Double Talk

Syracuse University institute continues to use discredited technique with dangerous effects

By Michael Burke
2 years ago

David Lehman can’t tolerate the sight of a keyboard. So five days a week inside his office at A-D Engineering, he chooses to work without one.

Using a keyboard, he fears, would be a constant reminder of the worst time of his life. Of a time that he dealt with severe depression. Of a time he spent worrying that he had seen his two children for the last time. Of a time he feared that he might be sent to prison for the remainder of his life.

It was 1993, and Lehman was separated from his children because of accusations that he had sexually abused his autistic, nonverbal son. The
accusations were later proven unsubstantial because they were made through a widely discredited communication method that was, and still is, regularly practiced at Syracuse University.

The method is called facilitated communication (FC), a technique designed to enable communication for nonverbal people who suffer from disabilities such as autism, brain damage and cerebral palsy. The method consists of a “facilitator” — usually a third-party aid trained in FC — providing support by holding a “user’s” arm, finger or shoulder as the user points to letters or types out messages using a keyboard. In Lehman’s case, his son, Derek, had typed with the help of a facilitator that he had been sexually abused by his father.

But as cases like that arose — in which parents were accused through FC of sexual abuse — so did skepticism about who actually controls the words typed through FC. That has prompted studies which have consistently indicated that the words originate not from the user but from the facilitator, usually subconsciously, like how one uses a Ouija board to “interact with the dead.” Though severe, Lehman’s case, which was dropped 10 months after the accusations were made, was somewhat typical for parents of children who use FC. Just last month, charges were dropped in Canada against a father accused through FC of sexually abusing his 35-year-old, severely autistic daughter.

Worse, there have been incidents in which experienced facilitators have used FC to have people with severe disabilities “consent” to sex or their own death, leading to cases of rape and murder in recent years.

And even when FC doesn’t lead to such consequences, experts say the practice of it on its own defrauds and delays the development of the people who use it, since they could be spending that time participating in other therapy that would likely be more helpful.

Despite that, the promotion and practice of FC is still the primary purpose of SU’s Institute on Communication and Inclusion, which is housed in the School of Education at Huntington Hall. The institute’s stance on the practice has
remained relatively unchanged over the years, with officials maintaining it works.

It’s why many experts blame SU’s institute, considered the epicenter of FC in the United States, for perpetuating continued belief in a method that has, over the last 25 years, destroyed lives, taken at least one and misinformed thousands.

“Syracuse should be completely ashamed of itself for allowing this to happen,” said Howard Shane, a speech pathologist at Boston Children’s Hospital who earned his Ph.D. at SU in 1975. “They’ve never asked the fundamental question: Is this real?”
Douglas Biklen was first introduced to facilitated communication by Rosemary Crossley, the original developer of FC, during a trip to Melbourne, Australia, in 1988.

Biklen, an SU professor at the time who later became dean of the School of Education, declined to be interviewed for this story. But in his book “Communication Unbound: How Facilitated Communications Is Challenging Traditional Views of Autism and Ability/ Disability,” he describes meeting two nonverbal children, Jonothan Solaris and David Armbruster, during his visit to Australia.

Through FC, Jonothan and David demonstrated linguistic capabilities that shocked Biklen and convinced him to make FC the cornerstone of his career.

“Jonothan’s easy grasp of the abstract concept ‘metaphorical’ and David’s facile sarcasm struck me as extraordinary,” wrote Biklen, who retired in 2014. “The content of their communication was ‘normal,’ not what one expects from children with autism.”

It contradicted just about everything Biklen knew about autism, he wrote. But rather than question who controlled the typing, he accepted the communication as valid and believed he had discovered something that disproved more than 50 years of research.
He chose not to quantitatively test the method himself because he believed running experiments on individuals would make them feel as if they were being presumed unable to communicate. He then brought the method to Syracuse shortly after a second visit to Australia in 1989 and, following a single meeting with parents and educators that lasted less than three hours, spread it throughout the community, according to his book.

