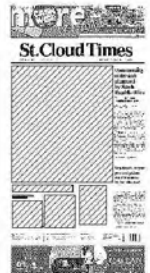


SERVICE ANIMALS

Companion clears the way



Carter Neville-Larson, 7, hugs his service dog Noah as his parents Annie Neville and Jake Larson, along with his brother Tyson Neville-Larson, 12, pose for a photo on Tuesday. ZACH DWYER/ST. CLOUD TIMES



Service dog, advocacy group helps family to navigate autism challenges

Jenny Berg St. Cloud Times
USA TODAY NETWORK

SAUK RAPIDS – Carter Newville-Larson is getting the hang of walking with his service dog, Noah.

The black Labrador retriever helps keep Carter — a 7-year-old from Sauk Rapids — safe and calm. Carter, who has autism, is prone to running away and sometimes gets hyper-focused on things. Noah helps with both.

“If Carter gets upset about something, we can have him turn to Noah and give him pets or give him a squeeze. It helps as a redirect,” said Annie Newville, Carter’s mother.

They also use a tethering system: Carter wears a belt that connects to a vest on Noah. It prevents Carter from darting away suddenly.

A parent or personal care assistant gives commands to Noah. Someday, Carter will be able to give the commands himself.

“That’s been saving us being able to go out in the community because Carter is now faster than I am,” Annie said. “That’s one of the biggest things that Noah does — is keep him safe.”

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“Now he can communicate really well. He transitions fairly easily. He has staff that know how to work with him; that’s really important — understanding autism and the reasons behind his behaviors.”

Annie Newville
Carter’s mother

It’s been a long road to get to this point — where Annie and her husband, Jake Larson, and their sons, 12-year-old Tyson and 7-year-old Carter, feel like they are making strides as a family after years of uncertainty about Carter’s developmental disability.

But there are still so many unknowns, especially when Carter struggles with transitions between grade levels and medical issues cause setbacks.

Luckily, the family feels better prepared to figure out what comes next thanks to Partners in Policymaking.

The nine-month program is for Minnesotans with disabilities and parents of young children with developmental disabilities. It provides information on the history of disability and self-advocacy movements, inclusive education, supported living, competitive employment and avenues to influence county, state and federal legislative processes.

For Annie, the program was “a wealth of information.” She applied for the program in the summer of 2016 and started it that fall. Now, she’s a member of several committees and helps other parents in the community better advocate for their children.

Her involvement comes because she remembers how it felt to be overwhelmed with information, uncertain about how to apply for services, and anxious about months-long wait lists for services when doctors were telling her to intervene as soon as possible.

“I did not want to be in the dark anymore,” she said. “It was such a struggle. I’m a pretty capable person and I had to struggle and fight to find out information.”

A wait for diagnosis — then a wait for services

Up until about 18 months old, Carter was hitting the developmental milestones. Annie and Jake started to get concerned when Carter hit 18 months because he didn’t know as many words as they thought he should. But he was babbling, making animal sounds and able to say words such as “mama” and “dada.”

Then he started slowly losing eye contact and withdrawing. He had what doctors now consider regressive autism, which is rare.

“By the time he was 2, he didn’t talk at all. He wouldn’t look at us. You couldn’t really get him to interact with you,” Annie said.

Both Carter’s doctor and a contact from the state’s Follow Along Program — which tracks a child’s development through the age of 3 — recommended Carter be evaluated for autism.

The wait list for an evaluation in Central Minnesota was nine to 12 months, which is not ideal when re-

search shows early intervention is key. Even in the Twin Cities, wait lists topped six months.

"I was not happy with that," Annie said.

Carter was eventually seen at Fraser Autism Center of Excellence in Minneapolis after about a three-month wait. Carter was diagnosed with autism spectrum disorder and mixed expressive and receptive language disorder. The family was given a packet of next steps.

"I thought, 'OK, this is going to be easy. I just start lining up these things,'" Annie said. "Well, I found out it wasn't easy."

The family's private insurance wouldn't cover occupational or speech therapy until Carter was diagnosed.

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Then once he had his diagnosis, the family couldn't afford both at the same time.

"How do you choose?" Annie said through tears.

She applied for federal medical assistance for children with disabilities to help cover things such as behavioral therapy, which private insurance might not. At the time, it was hard to find programming. Carter was too young to enroll in preschool through the school district.

"Fraser is telling me I should do something right now and there was nothing here," she said.

Doctors broadly split autism into three levels: People with Level 1 autism require the least amount of support and people with Level 3 autism require the most. Carter is considered to have Level 2 autism, meaning he requires substantial support and lacks verbal and non-verbal communication skills.

By the time Carter was 3, he was enrolled in-home Applied Behavioral Analysis service and preschool.

"I did half the day ABA so he could get that intensive one-on-one work — to work on his skills, improving his language, improving his vocabulary — and half the day preschool so he could work on social skills with peers instead of just with adults," Annie said.

Slowly, Carter continued to develop and gain the skills he had lost. He started talking and his eye contact improved. But transitions were still very difficult.

'A recipe for disaster'

"By the time he was ready to enter kindergarten, I was feeling really good about it," Annie said.

