



Texas

September 25, 2020

House Human Service Interim Charges Interim Charge 4 Ginger Mayeaux, Director of Public Policy and Advocacy, The Arc of Texas

Thank you for the opportunity to provide input on interim charge 4 and how it effects Texans with disabilities, their families, friends and communities. I am the Director of Public Policy for The Arc of Texas. The Arc of Texas envisions a world where Texans with intellectual and developmental disabilities are included in their communities where quality supports and services are available to meet their needs and choices.

Interim Charge 4 is particularly important to Texans with IDD as they rely on long-term services and supports not only for their health and safety but also an independent quality life. The charge mentions both institutional and home and community based services (HCBS). We are glad to see that the legislature is looking at the system as a whole and not in silos. Texas cannot sustainably address the needs and desires of all Texans without looking at the system as a whole.

The vast majority of Texans, as demonstrated by the number served and waiting on interest lists for HCBS waivers, choose to live in their communities. Unfortunately, the legislature has not prioritized funding of the interest list and the list has grown to over 160,000 waiting as long as fifteen years. While there is no wait for institutional care, the census has declined drastically over the years and the cost has increased exponentially. It is six times more costly for an individual to reside in an institution or State Supported Living Center (SSLC) than an individual with the same support needs to live in the community with an HCBS Medicaid waiver.

HCBS Medicaid waivers provide critical services and supports to individuals with disabilities as an alternative to institutional care. Since these services and supports (attendant care, nursing, employment assistance, etc.) are almost never covered by private insurance, individuals and families are faced with the unbearable decision of entering a segregated institution or waiting years with unmet needs. The



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Texas legislature must focus on the goal of rebalancing the system to support individuals in the most integrated setting, increase selfdetermination, and utilize state funds responsibly, which involves addressing many systemic issues within the system at once.

There are a lot of myths about individuals on the interest list, including that many are not eligible for services and/or do not really need them at that time. First off, although eligibility is not determined until an individual comes to the top of the list, it is important to note that 67% of individuals offered a home and community based services (HCS) waiver, the longest waiver waitlist, are found both eligible and accept the services. Second, the reason individuals and families sign up for services as soon as they learn of the list, is due to the long wait for services. Individuals and families cannot wait fifteen years from the moment they are in critical need to receive support.

Although some states have reduced their waitlist by implement prioritization categories, which does not mean they reduced or eliminated the list by providing needed services to their constituents. They did so by removing people from waitlist based on assumptions. This type of system has many unintended consequences and requires substantial trust, which has not been built in the Texas system.

Rider 42 from the 86th Regular Session directed the Health and Human Services Commission in conjunction with The System Redesign Advisory Committee (SRAC) to study the current interest list and look at recommendations to reduce or eliminate it. Unfortunately based on a short time frame, lack of existing data from the state, and COVID-19 the report did not receive approval from SRAC nor did it provide credible data and viable recommendations. Instead of utilizing Rider 42 recommendations, The Arc of Texas recommends utilizing recommendations from the Promoting Independence Workgroup and the IDD Strategic Plan, particularly on recommendations that reduce barriers to accessing services and supports, regardless of complexity of support needs.

In addition to funding the interest list, there are numerous ways Texas can improve access to long term services and supports for all Texans. Many of which are included in the two plans mentioned above. For instance, Texas must begin right sizing the system to reflect the needs and preferences of Texans with IDD by reducing the census at SSLCs. This can



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be achieved by placing a moratorium on admissions and consolidating some of centers. We can reduce admissions to SSLCs by improving quality of and access to services for persons with higher medical, physical and/or behavioral support needs through appropriate resource allocation and best practices such as the START model.

Finally, the long term services and supports system in Texas would not exist without the workforce of direct support professionals (DSP). The workforce "crisis" for DSPs has been going on for so long, it is no longer a crisis but a systemic issue. This has been highlighted during COVID-19 were DSPs continued working and supporting individuals with disabilities despite a lack of personal protective equipment (PPE) or adequate sick leave. Without the work of DSPs individuals with disabilities may not be able to use the restroom, get out of bed, eat, or access their community. DSPs are the backbone of the Medicaid long terms services and supports system.

It is time for Texas to not only adequately fund wages of DSPs but elevate the status of this important profession. We need to recognize the value of their work with action, not just praise. DSPs should receive benefits such as health insurance and paid time off. We should incentivize continuing education and access to career pathways for DSPs, which increases retention and improves quality. Until Texans regard DSPs as essential professionals, regardless of a pandemic, we will continue to see challenges for DSPs and Texans with disabilities will not have the needed support they deserve.

In addition, continuing some flexibilities allowed during COVID-19 can assist with shortage of DSPs. For instance, the allowance of community first choice (CFC) providers in HCS and Txhml to live in the same home as the person they are supporting.

As I stated before, Texas must look at the long term services and support system as a whole and address barriers for Texans with disabilities at multiple levels, including access to the community and workforce recruitment and retention, in order to see the positive outcomes we all desire.

Thank you again for the opportunity to provide input. If you have any questions, please feel free to contact me.

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