

PROLOGUE

Approximately 30% of children diagnosed with autism are non or minimally able to speak words. Historically, these children were institutionalized, heavily medicated, or both. Kathleen worked with these children in the school system when her son, Kris, was born. When Kris was first diagnosed with autism and didn't speak (he only spoke two words in his life), Kathleen grieved. But then she learned about the communication strategy called Facilitated Communication Training (FCT) and Kris ended up communicating with her with this method ([See Kris' story](#)). It gave her great hope for his future, but they never got that chance - Kris died three months later.

Facilitated Communication is one method that falls under the umbrella of supported typing and numerous individuals with autism have become independent, even reading their words ([vimeo.com/193191599](https://www.vimeo.com/193191599), e.g.) after initially using physical support of resistance or touch to their arm or hand. At the same time people with autism and their families were finding hope and success with communication, studies revealed that there could be influence when using the supports. Some professionals took this to mean there was no true communication and many professional organizations, in response to these studies, have largely stated this is a discredited technique that should not be used.

Not irrelevant here, there were instances of people being accused of child abuse by typers when using physical support. Because of the possibility for influence, this fueled the fire for detractors and the discussion turned vitriolic, including name calling, disrespect and even with one professional still using

the technique reporting death threats (personal correspondence). At a recent National Institute on Deafness and Other Communication Disorders (NIDCD) web conference, with two attendees who used supported typing, one of the organizers felt the need to address social media attacks by detractors, asking for participants to be respectful and not to return to past debates : “I am personally appalled and somewhat saddened about some of what is appearing in social media related to our meeting and this sort of attack behavior will not be tolerated here.” Beyond professional spheres, the debate has affected those communicating through typing leaving them frustrated at the constant question of validity and authorship ([See link](#)).




As Kathleen had experienced clear intentional movement using the FCT technique with her son, and later many others, she never discounted that communication with supported typing was true but also acknowledged the possibility for influence. She recently submitted a paper, based on her graduate school work, on the [neurology of supported typing](#) that proposes a neurologic explanation for the influence as well as other questions. Primary questions raised by these supported typing strategies include 1) How could someone learn to read without being formally taught? 2) If there is true communication coming from the typer, why is there so much influence when participating in the double blind studies? 3) How do the movement differences seen in autistic persons present and does it parallel the brain differences we see?

Kathleen uses a fiction venue to illustrate specifics with supported typing while interjecting expert opinion vignettes to address the controversies. Scientific, autobiographical and clinical reports are integrated to give the reader an

understanding for things like the unique way dyspraxia presents in autism, and why both the influence *and* true communication from users makes sense.

Supported typing can be life-changing for people with autism and their families. But, it is not accepted in schools or many therapy clinics and studies examining optimal implementation are limited in funding resources. Kathleen believes this is in large part to a lack of understanding and hopes this will shed some light on this poorly understood topic¹.

A NOTE ABOUT THE LAYOUT

This novel begins with a fictionalized story about supported typing. Dispersed between chapters are “Expert Opinion” vignettes where qualitative and experimental studies are integrated with autobiographical accounts and clinical observation. These vignettes are bracketed with this symbol:    .

If you have a hard time switching between fiction and non fiction, feel free to read the story first and then the non fiction parts!

¹ As there is no one size fits all approach when describing people with autism, I use people first language as well as identity first language based on the flow of the writing.

DAISY

At 78 Daisy still got up and went to work every day. Actually, even by stamina standards of most thirty year olds, Daisy had a lot of get up and go. So much so that her husband, Tom, and she had a running joke, actually more of an understanding, where if he needed a low-key vacation day to himself all he needed to do was ask.

While Daisy's genetic make up lent to high energy, a majority of that energy was fueled by her passion for her work. It was over 40 years ago when she first met Suzie - a frail young woman in what they called a disability institute in Australia. Daisy had been hired to provide educational services to residents. When Daisy first met Suzie, Suzie was laying on a gurney, as this was the only way the staff had figured out how to be able to move her around easily, as Daisy approached. Daisy had been told that Suzie could not talk and that she was severely retarded.

But, when their eyes met, there was a spark in Suzie's eyes that was more consistent with a thoughtful mind behind a mouth that couldn't speak words than retardation. At that moment, Daisy knew Suzie had so much to say, and Daisy knew it was her job to help her get it out. Of course, Daisy didn't know it at the time, but this would be the start to an incredible journey for both of them. Daisy would discover a way to support Suzie using a letter-board and Suzie would type her words. Several years later, Daisy would write a book, *Suzie's Coming Out* that detailed their journey.