In Syracuse, he encountered more nonverbal children who, through FC, were suddenly producing full sentences and displaying supposed knowledge that was not previously believed to be typical of people with such disabilities. One of those children was a girl named Mary, then a student at a Syracuse middle school.

“Mary, a student who often makes loud groaning noises and occasionally hits herself and gets up and down from her chair in the middle of a lesson is not yet producing open-ended communication consistently,” Biklen wrote in the book. “Yet in a seventh-grade science class, she was observed to be the first to
respond to her science teacher’s request for the metric measure of weight; she typed out GRAM.”

In response to students such as Mary demonstrating such abilities, Biklen “often wondered if we might be cuing students to their selections of letters and words,” he wrote. But there is no indication that he went further to investigate whether there was any substance to that uncertainty.

Instead, he continued to spread it without scientifically validating the method.

“Here you have a child who has never spoken a word in their life typing with the assistance of a verbal person,” said Jim Todd, a professor of psychology at Eastern Michigan University who learned of FC in 1990 and has since worked to debunk it. “… And you’re not assuming that the words are coming from the verbal person? It just seemed irrational to us.”

It also seemed irrational to some officials at SU. When he first arrived at SU in 1991, then-Chancellor Buzz Shaw met with a collection of faculty members who encouraged him to prohibit the practice of FC at the university, said Bruce Carter, an associate professor of psychology at SU who specializes in child development.

But Shaw believed fully in academic freedom and allowing faculty members to pursue what they desired, Carter said.

The following year, Biklen founded SU’s Facilitated Communication Institute — now known as the Institute on Communication and Inclusion — the first of its kind in the U.S.

“Biklen brought (FC) to this country and he had a reputation. And Syracuse is a reputable university,” said Shane, the Boston Children’s Hospital speech pathologist. “And so that gave it the legitimacy it needed. And if it wasn’t for that, I don’t think it would’ve spread like it did.”

...
The year after Biklen launched the institute at SU, David Lehman returned home from work on March 12, 1993. That’s when local police approached him in his Newmarket, Ontario, driveway to arrest him on the sexual abuse charges.

He spent a few nights at a local jail before being released on bail, and his two children — Derek and his daughter — were removed from his custody by child protection services.

As the case dragged out for months, Lehman began to neglect his health and struggled to remain productive at work. He would spend twice as long at the office on a daily basis, just to get an adequate amount of work finished.

It weighed so heavily on my mind that I struggled to function as an engineer. I mean, imagine trying to function with that on your mind. There’s a constant terror.

David Lehman

Lehman also battled depression throughout the ordeal, needing to be taken to the hospital three separate times over concerns that he might commit suicide. The depression lasted even after the case was dropped, and he ultimately opted to receive electroconvulsive therapy, a controversial method in which patients are electrically induced with seizures in an effort to relieve psychiatric illnesses.

The therapy cured Lehman’s depression, but he lost about six months of his memory as a result, a common side effect of the therapy.

To this day, he suffers from post-traumatic stress disorder, which is why he doesn’t use a keyboard — it triggers the PTSD.

At the time his case was dropped, Lehman was one in what was already a long list of parents who had been falsely accused of sexually abusing their children through FC. By 1995, there had been at least five dozen such cases, “the
substantial majority” of which were unfounded, according to research conducted by Emory University professor Scott Lilienfeld. The nature and the quantity of cases such as Lehman’s prompted studies that seemed to clearly debunk FC, but the practice of FC continued, and the cases have continued to pop up well into the 21st century.

In late 2007, for instance, it was Julian and Tali Wendrow who had their worlds flipped upside down in West Bloomfield, Michigan. They were jointly accused through FC of sexually abusing their nonverbal daughter, Aislinn, who was in high school at the time.

