

Disability Resources for Native Communities:

EPICS - Education for Parents of Indian Children with Special Needs Albuquerque, NM 505-767-6630 or 1-888-499-2070 www.epicsnm.org/for-parents

NAPPR, INC. - Native American Professional Parent Resources Albuquerque, NM 505-345-6289 www.nappr.org/our-programs

Native American Disability Law Center Farmington, NM 505-566-5880 or 1-800-862-7271 www.nativedisabilitylaw.org/home

Navajo Nation Office of Special Education and Rehabilitation Services Window Rock, AZ Phone: 928-871-6338 or 1-866-341-9918

www.nnosers.org

Zuni Youth Enrichment Project

Zuni, NM 505-782-8000 www.zyep.org

UNM AUTISM PROGRAMS

Autism Programs offered through the CDD are a collection of education, training and consultation services.

Our statewide programs focus on supporting and serving individuals with ASD, as well as their families, caregivers, educators and communities.

The family and provider resource team is a team of resource specialists can assist individuals with ASD, families and providers in finding autism specific resources as well as offer guidance in "navigating the system."

CONTACT US AT:

505-272-1852 or 1-800-270-1861 HSC-AutismPrograms@salud.unm.edu

We would like to sincerely thank the families who shared their stories for this project.



505-272-3000 2300 Menaul Blvd NE Albuquerque NM 87107 hsc.unm.edu/cdd





AUTISM, OUR STORIES, OUR VOICES

STORIES OF INDIGENOUS FAMILIES' JOURNEYS WITH AUTISM

"I am Navajo from Arizona, but live in New Mexico. My son "Yona" has autism and is 16. I had a lot of ups and downs when I was pregnant with him; he was 9 lbs 3 oz and I had a c-section. The minute I held him, my motherly instinct told me he was different. He was slowly hitting milestones, but it was a lot of extra work. I mentioned to my doctor that he might have autism, but had to advocate for a diagnosis until he was diagnosed by age 5. We had to constantly advocate for services. ultimately switching schools. Yona is now in high school and doing better. He has a great team helping him work toward independence. He pushes toward his independence now and is making plans for life after high school. It's been a major journey to get from not talking to being able to tell me his life plans!

We are traditional Navajo and my son participates and is a part of that. We found our harmony and balance through our culture and ceremonies. My son understands that this is who we are as a people and this is how we help ourselves. He connects with it on a deep level. The ancestors are there to help guide and move him forward in life. He will be looked after, after I am gone and he is older.

As a family, we researched autism and had to educate ourselves on it. We realized that we had to do more for Yona and that things take longer for him to learn. Adjustments needed to be made. Smaller steps need to be taken to teach. We would like families to know that early intervention and finding a way to work with your child is best. You have to work together with the programs and laws to make things happen. You have to advocate. Also, allow your child to practice independence. And don't be afraid to reach out.

I see a semi-independent life for Yona. I am choosing to be realistic and satisfied with the level he is choosing to live. I just want him to have a good life."

NOAH, KEWA/COCHITI

"I had my son in 2004. He was a surprise, I was healthy, and he came quickly. Almost immediately, I noticed something was different about my son. He was shy and attached to me. He did not like physical contact. He had a lot of meltdowns. I grew to accept it. It was hard because in the Pueblo we are supposed to acknowledge people, but it was difficult for him. He is very smart and stayed under the radar in school but started to need more support in grades 7 and 8 when we finally got a diagnosis. Online learning was hard on both of my kids so now Noah is looking for a GED program. He is now 17.

Our main challenge was getting a diagnosis. It would have helped him more to have an earlier diagnosis. I knew he needed support, but I didn't know what he needed. I kept asking and wasn't heard. I also wondered, "What did I do? What didn't I do? Did I make him this way?" What really matters though, is that the people around him know and accept him the way he is. They don't say that he is different.

Noah loves gaming, Pokemon and Spiderman. I don't think he really likes the attention of needing extra autism aides. Our tribe doesn't really have autism resources at this point. I think that many services that are available are not advertised as much as they should be. Programs should educate more and be out in the community more. Teachers should be more educated and be able to spot the signs. We need more autism awareness and information especially in Native communities.

My hopes for the future are for Noah to get his GED; I want to see my son complete his program but to be successful in whatever he wants to be. I tell him to "do your best, be helpful and happy." I do wonder how it is going to be when I am gone, but I know my daughter is going to be there for him. My family loves and accepts him and I know he is always welcome in our tribe."

"Our family is Navajo/Menominee and live in the Twin Cities. My son is 7 and in the first grade. He was diagnosed at age 2 and attended traditional school for the first couple of years, but now we have him in home school and he is getting more services and time. I am better able to adapt to his needs.

CK is very into dinosaurs and will do a deep dive into anything he likes. He has a huge interest in learning things. He loves nature and being outdoors. He also loves music. Even though he has autism he is also very social and empathetic although he has separation anxiety.

Ш

Z

0

Z

 \bar{z}

Ш

E/NAVA

Our biggest challenge was being so isolated. We felt like we didn't have a community to lean on or anyone to ask for advice. It was hard to find a Native adult to guide me. The stigmas around autism were also a challenge as well as adjusting to his needs. I've learned that routine is important, so is explaining things. Smudging is also important.

Traditionally, we revolve around our kids, we put their comfort before ours. We adjust to him and not make him adjust to our needs. Our children are precious beings. It's not about him being autistic, it's about me bringing him into this world.

For us, ABA doesn't align with our traditional values. Our traditional ways of parenting are what we need regardless of whether our children have autism. I wish I could say you are not alone, but a lot of times you are. Just remember to breathe.

In the future. I hope there are more therapies across the board for our kids other than ABA. Remember, the ability to say "no" is an option. It has made me slow down and take in the moments.

My hope for the future is that CK finds something that he enjoys. I see him as being able to have whatever job he wants. The world is his. The future is his."