

**HOUSE OF REPRESENTATIVES  
COMPILATION OF PUBLIC COMMENTS**

Submitted to the Committee on Human Services  
For HB 729

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Hearing Date: March 14, 2023 8:00 AM

REBECCA JAPKO

PART & SELF

BRENTHAM, TX

When I first became aware of the proposed statewide intellectual and developmental disabilities (IDD) coordinating council filed last session, I thought it might be an avenue for the families of the SSLCs to finally have a seat at the table and be able to inform Health and Human Services of the issues that many of our loved ones have faced. With that in mind, I am requesting a substitute language with the following changes:

Page 2, Line 21 & 22 Current Language

(G) a person or family member of an individual with an intellectual or developmental disability;

Requested change

(G) three persons or guardian/family members of an individual with an intellectual or developmental disability residing in each of these settings: Home and Community Based Services, Private ICF-IID and State Supported Living Center;

The argument that is always made is that individuals in the SSLCs could be served in the community at less cost despite the fact they require the most intense supervision no matter the setting where they live. My hope is that the bill will provide representation for those of us who have had the "community" refuse to care for our loved ones.

Many providers refuse to accept individuals with severe behaviors or they send them to the ER when they cannot manage their behaviors. With the increase in severe autism and upcoming HCBS settings rule that will prevent providers from evicting individuals at will, the number of individuals refused care will only increase.

As we all well know, the policy trend with respect to persons with IDD has been to close the ICFs — and to FORCE ON EVERYONE a ONE size fits all “community” living model that does not reflect person centered care. With all the HHSC Councils and Committees there is not one that allows the voices of the families at the SSLCs to have an input into the Texas IDD system of care at HHSC.

What many fail to recognize is that many of our loved ones lived in the "community" for most of their adult lives and those support and services available were not sustainable due to providers not willing or not able to meet their extreme support needs.

My hope is that this bill will provide a strategic statewide approach to IDD services and specifically calling on the various HHSC councils to make recommendations so that vulnerable individuals like my sister would have a pathway to the SSLCs that does not involve a trip to the ER or an extended stay at a jail awaiting competency restoration or having an extended stay at a psychiatric hospital. None of these scenarios is cost efficient and all are extremely traumatic to the person and their family.

Thank you.

Debra Wallace  
PART/ICF Advocates for Choice/National Council for Severe Autism  
Red Rock, TX

Debra Wallace  
875 Sand Hills Road  
Red Rock, Texas 78662

March 13, 2023

To: House Human Services Committee  
Re: HB 729

Dear Chairman Frank and Committee Members:

Thank you for your consideration of HB 729.

While Texas needs to address the needs of the IDD population in discussion within committees, there is a serious lack of representation on these committees for the severe IDD population, who require a much higher level of care than the general IDD population. TCDD, HHSC, the Governors Council lack representation of those who require an ICU level of care.

In 2019, at least six different people who are involved in organizations that represent this most vulnerable population applied to sit in committees at HHSC, and were rejected for reasons unknown. I personally have served on three separate Governors Councils for the Disabled, served on several non-profit boards, two special education advisory boards, founded a non-profit, taught special education, and advocated for 42 years statewide and in Washington DC. I personally applied to serve on a committee at TCDD, the Governors Council on Disabilities, and even HHSC. I received no response from the first two committees and a follow up question from HHSC regarding my ethnicity, before receiving a rejection letter. Other worthy advocates received the same letter on the exact same day, including my late husband, who was an attorney and dedicated advocate.

Ironically, we represent a population that is not properly represented by any organization serving on an existing committee or counsel in this state, and the severe IDD and severe autistic cannot speak for themselves. There should be a seat for PART, ICF advocates, and NCSA (National Council for Severe Autism) at the table.

Please expand representation for our loved ones and let those who know their needs represent them.

Respectfully,  
Debra Wallace  
Mother of Justin Wallace/42/Severely Autistic  
Vice President/PART  
Founder/ICF Advocates for Choice  
Affiliate/Nation Council on Severe Autism

Lauren Gerken  
Texas Council for Developmental Disabilities  
Austin, TX

Chair Frank and Members of the Committee,

Thank you for taking the time to read my testimony on HB 729, relating to the statewide intellectual and developmental disability coordinating council. My name is Lauren Gerken, and I am the Public Policy Analyst for the Texas Council for Developmental Disabilities (TCDD).

