

Thank you, members of the committee, for giving me the opportunity to speak to you today.

My name is Dianna Varady and I am the director of the Arkansas Autism Resource & Outreach Center, also known as "AAROC". We provide training and help finding services for families in Arkansas who have children diagnosed with autism spectrum disorders. I am also a parent of a child diagnosed with autism who has been on the Medicaid home & community-based waiver list for about 5 years.

As you might imagine, with approximately 1 in 65 Arkansas children now identified with an ASD, we get a lot of phone calls. Many times those calls are from parents of a newly diagnosed child who are seeking information about early intervention services. Sometimes we get calls from parents who are struggling with school issues, and sometimes parents simply call to talk about some of the issues they face at home caring for a child who may be exhibiting difficult behaviors. Sometimes the family is in crisis. One of the first calls I ever received at AAROC was from the father of a 10 year-old boy diagnosed with autism. His son slept an average of 3 hours per night, and not 3 hours in a row. He and his wife both worked,

so they took turns staying up with their son each night and were suffering from some pretty serious sleep deprivation which was taking a toll on their work performance and the general atmosphere at home. Their son had been on the waiver waiting list for many years and they were hoping that we might know of another way to get a caregiver to sit with their son just one night per week so that they might get a full night of sleep.

A more recent call was from a gentleman who was visiting his great aunt from out of state. He said that she was caring for her teenage grandson diagnosed with autism. This child did not have a method to communicate and was in diapers. His grandmother was dealing with her own health issues but was determined to keep her grandson at home with her. When I told this gentleman, who is in the military and who could not remain in Arkansas to help, that waiver services could help, but that they would probably have to wait for many years before receiving these services, he broke down and sobbed.

These calls are the hardest part of my job. There is nothing so heartbreaking than to tell a parent who is in such desperate need that the services they need are available through

Medicaid waiver, but that they will likely wait 8 years or longer to ever start receiving those services. Every time I utter those words there is an audible gasp on the other end of the line. Occasionally, I get a call from a parent telling me that they can no longer care for their child without help, and that they have made the decision no family should be forced to make, which is to say they have decided to place their child in an institution.

AAROC asked families in Arkansas to share with us why home and community-based services are important for them. We received statements from families all over the state, some included photos or even videos:

- We heard from the family of Tina in Marmaduke. Tina is 34 years old and is diagnosed with cerebral palsy. She lives at home with her parents who are experiencing their own health issues. Tina has been on the home & community-based waiver waiting list for 7 ½ years.
- We heard from Chelsea. Chelsea is 25 years old and lives in Farmington. She has high-functioning autism and would like to live independently, but cannot do so without supports. Chelsea loves to bake and her dream is to one day be a pastry chef. She has been on the waiver waiting list for over 5 years.

- We heard from Carson's family. Carson lives in Springdale. He's 11 years old and just graduated from 5<sup>th</sup> grade. Carson has a developmental disability and right now his older sister helps to care for him so his parents can go to work, but she'll be going to college soon and won't be able to help with Carson's care. Carson is #1881 on the waiver waiting list.
- We heard from Tyler's family in Hot Springs. Tyler is 11 and loves swimming and riding on the ATV with his dad. He is diagnosed with autism, but works hard to make progress every day and just read his first sentence last year. But Tyler is not potty trained and also runs away from his caregivers. His parents find it difficult to work and care for him by themselves. He is about #1600 on the waiver waiting list.

These are just a few of the stories sent to us. Some of the videos are posted on YouTube and I encourage you all to watch them. Sometimes they move me to tears. I am in awe of each and every one of them. They are beautiful and amazing and determined and I am just so proud of their fearlessness in sharing their lives with us. It takes tremendous courage for them to speak up and ask for this help, and truth be told they

probably wouldn't do so if the stakes weren't so terribly high for so many thousands Arkansans. As you consider Community First Choice and weigh all the arguments for and against, please remember Chelsea and Tina and Carson and Tyler and all the other people who need these supports, because it's my hope that doing so will tip the scales in their favor.

Thank you