

**Senate Finance Committee: Article 2**

**February 25, 2021**

**Testimony by Ginger Mayeaux, Director of Public Policy and Advocacy at The Arc of Texas**

Thank you for the opportunity to provide input on the state budget and how it impacts Texans with intellectual and developmental disabilities (IDD), their families, friends and communities. I am the Director of Public Policy and Advocacy for The Arc of Texas. The Arc of Texas envisions a world where Texans with IDD are included in their communities where quality supports and services are available to meet their needs and choices.

The quality supports and services used by Texans with IDD may include access to an attendant who helps with intimate personal tasks like bathing or dressing, nursing care, or employment assistance. Access to such quality supports and services allow Texans with IDD to thrive in their communities. These are basic human rights.

Most supports and services used by Texans with IDD are not covered by private insurance, so Texans with IDD depend on Medicaid waivers that allow them access to these to these critical services at home, as an alternative to institutional care. Since people with IDD are more likely to get ill and die from the coronavirus, being able to stay in a home and community-based setting and avoiding a crowded institution is even more critical during the pandemic.

To highlight the significance of the supports and services Medicaid waivers provide, I want to share the story of one of our members. Cruz is 6 years old and has cerebral palsy. Because of his cerebral palsy, he needs help for most daily activities, such as eating his meals, being transferred from his wheelchair, changing his clothes, and taking a bath. Cruz's dad works the night shift at his job, and his mom suffers from chronic back pain, making the ongoing support and care Cruz needs almost impossible for the two of them alone. The family was in crisis.

Through promoting independence initiative and a whole lot of work by the family and advocacy organizations, Cruz received a home and community based services (HCS) waiver. Since receiving the waiver services, Cruz and his family have seen dramatic improvements. His father has reported the following results:

- Before speech therapy, Cruz could barely say "yes" and "no." He is now able to communicate his thoughts and needs.
- Since receiving physical therapy, Cruz has learned to balance and even sit up on his own.
- Occupational therapy has taught Cruz how to manipulate and pick up objects.
- Cruz's parents can focus on spending quality time with their son instead of being struggling caregivers worried about their ability to financially afford vital medical equipment and care.



*Achieve with us.*

But perhaps the most striking example of what has changed for Cruz and his family is in this quote from Cruz's father: "We're not scared of the future anymore. We know that no matter what happens to us, or what life brings, Cruz will be OK. The fear of that was really difficult to control. ... We're so thankful for the HCS slot. I don't know where we'd be without it, and I don't want to guess."

Stories like Cruz's should be the norm, but this unfortunately isn't the case. Since access to Medicaid waivers are not entitlements, Texans like Cruz depend on the Texas Legislature to provide funding for the essential services they need. There are more than 166,000 Texans waiting up to 15 years for access to a Medicaid waiver. **Exceptional item (EI) 4 would fund 3,512 individuals** who have already been waiting far too long for these critical supports and services. At a minimum, we request that this item is fully funded. Texas needs to develop a long-term goal of ending the extensive waitlist which can be accomplished by funding 20% of the list for the next 5 biennia. By prioritizing waitlist funding to provide timely access to services in the most integrated setting, Texas can prevent crises, support families, and use limited funds most effectively.

In addition to funding of the waitlist, in EI 4, we urge you to continue our state's commitment to promoting independence and compliance with the *Olmstead* decision. To prevent a crisis-driven system, it is important for the state of Texas to maintain a waitlist or first-come, first-serve model of providing services in addition to providing dedicated waivers for Texans either residing in institutions who want to move into the community or prevent institutionalization of Texans with disabilities who are in crisis.

Lastly, we know the most effective and efficient way to address the waitlist and quality of care for Texans with IDD is through an adequate IDD strategic plan. A rider to develop and enforce the implementation of an IDD strategic plan would assist the thousands of Texans across the state, including those in your district, who want to live, work, and play in their communities. Now more than ever we see the need to plan and prioritize people with disabilities.