

**House Committee on Public Health
TCDD Comments on House Bill 119 by Landgraf
& House Bill 473 by White
March 10, 2021**

Chair Klick and Members of the Committee,

Thank you for taking the time to read my testimony regarding two substantively identical bills prohibiting organ transplant discrimination on the basis of certain disabilities, House Bill 119 and House Bill 473. My name is Linda Logan and I am the Senior 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.

The proposed bills are largely consistent with the mission and goals of TCDD.

Although organ transplant discrimination is illegal under the Americans with Disabilities Act, 44% of organ transplant centers across the United States said they would not add a child with a neurodevelopmental disability to the organ transplant waitlist (see <https://onlinelibrary.wiley.com/doi/full/10.1111/j.1399-3046.2008.01072.x>). Beyond that, 85% of centers might consider disability as a weighted factor when deciding whether a child should be added to the waitlist or not. In recent months, there has been a national push to ban organ transplant discrimination, with similar legislation being introduced in at least eight states and at the federal level.

These efforts have been fueled, at least in part, by research from the National Council on Disability (NCD) who found that, among other things, *discrimination continues to occur in the nine states that have enacted laws explicitly prohibiting such discrimination*. Discrimination is founded on the misconception that people with disabilities are unable to handle the organ transplant treatment and, as there are currently around 100,000 people on an organ donation list nationwide with a 3-5 year wait time, those with disabilities are valued lower than those without. The NCD report indicates that the foundation of such discrimination is completely unwarranted, showing that "if a person has a disability that is unrelated to the reason a person needs an organ transplant, the disability will generally have little or no impact on the likelihood of the transplant being successful. If a person with a disability receives adequate support, the person's disability should also have very limited impact on the ability to adhere to a post-transplant care regimen."

The following changes to the bill are recommended:

- In §161.471, Definitions, please note that in relation to (1) **Auxiliary aids and services, (D) provision of supported decision-making services**, the use of supported decision-making is voluntary, individual, and personal. It is not a "service" that is provided, but an approach to decision-making that an individual elects to use. Perhaps language such as "acceptance of supported decision-making as a legal and valid exercise of the individual's decision-making rights

under Texas Estates Code, Chapter 1357” would more closely reflect the role of supported decision-making plays.

- In the same section, the definition of **(3) Health care provider** seems inconsistent with the much broader American with Disabilities Act (ADA) definition of “disability” cited in the bill. Although we appreciate the emphasis placed on any other facility serving persons with intellectual or developmental disabilities, the same extension should be made to any other facility serving persons with any disability to which the ADA pertains.
- In the same section, the definition of **(5) Supported decision making** is confusing and it is unclear to whom this definition applies—the supporter in a supported decision-making agreement or the facility and facility professionals, i.e., health care provider, involved in the person’s care and treatment. The use of this term should closely follow the legal definition of this term under state law and not confuse it with other rights and responsibilities that may accrue to attorneys-in-facts or medical powers of attorney (subparagraph (A)).

Please find a term other than “supported decision making” to encapsulate the items enumerated in subparagraphs (A)-(F). The items relate to requirements for health care providers, not a supporter in a supported decision-making agreement. These responsibilities are not “supported decision making” as defined in Texas Estates Code §1357.002 as follows:

If language in **(5) Supported decision making**, is amended to follow the Estates Code, and language in subparagraph (B) is retained elsewhere in the bill, please note that an individual has a right under law to appoint a supporter and it is not necessary for any entity to “permit” such a designation. Please note that the role of the supporter is mutually defined by the individual seeking supported decision-making services and the supporter and would not necessarily include the provision of auxiliary aids and services or assistance in using assistive communication technology.

If subparagraph (F) of the existing definition is retained elsewhere in the bill, please modify it as follows: *if the individual has a court-appointed guardian or other individual responsible for making medical decisions on behalf of the individual, or for assisting the individual in making medical decisions as part of a supported decision-making agreement, ensuring...*

- With respect to §161.473(e), please delete the language related to allowing the health care provider to deny organ transplantation if it can be demonstrated that the provision of auxiliary aids and services would **fundamentally alter services provided or would impose an undue burden on the health care provider**. Without defining the terms “fundamentally” and “undue burden,” this allowance provides a fail-safe for the discriminatory refusal of services.
- It would be helpful if the bill contained language prohibiting health care providers from assessing the individual’s “quality of life.” Health care providers are qualified to assess the individual’s “quality of

health” and should be clearly limited to that assessment in determining suitability for organ transplantation.

- With these relatively minor modifications, HB 119 and HB 473 contain most of the elements of an effective antidiscrimination law with the exception of a “fast-track” procedure for challenging discrimination. This addition would help to ensure that people in urgent need of an organ transplant can obtain timely resolutions to their discrimination claims.

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