The communication technique Daisy and Suzie used would be come to be called Facilitated Communication and later Facilitated Communication Training. While Suzie was

able to demonstrate her competence in a court of law, many others who used the technique were not so lucky. In Daisy and other's excitement to share this life changing technique to others, the promoters didn't fully realize how much a typer might be influenced, especially someone with autism. And, some in the research community had done studies showing this, which, along with accusations that came out using FC, led to a ridiculously vitriolic debate in the professional disability community. On one side some scientists and professionals who read the studies became convinced that the only thing that was happening was that the typers were being led by subtle or not so subtle cues. But, to those like Suzie and Daisy who had found independent, life-changing communication with the method, there was no doubt it was a useful, much needed tool. They were firmly planted in the proponent camp of what was to be a very heated battle. Some would even receive death threats!

On this rainy, wintry Melbourne day in July, Daisy had arrived at the office by 8 am. She was in the process of evaluating several of her clients on the TONI-4, a test for non verbal intelligence that allowed for pointing to a single answer. Taking out the motor components of speaking or writing was imperative for her clients as most of these clients had been scored in what was referred to as "profound retardation" when they participated in intelligence tests that required more complex motor skills, for them to write or speak. Or, more common they were pronounced retarded by a physician with no intelligence test, based on the fact they couldn't speak words out their mouths.

Daisy had been working with her first client, Eugene, for over ten years. During that time, Eugene had written and published a poetry book and passed a 19th century history exam - among other things. But that didn't matter to those who would say that it only meant his communication partner did all those things. Limiting his accomplishments to the only explanation they had - that all this was the result of influence by their communication partner. It didn't matter to them that that partner had not attended some of the classes and had dyslexia.

"Good morning Eugene and Sonya!" Daisy greeted Eugene and his current caregiver. Like so many folks with autism, Eugene had a hard time keeping good caregivers. Too many didn't understand the reason for some of Eugene's, as he described it, quirky behaviors. But Sonya seemed to be getting how Eugene's body and brain didn't work together. More importantly, she understood and accepted that Eugene understood everything she said - he just had a hard time getting his body and speech to respond.

"Good morning Daisy!" Sonya chimed back with Eugene waving his hands and rocking beside her.

As with most of her clients, Eugene had a special affection for Daisy. Unlike so many people who came into his life, Daisy saw Eugene as a competent, capable being. She saw beyond his autistic mannerisms and saw what Eugene named the "True me!" After so many years having teachers and therapists talk in front of him; saying things like "He can't talk" to another. Of course, there was little else that he would love to be able to do more than talk - he didn't need any reminders.

At other times when he was dysregulated and struck a table hard, or, to his horror, a person, some would tell him

"Nice hands!" Other times he laughed inexplicably when someone stubbed their toe, and many teachers and staff thought his "behavior" represented what he felt inside - that he thought it was funny. It wasn't that he didn't want to be nice, or thought it was funny. It was he didn't have control over his body, and for whatever reason emotional moments triggered laughter. Eugene never fully understood this until he met Daisy. He was grateful. Daisy understood him. She saw beyond his autistic body and helped Eugene discover his true self.

"Come on Eugene! Let's show them how smart you are!" cheered Daisy, sensing Eugene was anxious. She gestured towards the therapy room.

Eugene was anxious, but also excited. He had been through so much testing in his life. So many tests filled with items he couldn't complete even though he knew the answers. If it weren't for Daisy's belief in him, he would probably be resorting more to his anxiety-relieving autistic patterns. But on this day, he rocked back and forth while slapping his hands on his legs but didn't feel the need to expand beyond those minimal patterns. He could control his emotions, to some degree, knowing that Daisy was there.

To support Eugene to the chair, Daisy touched him lightly on the shoulder. The slight touch allowed Eugene to initiate moving towards Daisy's therapy room. And, over the next 30 minutes, they sat side by side diligently working through the TONI-4. Eugene was focused and calm, typical for when he worked on academics tasks. That's one thing the opponents of supported typing didn't have a good answer to. Why so many typers, who under typical circumstance had a tendency to be very dysregulated - to jump or pace or flap

their hands, would sit for an hour focused and calm when they were engaged in a cognitive task that involved typing.

