

Robbinsdale woman helping others make sense of disability programs

By ALAINA ROOKER

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Michelle Coulon's biggest piece of advice is to never say never. Soured by her experiences growing up as a twin, Coulon shied away from the possibility of adopting twins when she and her husband, Jon, went through the foster care process.

"I hated being a twin, but there were these twins available. We were open to having two kids," she said. "Our caseworker said we were practically set up."

The Coulons met Nolen and Kayla when the babies were 3 days old. Due to the nature of the foster care system, the twins weren't adopted by the Coulons until they were 3 years old, though they lived under their roof until that time. Today, the twins are about to turn 9. Each wants an electric scooter for their upcoming birthdays.

Raising twins came with a familiar set of challenges and a host of challenges that were a little more foreign, in Coulon. Nolen and Kayla are not what Coulon and the disability community calls "neurotypical." Both children have autism, fetal alcohol syndrome, moderate intellectual disabilities, anxiety disorder and a speech and language disorder. The two have grown up being analyzed, tested and retested to track their development. They comprehend at about a 4- to 5-year-old level, or half of their actual age, which doctors estimate will be consistent throughout their lives.

Still, "that gap keeps getting bigger," said Coulon, of their cognitive and actual age.

When new challenges in their development arise, it is tricky to pinpoint which disorder is the one causing it to manifest. Coulon said explaining the disorders as separate from each other is a fruitless endeavor.

"I'd love to get in their brains," she said. "What they perceive, a lot of it is all backwards; up is down and on is off. When they're talking to you, sometimes they are expressing how they're feeling and thinking, but they're perceiving that onto you. Being able to express what's

wrong or what's hurting is a challenge."

Making the personal political

So much of Coulon's time is devoted to managing all of her children's needs that it was difficult for her to look beyond her day-to-day life and a support group she attended for parents of neurotypical children. She owned and worked in a salon for 20 years, receiving minimal support from government programs, until several disability advocate friends served her with an intervention.

"So many of us who have kids that we want to think of as neurotypical, and we don't want to ask for help," she said. "I like to help people, I don't like to ask for help. For so long I thought, 'sure, my kids are a little more challenging, but that's okay.'"

In the end, it was another failed attempt to say "never." Last month, Coulon graduated a yearlong educational program called Partners in Policymaking, which turns those affected by disability in their own lives or families into advocates. The program began in Minnesota in 1987 and has worked to give a political voice to people in the disability community in areas of employment, education, and quality of life. Over 27,000 people have completed the program to date.

Through the program, she has been able to on challenges in the system, especially in education. When the twins were attending Robbinsdale Area Schools, Coulon was right there with them, navigating the world of individual education plans without much help from staff.

"Right now when you ask a social worker or special education teacher about services they don't know much about them or discourage families from looking into them," Coulon said. She found similar issues when it came to navigating programs at the county level: workers encourage people to stick to their given services, warning that any re-evaluations could mean a loss of services for families. It's a very serious,



threatening possibility, said Coulon, but one that has never happened to her nor to anyone else she knows disability community.

“So, why are these caseworkers encouraged to say this to anyone who calls?” Coulon wondered. “Thankfully, I have amazing friends who knew that was going to happen, and literally gave me the words to say to move forward.”

A part of her program has been creating a step-by-step guide for this exact process, so others can have the words to say.

“It’s hard enough to make that call in the first place,” she said. “It’s so overwhelming when you’re already just trying to survive in a world of chaos. I can’t imagine how many just hang up the phone and give up.”

‘Hear their voice’

Life with a disability has been a challenge under the current pandemic. There was no change with learning, as she homeschools the children, but many therapies have been on hold. Nolen and Kayla especially miss their hippotherapy sessions, or therapeutic horseback riding, at Hold Your Horses in Greenfield. Coulon has been busy reinforcing life skills and phonics in hopes that the two will someday be able to read and support themselves independently. A neighbor whose needs are similar to the twins is especially meaningful to Coulon, who has watched her twins find less and less in common with others their age.

Another “never” lesson has materialized: Coulon’s perception of her children has changed. She is actively focusing on what her children can do versus what they can’t. The results have amazed her.

It’s called person-centered thinking, Coulon said, another concept she learned from the Partners training. To begin, Coulon was given a workbook to be completed with the twins. Despite her wariness, both were able to complete the workbook fully, thoughtfully and in ways she didn’t know they were capable of.

“It’s not like I haven’t answered these

questions for them multiple times, but

this was the first time I said, ‘Let’s see what you got: What do you like to do?’ And we got up to like 15 things,” she said.

In Kayla’s recent reassessment, she spoke directly with her assessor during the interview portion instead of her mother speak for her. Typically, assessed children had a few short interactions with assessors, and a parent completes the interview to fill in the blanks. Coulon realized it was an opportunity for her daughter to be involved in a process that affected her life, which she had learned from her disabled peers in the Partners program was something they wished their parents had done. Kayla was able to answer all of the questions, surprising even her assessor, who resolved to conduct more meetings in this way. Kayla, too, felt the love.

“You could see her feeling empowered and encouraged,” Coulon said of her daughter. Now the family is looking at things the twins know they enjoy and letting their responses shape what their futures will look like. It might seem like normal thinking for neurotypical families, but for the Coulons, it’s a groundbreaking shift they didn’t know they could make.

“My thinking now is how can I help them be the best people they can be, and hone in on what they enjoy and love,” Coulon said.

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(SUBMITTED PHOTO)

Nolen Coulon grins during a therapy session at Hold Your Horses in Greenfield.



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LEFT: Nolen Coulon smiles from horseback at Hold Your Horses in Greenfield. **RIGHT:** Nolen's twin sister, Kayla, feeds a horse. The twins receive therapy through riding and learning about the animals.