



## Case Study

### ***Breaking the Silence with Nonverbal Autism***

**By Peter Rothenberg**

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In *Pedagogy of the Oppressed*, author Paulo Freire demonstrates that nothing is more empowering than teaching people to name their world. As therapists, we know this applies especially to our clients' inner worlds. Even relatively high-functioning people can find it difficult to know what they're experiencing and how to express it. Imagine what it must be like for the people with autism who don't talk but have a world of perceptions, feelings, thoughts, fantasies, and desires swirling around inside them. Imagine the frustration, isolation, and confusion they experience.

For the past 30 years, my work has included individual and group therapies with developmentally challenged and autistic clients (mostly people with Asperger syndrome). My goal with these clients always seems to involve helping them, their caretakers, and their families to see them as full humans, with strengths and weaknesses, rights and responsibilities, and rich internal lives—not just external behaviors. After all, perceiving people primarily through disabilities, whether patronizing them or focusing on their limitations, only further isolates them.

When Stephen's mother called to ask if I'd be willing to try to work with her son, a 38-year-old man with autism, she explained that since he was nonverbal, he had to use facilitated communication (FC) to talk. FC is a controversial method, which involves a facilitator supporting the client's arm in a way that allows and encourages him to type with one finger on a keyboard. The facilitator then says what the client is typing. Critics have pointed to the lack of scientific evidence confirming that the communication is really coming from the client and not controlled by the facilitator. However, the more I examined the FC research, the more I realized that it posed the same problem as many studies of psychotherapy: the more we put a subtle emotional process under the

microscope and dissect its components, the more artificial it can seem.

Stephen's mother sought me out because of her concerns that his father, with whom he lived, wasn't allowing his son "to experience his full adulthood," as she put it. She felt Stephen was suppressing his feelings out of fear and a desire to please him. I'd never been involved with FC before, and had no idea what to expect in working with Stephen and his facilitator, but I agreed to see them.

### **Enter Stephen and Holley**

A week later, Stephen and Holley, his facilitator of 25 years, walked into my office and sat on the couch with a large keyboard nestled between them. Stephen made unusual noises and faces and uttered only a few words. As soon as I greeted him, he began typing, explaining that he'd had a previous therapeutic experience with Holley facilitating, but that the sessions had included his father, which he'd found very constricting.

Stephen's parents had divorced when he was two years old. He'd lived with his mother until he was 15, when a huge surge of hormones and no ability to verbally communicate resulted in him physically attacking her on several occasions. Within a short time, he went from a tender, sweet, loving child to an adolescent who couldn't control his impulses. This was 27 years ago, when resources for families with autistic children were scarce. The family's solution was for Stephen to live with his father, stepmother, and stepsiblings, who had more time and money to care for him.

I found it odd that the previous therapist hadn't met with Stephen without other family present. If they'd seen him without his father, he'd likely have had a markedly different therapeutic experience. Now that he had his own therapy, his thoughts, feelings, and worries poured off that keyboard. In my 48 years of practice, I'd never experienced anything like it!

Nearly every session, he typed—and Holley vocalized for him—about how life-altering it was to be able to examine and express his inner experience. At the time, he was taking a creative writing class at a local college, and after a month of therapy, he wrote this poem about our sessions: "I have been given a gift / that has inspired me / to renew my commitment to life. / I have been given / a kind person to talk to / who has not known me before. / He is a good, interested, and decent listener / in those structured / sixty minutes / in which I felt free / to share / who I am. / We all need / someone to talk to /

who honors our lives / in a certain / objective manner. / Someone to talk to / has saved me / on this day."

Reading this, any initial skepticism I had about FC disappeared. Holley was a trained professional and obviously dedicated to Stephen, but she wasn't a poet. In sessions, she'd gently urge Stephen to respond to my questions and comments, but I had no doubt that the words she vocalized came from him. At this point, with Holley's facilitation, Stephen and I have been meeting every other week for four years. Asked why he thought we seemed to form an alliance so quickly, he said it was a relief talking with someone who has a great "crap detector."

Of course, not every nonspeaking person with autism is as perceptive and creative as Stephen; however, his therapy brought up several themes that regularly come up with my other clients who have autism, such as how shocking it is for them to find out that their feelings are normal. Again and again, Stephen typed about how amazing it was for him to discover that "it's okay, it's really okay, to feel what I feel without shame." For instance, Stephen had always thought that if he loved someone and was annoyed or angry at them, it meant something was wrong with him and he'd better keep quiet about it. To hear that people can and do feel more than one way about things and don't have to deny or project their feelings was truly liberating for him. He discovered he could be critical and frustrated with his family and still love them and not feel guilty.

In one session, Stephen was talking about how he "acted better" when he wasn't with them. He'd broken a toilet at home, and said he thought his motive had been "to make it harder for them, so they'll let me live somewhere else." He said he wanted to explore other living options with his mother and Holley, but he was afraid his father would "pop a cork." As we discussed his fear of confronting his father, I wondered if he was worried that his father wouldn't be okay without him. As we explored further, what emerged about their relationship was a mixture of love, fear, and mutual protection.