Julian and Tali were immediately separated from Aislinn and their son, Ian. The children were sent to a foster home, with Julian going to jail and Tali to her mother’s home, where she was kept on house arrest. Tali said Julian spent much of his time in jail in solitary confinement, where he was kept in his cell for 23 hours per day and was never allowed outside.

Tali, meanwhile, was forced to take time off work without pay. The only time she was allowed to leave her mother’s house was to go to the doctor, but that required that her doctor first send a letter to the jail confirming she had an appointment.

She ended up canceling most of them.

“Can you imagine that? Calling the doctor and saying, ‘Can you please send a letter to the jail that I have an appointment?’” she said. “It’s humiliating.”

Like Lehman, Tali experienced fear that she might have seen her children for the final time. But some of the worst fallout came after the case was dropped three months later, and the family was reunited.

When she returned to her job at the county’s attorney’s office, she said she was let go without an explanation. To this day, she still hasn’t held beyond a part-time job and is looking for full-time work.
Having that accusation out there ruins your reputation.

_ Tali Wendrow

And it wasn’t until last year — eight years after the original accusation was made — that the Wendrow family won a civil case against the prosecutors in the original criminal case. That was when Tali said she felt like the “dust finally settled.”

“But after the dust settles, you still have to brush yourself and move on. The whole thing threw everything off,” she said. “… I look back and say, ‘Eight years, wow.’ People go through high school and college in eight years.”

• • •

When Anna Stubblefield had sex in 2011 with a nonverbal man who has cerebral palsy, she didn’t think she was doing anything wrong, even though she was ultimately found guilty of aggravated sexual assault.

That’s because, experts say, she was adhering to FC instructions emphasized at SU’s Institute on Communication and Inclusion.

Stubblefield, then a philosophy professor at Rutgers University, received certification as a facilitator from the institute, where she was taught to always presume competence in FC users. Stubblefield thus presumed the man, identified publicly as D.J., was able to consent to sex, and claimed in court in 2015 that her sexual relations with him weren’t rape because he “consented” to them through FC.

But psychologists determined D.J. mentally incompetent and unable to consent to sexual acts. The judge in the trial ruled that FC failed New Jersey’s test for scientific evidence and a jury found Stubblefield guilty of two counts of aggravated sexual assault in the first degree. Stubblefield was ultimately sentenced to 12 years in prison, where she remains today.
Though the instances of unsubstantial sexual abuse allegations are the most documented, there are other serious consequences that have resulted from the practice of FC, like Stubblefield’s case.

After the case gained national attention when it was featured in an October 2015 New York Times Magazine piece, SU’s Institute on Communication and Inclusion released a statement reminding those who practice FC to follow the institute’s “best practices” — which include gradually lessening physical support and making sure that the user’s eyes stay on the keyboard. But the statement didn’t mention that Stubblefield was trained at SU.

The importance of presuming competence in all people, regardless of their disabilities, was what Stubblefield did with D.J. and was a cornerstone of Biklen’s philosophy when he established the institute.

“For me, the idea of presuming competence ... is the most optimistic and appropriate way to go through the world,” said Christine Ashby, the current director of the institute, in a March interview.

Experts thus say that the Stubblefield ordeal likely never would have occurred if not for SU’s practice of FC. But they also go a step further, arguing that SU is at the root of all issues that have arisen as a result of FC.

There was also the case of Gigi Jordan, a New York woman who in 2010 killed her 8-year-old autistic son by force-feeding him painkillers and other pills. Jordan, who was convicted of first-degree manslaughter, testified that her son wanted to die because he had been abused by his father, something Jordan said her son told her through FC.

And then there are the hundreds of people who practice FC but don’t type out accusations of abuse. Who aren’t sexually assaulted like D.J. was. Who aren’t killed like Jordan’s son was. But they and their families are being misled, experts say, when FC advocates presume competence in their ability to communicate when evidence suggests they might not be able to.
“You’re claiming something about them that isn’t true, and then you’re superimposing onto them a personality that they don’t have and superimposing onto them words they haven’t spoken,” Todd said. “... It’s not criminal in the technical sense, but it’s criminal in the ethical sense.”

