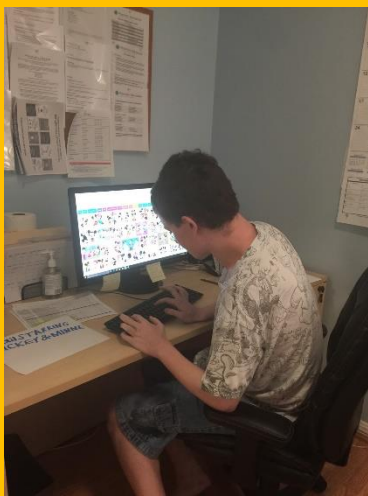


February Waiting List Story: Meet Connor

My name is Connor. I have a brother named Brett. When we were really little, more than 20 years ago, someone noticed Brett was acting differently than other children. My parents found out he has autism. Then, they found out I do, too.

We started special ed preschool right away, but preschools then didn't understand like now that kids with autism often need help learning how to learn. The people at preschool didn't understand how to teach me in ways I learn best. Then at home, people helped my mom teach me using Applied Behavioral Analysis (ABA) therapy, which is very expensive and wasn't covered by health insurance at all. I learned to do a lot of things really quickly, but abstract ideas were really hard.

By first grade, there was an autism program for me at school. My mom came every single day to help me and my teachers. Then, the next year, the school said they could teach me without mom coming. I am smart and figured out quickly that I could get out of doing things I don't like to do if I hit or grab or scratch. School would call my mom and ask what they should do. She tried to help. Things got harder at home. My brother would want my mom's attention when she did things for me. My brother also talks a lot, which I don't like. I started having really bad meltdowns because I couldn't say if things were bugging me or say what I needed.



Connor working on his computer, a new skill in his new home!

My mom got stressed out trying to deal with my brother and me alone a lot of the time because my dad had to go work every day so we could pay for things we need. When I was eight, my mom found out about the Medicaid Waiver and got me on the waiting list. When I was 13 and going into middle school, the schools in Fairfax decided they didn't have the resources to keep me and others safe when I had behaviors. So they helped me enroll in a private school where I could go year-round and people understood how to help me with my behaviors during teen years that are hard for anyone but even more so when you can't say what's on your mind.

Things were better at school, but really hard at home. I communicated with behavior. My mom has scars on her hands from me digging my fingernails into her when I was mad or frustrated. It was hard to find anyone who could help my mom out or stay with me so my mom and dad could do something together. I need people who are smart problem-solves and good at anticipating needs to keep everyone safe. It was hard to find people who wanted to help me since the Waiver pays \$11.70, with no benefits, even if I hurt them when they were on the job. Everyone who had the training and ability to work with me could make a lot more money doing something else or even work with other kids with autism who weren't as challenging as me.

So for many years, I was with my mom or dad every single minute outside of school. You can't go to community activities either if you don't control yourself in a group. After waiting almost 14 years, I got a Waiver in 2014, just before I was graduating from school. It was a year when there were not a lot of Waivers funded, and at first it seemed I wouldn't have one. Without one, there would be no way any

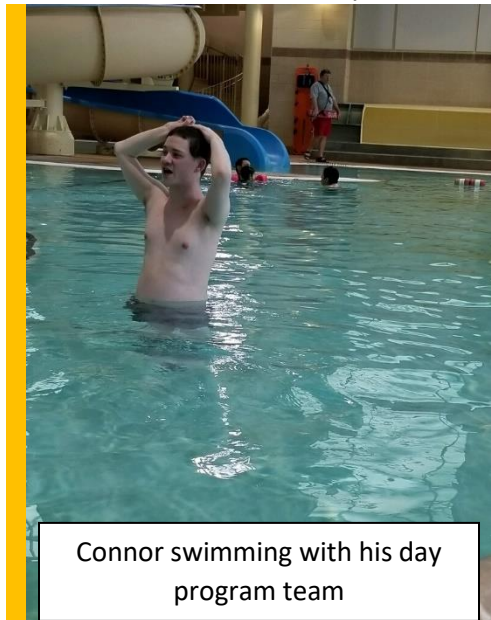
service providers would give me a chance in one of their programs. Mom cried at my graduation. I know she was proud of me, but also scared for the future.

Sadly, once I could no longer spend my weekdays at school, lots of adult programs told me they didn't have the resources to serve me. So after waiting 14 years for a Waiver, I waited five more months to find anyone who would take my Waiver because then it was really hard to get any extra funds to help with my extra needs. (I can't verbally tell people all my thoughts so I hit or pound my head on something. I don't like it when people are noisy or get too close to me.)

I was home with my mom every day and I missed having as much structure. Finally, a single spot opened up at a forward-thinking day option that is really good helping people with complicated behaviors. It was only part-time and lots of people wanted it, but we got it. Mom was so happy. I finally had a place to go.

Once I started going to my day option, my support coordinator had to decide whether the transportation option offered through the waiver would work for me. She and my mom weren't sure, so my mom spent hours in the car each day driving me to and from my program. It was worth it to have a place to go on certain days. I like to do the same things each week, and I like to know my routine. For a few years after I got out of school, I often got upset and couldn't say what was wrong. Mom wore a helmet whenever she was at home with me so I couldn't grab her hair or hit her head with my head if I got upset. I've grown a lot since then. I have learned how to go on short trips with a few friends and how to go to the sensory room if I need a break from people and noise.

The best thing is that last summer I found a new home. Now my parents aren't so worried about what will happen to me if something happens to them. The same group that runs my day program had a house with space they thought was just right for me. I have three housemates, and we always need three people on staff to keep us all safe. My team recently did my new Supports Intensity Scale assessment (SIS) to help my service provider get enough funding to cover the cost of the extra staffing I need. While my score did show higher needs, my service provider decided to seek a customized rate so that my behavioral needs don't take away from other program needs. Happily, I have a customized rate to pay for what I need.



I am doing a lot better these days at not hurting myself or others. I think that is because everyone really tries to individualize things to help me learn to self-regulate and have better control. Even Logistcare, which I now use to go to and from my day program, knows I need to ride with quiet people and I need to be picked up last and dropped off first. The first time I rode in a van was a disaster. I bit a guy who screams a lot who I had to ride with. It wasn't his fault, but it turned out he is Hepatitis B positive. So for a while there was a chance I got exposed, but everything turned out OK.

My life is not perfect. I still worry about my mom, who is living with my brother, who gets mad at my mom because he has lots of needs and gets frustrated. I still sometimes get bad headaches that make me hurt myself. But the Waiver made so many doors open up. I have a good place to go and learn during the day and a great home at night. Come by if you would to spend time with me watching one of my Disney VHS tapes. I have DVDs, but I still love my videos the best!

Please remember that each of the more than 12,197 people on the Waiver waiting list have a story and need your help, too. You can change their futures like my Waiver has changed mine. Please fund the waiting list! End the wait, start a life.