"Dr. R, are you really telling me that it's normal to have all these contradictory feelings for my father? I always thought it was my autism and felt guilty as hell," he told me. "But what do these feelings mean?"

"Yes, Stephen, that's exactly what I'm telling you. And it means you're human," I replied.

Stephen wrote the poem "I Protest" after that session: "Crushed (down) / to the core / I protest. / I argue / with my own voice / for getting sucked into / the hypnotic messes / of

a world around me / that is not immersed / in the truth. / Undercurrents / of my former self / surface, / and I remember / knowing a miracle, / the me that has always been: / wise, safe, / strong, loving / and brave, able to / face anything. / Crushed no more, / I remember/ my original self."

### **Working with Ambivalence**

Another typical theme that emerges with many of my clients with autism as they grow older is the conflict between wanting to take responsibility for reducing certain behaviors vs. not wanting to relinquish the power of the "spoiled, acting out, weird kid," as Stephen put it. From the beginning, Stephen wanted to work on his behavior at home, some of which he described as "typical autistic stuff," like making noises, and some as "passive-aggressive issues," like taking no initiative and depending on others for daily living activities he could do himself.

On the one hand, Stephen feared his family's disapproval and struggled with whether he deserved his pain because, as he put it, "I'm such a burden to them." On the other hand, he frequently typed about how he felt disrespected at home, didn't have a voice there, and resented the way his family often talked about him as if he weren't present. He especially hated how his father and stepmother disrespected his mother, but he felt too frightened and powerless to tell them how much it hurt his feelings.

In one session, he typed about his father being "on the warpath" at home. He wanted to explore his fears of his father, as well as the loyalty he felt toward him because "he takes care of us." At one point he typed, "I feel very respected outside of the house. Then I have to go back home—it's the toughest thing in my life, tougher than the autism!"

Stephen expressed the themes of this session in his poem "Hurt": "It is / sometimes / a confusing inner life/ for me / when I am hurt. / Then, I remember / that I love the ones / who hurt me, / though I do not love it / when they hurt me, / when their vile language / cuts into my psyche, / when my sister tells me / 'If you ever fucking do that / again, Stephen, / I will kill you!'/ Or when my stepmother and other family members / demean and trash my mother / with horrible accusations / in my presence."

We're still working on the ambivalence Stephen has toward his father. He loves him and feels he's his favorite child, but he sees him as manipulative, controlling, and hypocritical. The one exception to Stephen's remaining fearful of even the mildest confrontation with his father was when he was able to tell his case worker, in his father's

presence, that he felt overmedicated. In “Mixed Feelings,” he wrote: “I believe / my higher purpose / is to understand / and to forgive, / to love others, / (and myself), / in the face of / an awareness / of all of our faults.” This is typical of Stephen’s artistry as well as his defenses, and I always struggle with how much to support and how much to challenge. Usually, I try to do both, as in this case, where I shared how much I admired his ability to find the silver lining, while sometimes worrying that in his efforts to love and forgive, his needs and feelings got ignored. In response, Stephen remarked, “Dr. R, I hate how right you are—that’s why I love coming here!”

*"I am an adult with a spirited child that lives within me.  
There is no reason for them to be apart."*

By year three, Stephen was working out his dilemma with feeling “caught between the little, spoiled kid and the self-respecting, capable adult.” I emphasized that the little kid side of him was terrific—filled with creativity and a sense of wonder and joy. Rather than get rid of the kid, I suggested he learn how to tell the kid to slide over from behind the wheel and sometimes let the adult part of him drive.

It isn’t easy to differentiate difficult-to-control autistic behaviors from more intentional passive-aggressive ones, but Stephen admitted he sometimes did things just to piss off his family. After I’d helped him see that his underlying feelings were okay, but that the way he was acting them out wasn’t, he said the thrill of irritating people at home was gone. He realized he couldn’t expect to get the respect he wanted if he acted like a child.

Here are some lines from his series of “Growing Up” poems. “I faced myself / in the mirror today; / there was / no one else around / to look at! / More seriously put, / I want to be / an adult / and give up childish things, / yet I want to maintain / my last line of defense, / to control my life / by being a little / or a lot more / uncooperative / with simple daily chores / and caring for myself. / These I resist / as though I am / a warrior, / yet I have nothing to prove by this: / there is no victory in it. / I want my situation / to change, which means / I have to change. / Might as well grow up!”

In the final poem of this series, he wrote: “Why is life so disturbingly hard, / yet simple? / I am an adult / with a spirited child / that lives within me. / There is no reason for them / to be apart.” In session, he typed, “I tell the little kid, ‘I love you, but you have to stop

being so irritating.” It’s hard to get used to feeling so close to someone who communicates profound things to you and doesn’t even look at you, but it’s also hard not to be profoundly moved. Certainly, both Holley and I were on this day.