To Shane, all that’s problematic with FC can be traced back to a single culprit.

Who’s responsible? You tell me. Had Syracuse in the 1990s listened to the research that showed that this is all nonsense, all of this would have been avoided.

Howard Shane

Since the early 1990s, there have been about 40 experimental studies which have strongly indicated that authorship in facilitated communication belongs to the facilitator, rather than the user.

One of the earliest such studies came in August 1992 at the Oswald D. Heck Developmental Center in Schenectady, New York. Twelve individuals living at the center who used FC and their respective facilitators were used in the study, which involved displaying pictures of everyday objects and asking the users to type out the name of the object.

In some scenarios, only the user was shown the picture. In others, both the facilitator and the user were shown a picture, with each being unable to see what the other was shown. Sometimes they were shown the same picture, while other times they were shown different ones.

This is considered the “double-blind” model of testing and the results were telling: The 12 users were unable to produce correct answers without the facilitator being shown the same picture as them.

When the facilitator and user were shown the same picture, 10 of the 12 users were able to produce correct answers. But when the facilitator and the user
were shown different pictures, the only “correct” answers typed were for the pictures shown to the facilitator, never for the pictures shown to the user.

For example, if the user was shown a picture of a toothbrush and the facilitator a shirt, the word “shirt” was frequently typed out and “toothbrush” was never answered.

A number of studies have since been performed following the double-blind model — most recently in 2014 — by researchers in Finland — and each has come away with similar findings.

The studies have led to a number of professional organizations taking stances against FC, including the American Psychological Association, the American Speech-Language-Hearing Association and the American Psychiatric Association.
Over the years, though, proponents of facilitated communication have largely dismissed the results of the studies, arguing that FC users, of which there are hundreds, are not able to produce correct answers in testing situations because they become afraid.

“A double-blind test is a very stressful situation,” said Ashby, the current director of SU’s institute. “… When you put people in a situation where you’re trying to prove whether or not it’s really them, it’s not an ideal situation. Because you’re starting from the presumption that it’s not them.”

But FC critics have zero tolerance for such arguments. There is no research suggesting that the people who use FC become especially flustered or scared in those situations, experts said.

“The FC users are supposedly suddenly able to communicate for the first time, but they all become too nervous to identify a simple object when asked? It’s patently ridiculous,” said Todd, the Eastern Michigan psychology professor who has a Ph.D. in developmental psychology. “And these folks say there are hundreds of people using this with success, and out of hundreds they can’t find one person who is confident enough to show it works? It defies all credibility.”

Experts largely attribute the continued existence of FC to vulnerable parents and families who will do just about anything to attempt to communicate with their loved ones. Especially if they’re told by professionals such as Biklen, Ashby and others that the practice works.

“They don’t stop to think about that,” Todd said of such professionals. “They just say, ‘We’re just going to throw it out there and hope and pretend it works.’”

“I do have an issue with the advocacy and promotion of FC in the absence of strong data that it actually works,” added Carter, the SU associate professor of
psychology. “Because I don’t like the idea of giving people false hope. I find that troubling.”

... The current Institute on Communication and Inclusion (ICI) is a multi-office room at 370 Huntington Hall, down a skinny hallway in the corner of the building’s west wing.

In many ways, the institute is the same as it’s always been, despite changing its name from the Facilitated Communication Institute in 2010 to represent “a broadened focus,” according to its website. Research and training for FC is constantly being done, and includes training sessions for the general public, monthly discussion sessions and training workshops. The best practices outlined on the institute’s website are largely the same as the ones outlined in Biklen’s book. The specific FC method itself, Todd said, also hasn’t changed.

