biklen last year introduced facilitated communication to the Syracuse City Schools and other local school districts. He held workshops to train speech therapists and teachers, encouraging them to closely monitor each child’s progress.

At Syracuse’s Edward Smith Elementary School, more than 30 autistic children attend normal classrooms, using facilitation to communicate with their teachers. Following the advice of Biklen, the teachers compile each day’s work in folders to evaluate their headway.

Grace Burritt, a speech and language therapist at Smith, works with autistic children both in the classroom and in private sessions. She learned about the facilitated communication method at a meeting held by Biklen.

In one kindergarten classroom, Burritt works with a five-year-old autistic boy. She asks him about his weekend visit with a former teacher. “I enjoyed it,” he typed.

Biklen points out that students sometimes make spelling errors or forget to add spaces between words. Still, the phrases can usually be understood.

Burritt also works with a seven-year-old boy who has written stories for her about Earth Day and alligators. “He writes many complex sentences about topics you’d never expect,” she says.

Another student gets extremely frustrated when she spells something wrong and throws temper tantrums on the floor before getting back up on her chair to type another phrase.

Burritt is patient with her students, because the relationship between facilitator and student is important. It often takes a long time to develop a trusting, comfortable rapport. Once that happens, the student is more likely to open up.

Biklen’s research with facilitated communication is serving as a beacon for others worldwide working with people who have autism.

Syracuse is the North American focal point, “but it’s spreading quickly,” Biklen says. Last year alone, Biklen and his staff trained more than 1,000 people to use facilitation. Those people, in turn, trained others. “We know that there are well over 1,500 people who are using the method,” says Biklen.

Facilitated communication is being used in much of North America and Scandinavia, as well as Canada, Greece, India, and Germany, among others.

Biklen created a 13-minute videotape titled, “I’m Not Autistic on the Typewriter,” which introduces the facilitated communication training method.

Although the method is primarily used with those with autism, Biklen also works with children who have other developmental disabilities that stem from neuromotor problems. “Poor muscle tone, high muscle tone, certainly problems with speech,” explains Biklen. “Those are the initial criteria—either people who lack speech or who have highly disordered speech, and for whom access to typing is a realistic possibility.”

Biklen has already begun experimenting with facilitation for people with such conditions as Retts syndrome, Down syndrome, and cerebral palsy.

This fall, Biklen will publish a book on his research with the method and those with autism.

The goal of facilitated communication is for students to one day be able to communicate free of physical support—something that Biklen is confident many people, over time, are capable of doing.
Douglas Biklen, director of the division of special education and rehabilitation at Syracuse University, knew a good thing when he saw it. He discovered facilitated communication in use Down Under, brought it back to America, and refined it for use with autistic students.

out actual hand support, needing only a touch on the elbow or shoulder. “We don’t really understand why the touch is important,” Biklen says.

“We find, however, that each time a new facilitator is brought in to work with an individual, we very often have to start back at the hand or wrist,” says Biklen. Slowly, the individual is phased back into typing with lighter support.

The ultimate hope is that, through facilitated communication, autistic individuals will lead more typical lives, communicating not only with teachers and parents, but with the community or in the workplace.

A Syracuse group home for young men with autism is trying facilitation to stimulate communication between residents. When one person wants to say something to another, he types it, and shows it to the other, then giving him the chance to respond. A practice such as this could be the first step toward independence and greater assimilation into the community.

Referring to her elementary age students, Burritt believes that these children will grow up to live fairly typical lives. “Who knows?” says Burritt. “We could have friends someday who are autistic, with whom we’d have conversations, communicating through facilitation.”

“I think this will dramatically change how we think about autism,” says Biklen. “I’m not prepared to say that everybody with autism is in the so-called range of normal intelligence. But I’m also not prepared to say otherwise either. We don’t know just how far this is going to go.

“It appears that most of the students we’re working with are intellectually able to do lots of normal things,” says Biklen, “and we’re going to have to figure out how to assist them in becoming a part of daily activities.”

For David Schneiderman and his parents, that is no easy task, but one they’re working toward.

“The hardest thing is that we have a kid at two different levels,” says Herb Schneiderman. While David is now expressing intellect and emotion, his behavior is still that of someone who is developmentally disabled.

“It’s surprising to see how unraveling the outward appearance is,” says Biklen. “In other words, you see how people look and they appear to be not paying attention, they appear disinterested in the people around them. They appear to be not attending to what’s going on, and, in fact, they’re attending to everything.”

For the Schneidermans, the challenge is to work with and nurture a young man whom they no longer view as mentally retarded.

The Schneidermans talk to David like a typical young adult. “I get the sense that he’s clearly listening,” says Herb Schneiderman. “I have no doubt that David is processing the things that people say.”

Each day does not bring a major breakthrough for David and so many like him. But when progress is made, it’s a milestone.

“We never know what to expect,” says Schneiderman. They do know, however, that the road will be long and hard, and that David still has so much to say.

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