TCDD is established by state and federal law and is governed by 27 Governor-appointed board members, 60 percent of whom are individuals with developmental disabilities or family members of individuals with disabilities. The Council's purpose in law is to encourage policy change so that people with disabilities have opportunities to be fully included in their communities and exercise control over their own lives.

#### Legislative Purpose

Texans with intellectual and developmental disabilities (IDD) must navigate a complex system of services ranging from waiver referrals, special education and transition to adult life, nursing and attendant care, to employment services. These systems offer wonderful opportunities, but also significant barriers and confusion.

As monitors, providers, and administrators of the systems and services, it is crucial that statewide IDD systems collaborate and plan together to improve access and understanding for themselves and the individuals they serve. HB 729 would advance an effort to improve systems by establishing a statewide IDD coordinating council with the purpose of ensuring a strategic statewide approach for IDD services.

The duties of the council would include:

- Developing and monitoring the implementation of a five-year statewide IDD strategic plan,
- Developing a biennial coordinated statewide IDD expenditure proposal,
- Annually publishing an updated inventory of state-funded IDD programs and services, including a description of how these programs and services further the purpose of the statewide IDD strategic plan and an estimate of the number of individuals who are interested in receiving those programs and services, and
- Potentially facilitating opportunities to increase collaboration for the effective expenditure of available federal and state funds for IDD services in Texas.

#### Additional Information

In 2015, legislative action established the Statewide Behavioral Health Coordinating Council with a directive to develop a collaborative five-year behavioral health strategic plan, which was considered incredibly successful by the agency, advocates, and legislators. Recommendations in the Behavioral Health Strategic Plan provided a critical foundation for legislators to build on and cite when exploring funding allocations and legislative action.

Lauren Gerken  
Texas Council for Developmental Disabilities  
Austin, TX

Thank you for reading more about HB 729.

In February 2019, the group published its Texas Statewide Behavioral Health Strategic Plan Update for 2017-2021, including a section recognizing the unique challenges the IDD population faces in Texas and provided an overview of the services and supports available. The update called for a coordinated action plan for IDD services across the state, since one did not exist at the time, and since the needs of the IDD population could not be addressed properly as a subsection in an existing plan.

HHSC then released an IDD strategic gap survey, conducted to “gather statewide stakeholder input to identify gaps in the Texas IDD system and inform the development of the Statewide IDD Strategic Plan.” The survey was distributed online by HHSC and received nearly 5,000 responses. As a result, HHSC developed an IDD Strategic Planning Group, which differs from a council in its mandate, formality, coordination, and representation.

In January of 2022, the IDD Strategic Planning Group published the Texas Statewide Intellectual and Developmental Disabilities Strategic Plan, which has goals and objectives set through 2025. The three goals were:

1. Empower and support people to pursue the lives they want to live,
2. Deliver services in the most integrated setting according to each person’s needs and preferences, and
3. Enhance performance of systems.

This Planning Group outlined specific recommendations to achieve these goals. Unfortunately, due to the limitations of a “group,” particularly in its mandate, coordination and formality, and interaction with the Texas Legislature, these goals have not been met. The council created by HB 729 would receive the appropriate mandate to oversee the implementation of this IDD strategic plan in partnership with the appropriate decision makers in our state to achieve these goals.

The IDD Strategic Planning Group acknowledged that with an IDD Coordinating Council, IDD services and strategic efforts have great potential to complement and match “the success of the Statewide Behavioral Health Strategic Plan and the transformation of the HHS system [that] demonstrates the value of a coordinated effort working toward common goals” (IDD Strategic Plan, 2022, p. 6). In other words, HHSC has reflected on the success of the Statewide Behavioral Health Coordinating Council, found on pp. 12-21 in the recent plan, recognizing that the IDD community needs the same opportunities for coordination and success.

It is worth noting that TCDD is a statewide council focused on IDD issues; however, its purpose, membership, and activities are different than those of the entity proposed by this legislation. According to the current text of HB 729, TCDD would have a designated representative on the new council.

Thank you again for reading my testimony. I will follow up with an electronic copy, so you can access the link to the current strategic plan. Please do not hesitate to contact me with any questions.

Linda Litzinger  
Texas Parent to Parent - Public Policy Specialist  
Austin, TX

Texas Parent to Parent supports this bill to create an inter-agency committee to support people with IDD. Thank you