Later, Stephen told us that lately he didn’t know if he wanted to be “cured of autism” (his words) because he wasn’t trained to be without it. When asked to explain, he typed, “I guess the secret is to accept the cards you’ve been dealt and get help where you need it.” I believe he was equating being “cured of autism” with relinquishing immature behaviors, but his statement surprised me. What emerged in the discussion was Stephen’s feeling that, besides the obvious challenges he faced, he felt a kind of pride in his identity as an advocate.

Recently, Stephen invited his mother to a therapy session. He loves her dearly, though his contact with her is limited by his father to monthly dinners. He used the session to tell her that he needed her to hear something important without just reacting with platitudes, which Stephen called “being a Jewish mother.” Then he told her he was profoundly sorry that he’d hurt her by acting out aggressively as a teenager, and that even though kids with autism sometimes do that, he needed to take responsibility for it.

Immediately, she tried to cancel out his remorse and regret by saying, “Oh my God, Stephen, it’s okay! I completely understand! I just feel bad that you feel bad!” At that point, I stepped in to tell her that I knew she wanted to take away her son’s pain, but what he really needed was for her to hear him and respect what he was telling her about needing to take responsibility. With a little help from me, she was able to let Stephen accomplish this goal. I felt deeply touched to witness how this extraordinary, nonverbal man was “finding his voice” and taking leadership in healing an old wound with his mother.

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Needless to say, I love working with Stephen, a perceptive and deeply honest client. Going forward, I suspect the hardest issue for him will be advocating for himself, especially in regard to his living situation, since he’s concluded he really does want more independence.

In a recent session, I asked Stephen, his mother, and Holley what they saw happening as a result of therapy. His mother said, “I wanted Stephen to express his feelings but had no idea that therapy was going to be so important for him. He’s using it as a beacon of

hope.” Holley added, “Stephen has discovered he’s a valuable part of the human race, not just some guy sitting in the corner.” More than anything, he wants people to know that “therapy is not just for people who talk.”

What I learned from being with Stephen and Holley is that the relationship between client and FC facilitator is above all one of deep trust, not unlike the relationship between therapist and client. It requires that Holley be an active listener, who puts her thoughts, feelings, and opinions on the shelf, so she can be a conduit for Stephen’s inner world to come through. It’s obvious that Stephen clearly appreciates how she honors him.

In the final poem of his “Keyboard Series,” Stephen wrote: “I think of my friends, / and the multitude of others / who are still silent, / who have not been given / the chance / to come home. / I will fight for them. / I will pray for them. / And I will always / be grateful / that I am home, / in this place / of my true self, / through the gift / of a keyboard.” He dedicated this poem to the people with autism who remain in silence and have not been given the opportunity to use FC with a keyboard and a dedicated facilitator like Holley. “Just because I can’t talk doesn’t mean I don’t have anything to say,” he added—which was clear from the moment I met him.

## **CASE COMMENTARY**

*By Ron Taffel*

Let’s face it: even experienced therapists who work with a wide range of clients are likely to be stunned by the power of Stephen’s poetry. How could we not be moved by such awareness, psychological nuance, and self-reflection?

Much in the way Holley gives voice to Stephen in treatment, Peter Rothenberg gives us a window into Stephen’s inner world and emotional capacities beneath the shroud of his nonverbal autism. At its core, this case study is a challenge to diagnosis and an example of how labels often disguise our humanity: the diagnoses of autism and spectrum disorders being particularly heavy handed. They make every poem of Stephen’s, every metaphor, every insight, his ambivalences and interpersonal attachments, all the more stunning.

At the same time, brief case summaries lead to questions about ordinary therapy matters, especially so in a treatment with seemingly different parameters. For example,

how did the nature of facilitated communication affect the dynamic between Stephen, Holley, and Peter? Clearly, the therapy offered Stephen the chance for a reparative experience, a cooperative and respectful mother and father, but did Rothenberg and Holley ever speak to each other? What were conversations in treatment like—client and therapist talking about the details of life, or was it the happenings of each week, or maybe sports? Did they set behavioral goals between sessions? What occurred that made Stephen believe Rothenberg was a great “crap detector”?

How would one describe their edge of intimacy, the space within which client and therapist work through rupture and repair and uniquely hold each other? As Rothenberg reports, Stephen did not look directly at him, and yet, given his openness, theirs must have been a truly genuine, ongoing connection. Despite my clinical curiosity, though, I have no questions about the therapeutic conditions here, ones that exist in all good treatment. Clearly, Rothenberg is a veteran, focused listener and provided unwavering positive regard. He saw far beyond diagnosis, empathically grasped the contradictory elements of human nature, and was an exquisitely patient teacher.

In doing so and receiving Stephen’s poetry in return, Rothenberg reminds us that when psychotherapy works, it’s above all else a life-empowering exchange of gifts.

Stephen puts it best, his words a compass to therapists who navigate the often wild crosscurrents of clinical technique: “I have been given a gift / that has inspired me to renew my commitment to life. / I have been given / a kind person to talk to / who has not known me before. / He is a good, interested, and decent listener / in those structured / sixty minutes / in which I felt free / to share / who I am.”

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