Carter had progressed from mostly special education classes to being included in general education classes with his neurotypical peers. But right before school started, Carter got a bad ear infection and his ear drum burst.

And every time Carter got sick, his eye contact and speech would decrease.

The transition to a new school and new teacher was hard enough. The regression of behaviors made it even worse.

"It was the recipe for disaster. Kindergarten was a huge setback for us," Annie said. "We had another really hard transition in first grade."

Since then, things have been slowly improving.

"He has been progressing and developing. ... Now he can communicate really well. He transitions fairly easily. He has staff that know how to work with him; that's really important — understanding autism and the reasons behind his behaviors."

Noah helps, too.

"Kids are more likely to interact with Carter now because he's got this cute dog with him so it's giving him more opportunities for social interaction," Annie said. "I think it decreases the chances of him getting bullied."

Annie and Jake worry about Carter getting bullied, the same as they worry about him running away and getting hurt, the same as they worry about whether he will be able to go to school or get a job or live on his own someday.

The fact that Carter is mostly unaware of other people is a catch-22. He doesn't realize he's different or feel sorry for himself. But for his parents, it's hard to not see him have the same things as other kids his age.

"He doesn't have any friends. And most 7-year-olds have friends," Annie said, again fighting back tears. "He can't be left alone for a second. Most 7-year-olds you could send to the back yard and say, 'Go play.' We have a fence now, too, so we can keep him contained but he needs constant supervision."

Annie and Jake worry about how the stress affects Tyson, too.

“Carter requires more attention so I am constantly trying to make sure Tyson doesn’t feel like he’s not getting enough of it,” Annie said.

Annie and Jake make sure Tyson has plenty of play dates and opportunities to be in activities. But even then, it’s hard for the family to be together. If Tyson has a basketball game and they don’t have a personal care assistant to stay with Carter, one of the parents usually stays home.

“That’s what we’re working toward — not being a split family,” Annie said.

It’s not all bad, Annie assures.

“He’s adorable. He is so funny and so smart,” she said. “Then he just has this giggle that just warms your heart. It’s just pure joy.”

And they don’t take his success for granted.

“The wins feel so big,” she said. “I think maybe you work a lot harder for his milestones and so they feel bigger.”

Finding her ‘people’ at Partners in Policymaking

When Carter was first diagnosed with autism, Annie said she was “so overwhelmed, lost,” that she didn’t sign up for Partners in Policymaking right away.

“I couldn’t imagine taking a weekend every month and going down to the (Twin Cities) for training,” she said.

But once she caught her breath, she wanted more. It was a life-changing decision.

“All the people knew the struggles of raising someone with special needs,” she said. “Everyone you are there with is compassionate and reassuring. I felt like these were ‘my people.’”

The Governor’s Council on Developmental Disabilities created the program in 1987. Since then, it has become a model for other states and even globally. The goal is to help people bring their voices to public policy. At one of the sessions, participants learned how to write letters and talk to local, state and national representatives.

“Two different times, (U.S.) Sen. Al

Franken used my story on the (Senate) floor,” Annie said, referring to a conversation about possible cuts to medical assistance. “That made me realize I can make a difference. I can affect change. I can make my community better. I can advocate for my son and for other people.”

She’s now the chair of the Governor’s Interagency Coordinating Council on Early Childhood Intervention, a member of a regional Interagency Early Intervention Committee, a member of the Benton Stearns Education District Special Education Advisory Council and a member of the Minnesota Autism Council working group.

“Early intervention is my passion,” she said. “I know it can change lives. I feel so passionate about it. And I know the money we invest when they are younger is going to save us money in the end because they are going to need less services and less help because they are going to have gained so many skills.”

Looking ahead — and finding help

Navigating the world with an autistic child is a full-time job with little respite.

“I feel like raising Carter and learning about autism and accessing services has been like this marathon and every time I’m almost to the finish line, they move the end,” she said.

“I kept thinking things would get easier as he got older, and that has not necessarily been the case,” she added. “It’s actually harder because you have to watch him like a 2-year-old but he has the strength, agility and speed of a 7-year-old.”

Noah the service dog will help increase the family’s confidence in public. And they hire athletic personal trainers to run and explore at parks and in the community with Carter, Annie said.

In February, the family plans to take their first family vacation — a Caribbean cruise with the assistance of Autism on the Seas, which caters to families with children who have autism and other developmental disabilities. If the vacation goes well, Annie will promote the company on her Facebook page — St. Cloud Area Autism Early Intervention.

She created the page as a “safe, friendly place to discover resources and share experiences.” It’s something that would have been incredibly helpful to Annie when Carter was first diagnosed.

“I wish that would have been out there,” she said.

How to sign up for Partners in Policymaking

Minnesotans with disabilities and parents of young children with developmental disabilities can apply for the free leadership training.

The program offers eight sessions over nine months in Bloomington. Sessions cover the history of disability and self-advocacy movements, inclusive education, supported living, competitive employment and avenues to influence county, state and federal legislative processes.

The first session for the 2019-20 program is Sept. 13-14. Costs for the program are covered by a federal grant, and include child care and respite allowances, overnight accommodations, meals and mileage reimbursement.

Applications are due by Monday, July 8. People can apply online at mn.gov/mnddc/partnersinpolicymaking/class37/application.html.