“I’ve seen it in court,” he said. “I’ve gone to the workshops. It’s no different than it was back then.”

What has changed is the level of support for the institute, both in Syracuse and from some other organizations that have promoted FC.

The University of New Hampshire’s Institute on Disability, long considered another FC leader, recently disbanded its practice of FC, said Matt Gianino, director of communications at that institute, in an email.

SU’s Communication Sciences and Disorders Department, meanwhile, left the School of Education — where the ICI is housed — in 2002. Publicly, SU said the move was influenced by “multiple factors.”

But Shane, who earned his Ph.D. in speech pathology in SU’s CSD department, said he was told by “high-level people in the department” that the move was because the department didn’t want to be associated with the institute. Shane wished not to identify those people.
Carter added that he heard “rumblings” that CSD faculty members felt as though their research was being devalued by them belonging to the same school as the institute.

Linda Milosky, chair of the CSD department, said in an email that the department “does not engage in research or provide clinical services involving Facilitated Communication” but declined to be interviewed.

And though former SU Chancellor Nancy Cantor frequently and publicly supported FC — in a 2007 speech she seemed to correlate the effects FC has on autistic people to the freeing of slaves — it is unclear whether current Chancellor Kent Syverud has endorsed the method. University officials deferred comment to Ashby to speak on the university’s behalf for this story.

Cantor, who is now the chancellor at Rutgers University-Newark, declined through a spokesman to comment on this story.

But even as support dwindles, Todd theorizes that SU’s institute will continue to exist as it currently does until a lawsuit accusing the institute of educational malpractice is won.

Currently, there’s no real precedent of educational malpractice, said SU College of Law professor Peter Bell. He added that for such a lawsuit to be won, it would need to be proven that “no reasonable instructor in that field would use that technique.”

**It wouldn’t be impossible. It’s just going to be really hard.**

*Peter Bell*

Todd acknowledges that. After all, there has already been one such lawsuit filed against SU. Mark Storch of Red Hook, New York, filed a lawsuit in 1994 accusing the university and Biklen of fraud after Storch was falsely accused through FC of sexually abusing his daughter. The lawsuit was dismissed in 1995.
But many experts continue to hold out hope that the practice of FC will end. It’s a hope they’ve held for roughly 25 years. A hope that, over those years, has largely turned into disappointment.

“It’s deeply frustrating to be dealing with the same issues here in 2016 that we were dealing with in 1991 and 1992,” Todd said. “The scientists have done their due diligence.

“But we plug along and hope that we can help people not come to harm.”

Comments
Published on April 11, 2016 at 1:04 am
Contact Michael: mdburko1@syr.edu

You must be logged in to post a comment.

1. Tony966 2 years ago
Time to put an end to this. It’s done more harm than good and the University is better than this nonsense or should be.

2. Jason Travers 2 years ago
This is a great piece by a student journalist who understands the research better than the supposed scholars who promote this nonsense. And what a coincidence: Ashby and the crew from Syracuse U are TODAY at the largest educational conference in the country to promote facilitated communication: http://convention2.allacademic.com/one/aera/aera16/index.php?cmd=Online+Program+View+Paper&selected_paper_id=1063063&PHPSESSID=juspc0qd6rt0tc1ebmq2luhe4

3. Fred Jordan 2 years ago
I remember the chaos wrought by Facilitated Communication in the 1990s as well as the technique being thoroughly debunked. While academic freedom should be a broad cloak of free expression, the
teaching and dissemination of disproven, ineffective, and damaging beliefs and practices strains the concept past the breaking point. It’s time to put this to bed. Excellent article.

4.

**ShadrachSmith 2 years ago**
Janet Reno put innocent men in prison using feminist interpretations of children’s memories. Hillary so admired Janet Reno that she got Bill to appoint Reno Attorney General, where Reno did much evil. Due process under the law is a good thing, empowering feminist star chambers is not.

5.

