

Toronto Star: Unlocking Carly

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"So I had a cool interview with a Toronto Star Newspaper reporter. I'm not sure when the story printing or how long it is. The only thing I'm sure of is how cute the photographer was. So cute. I talked to them about autism & I was showing off how easy it is to talk with WordQ and my Ipad. Doctors and scientists are only partly going to help autism technology and innovators are going to bring autism to the next level."

How does a non-verbal, 16-year-old autistic girl communicate?

Go back to the opening paragraph.

Carly Fleischmann wrote it. When she was very young, her parents were warned she would probably have to be put into an institution. But this autistic teen is now very capable of communicating. And she does so regularly, with wit, wisdom and typical teen chutzpah — via Twitter, Facebook, email and her website, carlyvoice.com, where she posted news of her interview with the *Star*.

The Grade 10 student types with one finger. Software programs like **WordQ** predict words, and she chooses which ones to use. The software Proloquo2Go translates her text to voice, letting Carly "speak" to fellow students at the mainstream high school she attends, where she's in a gifted English class.

She types a message for *Star* readers: "Everyone has an inner voice waiting to come out."

Technology has unlocked Carly's world and enabled her to tell people what her lips cannot: She is an intelligent person with opinions, hopes, dreams, she likes cute guys, she has a whimsical sense of humour, she's a person with up and down days like everyone else. She is also helping the families of others with autism understand them.

It wasn't easy finding out who Carly is.

She was diagnosed with autism just after her second birthday, says her mom, Tammy Starr. As a baby, Carly did not progress at the same speed as her twin sister, Taryn, who does not have autism.

Soon after Carly's diagnosis, her parents enrolled her in the [Zareinu Educational Centre](#), a private Jewish day school and treatment centre. That's where she met Barbara Nash Fenton, a speech language pathologist and head of the Zareinu's speech pathology department.

"While we had a gut feeling that she was intelligent, we had no way of proving it," said Fenton, who still works with Carly each week. "She wasn't testable in a reliable way on any standardized protocol. Given what I have since learned about her, I have learned that you can't judge a book by its cover."

Carly also has severe apraxia, a disorder which prevents her from speaking. She started an intense therapy regimen called ABA, which involves positive reinforcement and repetition, at the age of 4 — 40 hours a week.

"Without it she'd still be staring at her hands, rocking, destroying furniture. We used to go through so much furniture just from the rocking," says Starr.

One day, when Carly was 10, she and a therapist were working with the alphabet screen of a device to type words she knew how to spell. Carly was "fussy" that day and wanted to stop and she typed the word "no." Then, she typed

more words to explain she felt sick. It was the first time her spelling was purposeful and spontaneous, said Fenton.

About six months later, Carly's sentences started tumbling out.

It was a revelation for her family. When CTV interviewed them in 2008, her father, Arthur, said: "We realized that inside was an articulate, intelligent, emotive person that we had never met. She was 10 at the time..."

Now Carly regularly converses with her family. Sometimes her mom will be downstairs at her office and she'll get MSN messages from Carly "We'll have a conversation that way," she says. "Or if my husband's at work, she likes to talk to him that way. She likes that more than face to face."

Being able to post messages and converse on her website means Carly can vent frustration and give honest, tough answers.

When someone asked her if she ever feels sorry for herself, she said, "I would like to be a normal kid. I do like things about being me but I still wonder what it would be like to be like my sister."

Through the technology, Carly is able to explain her inner thoughts and shed light on autistic behaviour. A doctor once suggested Carly was hearing voices because she would sometimes just start laughing. Carly calls it "audio filtering."

"She might start laughing about a joke she heard two days ago, but she's only getting to it now," Starr says.

On her website, Carly offered advice to a mother who wrote about her autistic daughter being calm one minute and screaming the next.

"She is audio filtering and breaking down sounds noises and conversation throughout the day ... It's our reaction from finally understanding things that were said and done last min; last day; last month. SHE IS FINE AND TELL HER TO KEEP IT UP."

During a recent interview at her home, she describes what she does when not at school. She thinks about it, smiles and then types on her laptop: "I love to twitter an be a typical teen."

When asked what she would most like to do some day, there's another pause. Carly types: "I would like to work for Obama as a embassedor."

In between messages, she nibbles a few potato chips, a favourite snack and motivator. It's not easy for her to sit and focus.

Without computer assistance, Carly's family might never have met her.

"Technology has definitely been the key to unlocking her 'inner voice,' as she likes to call it," Fenton says. "Without technology, the options available for her to communicate would have been very limiting. She still would have been highly intelligent, but we probably would never have known."

The word on WordQ

The **WordQ** software that Carly Fleischmann uses has a couple of Toronto connections – it was created at the [Holland Bloorview Kids Rehabilitation Hospital](#) in the late 1990s, licensed to Quillsoft Ltd. and is now distributed in worldwide by Strategic Transitions in partnership with Quillsoft.

The second connection to the city comes in the person of Neil MacGregor, now living in the U.S. where he's national vice-president of learner development for **WordQ** and its companion **SpeakQ** (text to speech) software.

Born and raised in Toronto, MacGregor, 30, has a learning disability that resulted in him being illiterate until Grade 6.

He has a problem decoding symbols so reading and writing was an exhaustive process. By the time he got to high school, his teachers were talking him out of going to university. One told him he “couldn’t possibly finish” and it would be a waste of money.

However, in 1999 there was a national pilot project being done which was evaluating students with learning disabilities and what they’d need to succeed at university and it enabled him to attend University of Guelph, even though an evaluation showed him reading and writing at a Grade 7 level. With recognition of his disability and using various technologies available at the time, he was able to develop strategies, persevered and completed a BA in philosophy, finishing at the top of his class.

Today, MacGregor uses **WordQ** and says he copes “using the very tools I represent.”

*The Ontario Ministry of Education has licensed **WordQ** for the province, meaning school boards can provide it to students.*