Not surprisingly, Eugene did well - he only got one out of 60 wrong. When he was finished and Daisy told him the score, Eugene visibly relaxed and they talked about the test. Funnily, Eugene got a little stuck on the question he got wrong. Turns out the question asked if a block was to the right or left of the triangle and Eugene got it mixed up. Which made sense, Eugene often had difficulty with directional cues unless he was clued in by the context and he had no context to navigate.

"What else do you want to tell me?" Daisy asked as she retrieved an IPAD from her bookshelf and opened up the communication APP. She then squeezed Eugene's elbow and he moved his fingers to the letters and typed, "THAT WAS EASY!"

Seven more client sessions later with a lunch break squeezed in and Daisy was ready to go home. Tom, was her rock. Suzie had come to live with them eventually, and they had many happy years as a family before Suzie died at thirty-seven. So, it was just she and Tom now.

Tom was a great cook and he delighted at treating visiting American friends to his famous kangaroo curry. Or, at least famous to his family and friends! It was more famous for the reaction he got than how awesome the curry was. Daisy wasn't sure what he was planning for dinner, but she looked forward to it nonetheless. Tom kept her grounded and Daisy loved their quiet evenings together, even if she sandwiched it

between answering the many emails she received, and answered, sometimes late into the night.

As she did every afternoon, Daisy checked the metro schedule. Never mind that she had taken the metro for more than 30 years, facts like when the trains run never seemed to manage to stick in her brain, something she attributed to her ADHD. Well, she had never been officially diagnosed, never really saw the point as she liked her life and seemed to be doing well enough, so why rock the boat?

Beyond enjoying a partner who liked to cook, one of the many reasons Daisy was grateful for Tom was his patience and humility as a steadfast, patient partner who often waited behind the scenes as Daisy was stopped by yet another participant at a conference needing support or as Daisy dashed off to respond to a recent email from a family. Daisy rarely said no, always lending an encouraging word and hope to parents looking for support on communication strategies. Strategies that might be the only reason their child could communicate with them - their avenue to the world. Tom was always there by her side, and Daisy knew that without his support, she would have a lot less space to hold her clients. Remembering Tom waiting at home, Daisy grabbed her bag and rushed out the door.

She would have to run if she was going to catch the 6:10 train, but then she pretty much would have to run any time she was catching the train; at any given moment Daisy had at least ten things on her plate at a time; had a tendency to distraction; and was consistently running late. Beyond that, Daisy didn't waste time. Ever since, maybe even before, she met Suzie, Daisy had a passion for providing opportunities to people like Eugene, who had been marginalized by how society understood them and Daisy had a way to

"unmarginalize" them and she wasn't going to waste any time.

Daisy grabbed some files and an article she wanted to read that one of the parents had shared with her on a new typing technique called "Spelling to Communicate", or S2C for short. Daisy stuffed the files and article into her shoulder bag and, with coat unzipped, headed out the door toward the metro stop. Daisy didn't even like to stop long enough to do things like zip up her jacket.

He leaned against a pole under the cover of the metro platform. The pandemic had made things easier for him to disguise himself - especially in the winter. He just had to throw on a mask and don the hood of his sweatshirt. He would throw the sweatshirt away when he was done.

He had never met Daisy but he wasn't worried about recognizing her as he had seen a couple of pictures and the crowd at the Metro station was thin. The job shouldn't be too difficult. Just a quick shove and then escape quickly to a car that was parked below the platform. He had taken off the plates and left it there earlier in the day.

Daisy arrived on the platform with a minute to spare. At first he didn't recognize her, but just as he heard the train in the distance, she turned her head and he recognized her profile. Daisy stood maybe ten feet away and he took a couple steps towards her. In just a moment, the train would

be close and he would shove her onto the tracks. Job accomplished and he would get his payment.

Daisy noticed someone approaching out of the corner of her eye, a chill started up her spine. "Don't be ridiculous." she told herself, but still felt uneasy. Glancing down, she noticed her shoelace was untied.

He saw her glance over at him but he wasn't worried. There's no way she knew what he was there for - that he was planning on throwing her onto the tracks. Save some crime bosses, most people didn't walk around thinking someone was going to murder them. Especially someone like Daisy, whom most everyone loved.

The train approached and his body tensed in anticipation. Just at that moment Daisy leaned over to tie her shoes. The man felt nothing but the wind from the train as he lurched forward to push Daisy. He missed and fell onto the tracks just before the train arrived. Oblivious to his intentions. Daisy stood horrified as she heard his screams. She had no clue that in a weird way her ADHD brain had just saved her life.