**Fred Jordan 2 years ago**
Feminism consists of a wide variety of disparate and often contentious schools of thought, so there’s no need to make a sweeping statement. The problems with FC and the railroading of innocents started before Reno. We could see the roots planted in the moral panic surrounding day cares in the late 1980s which was itself the product of a multitude of factors, such as the rise of therapeutic culture, crime shows and the 24 hour news cycle, and concern about rapidly changing gender roles. A number of progressive and reactionary cultural forces converged to make a mess in the 80s, and it’s likely that the same were at work when FC appeared on the scene in the wake of the daycare fiasco. 

On a different note, Nancy Cantor claimed the following in 2007: “while the controversy about facilitated communication in the research literature in psychology and education never seems to tire, the compelling testimony to its power is written and rewritten in the stories of autistic individuals, turned public scholars, college students (including Jamie at Syracuse), actors and film-makers and writers, whose lives it has turned around – and freed.”

(http://www.syr.edu/chancellor/speeches/ImaginingAmericaAnnualConferenceRemarks090707.pdf)

As a proponent of facilitated communication, she bears a great deal of responsibility for the continued promotion and dissemination of this pseudoscience. Her thinly-veiled scorn for empirical research and fondness for anecdotal evidence are striking examples of rejecting the scientific method (something that’s all-too-common in higher education these days) as a means of deflecting criticism through narrative rather than evidence. This is how awful, illogical, and unsupportable ideas can thrive in the face of ever-mounting evidence against them.

6.

**ShadrachSmith 2 years ago**
Your opinion is noted, but my point stands: feminism is the enemy of due process under the law in America. You know that as well as I do.
7. **Arthur Golden 2 years ago**
Jason – as I emailed you and James Todd over 2 weeks ago, I am part of a group of facilitators that are arranging to do a replication of the 1992 Wheeler study (done at O.D. Heck) and I feel strongly that “all sides” should cooperate in this effort. While awaiting comments from other facilitators, I plan to email you again on Thursday, April 14, 2016.

8. **Arthur Golden 2 years ago**
On March 25, 2016 I informed Professor James Todd that I had found a replication site with a number of FC users where I was trying to arrange for testing. Then in this article published over 2 weeks later, he is quoted as follows:

“The FC users are supposedly suddenly able to communicate for the first time, but they all become too nervous to identify a simple object when asked? It’s patently ridiculous,” said Todd, the Eastern Michigan psychology professor who has a Ph.D. in developmental psychology. “And these folks say there are hundreds of people using this with success, and out of hundreds they can’t find one person who is confident enough to show it works? It defies all credibility.”

I plan to email him again on Thursday, April 14, 2016 and I look forward to his favorable response now that I have found so many persons willing to show it works.

9. **k8 2 years ago**
As an Inclusive Elementary and Special Education major, I have had the opportunity to speak with users of FC and work with students who use other alternative communication devices. Based on these experiences, I find the claims being made against FC to be completely unfounded. Having observed FC personally, I can attest to the validity of it and to the positive impact that it can have on individuals who use it. FC and other forms of alternative communication allow people with disabilities a chance to be heard. In fact, the ultimate goal of FC is to fade support over time in order to encourage the user to gain complete independence in typing. To compare FC to a “Ouija board” is laughable, at best. Although there are many critics to and controversy surrounding FC, please avoid taking this information at face value. Instead, talk to individuals using FC and research the subject further. To fail to provide people with disabilities alternative means of communication is to deny their voices. Furthermore, to suggest that people who are unable to communicate verbally simply cannot communicate through typing is failing to presume competence in these individuals.
End this farce.

By chance just came across this article…wow! Syracuse is still practicing this? Yes, this is a great article by a thinking and objective journalist who has taken the time to understand the subject. I cannot understand Syracuse's failure to see the flaws generally and the harm specifically done by this “technique” that S.U. should have discontinued long ago. It is shameful.