

## PUBLIC COMMENTS

HB 119

HOUSE COMMITTEE ON PUBLIC HEALTH

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Hearing Date: March 10, 2021 8:00 AM

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Dennis Borel

Coalition of Texans with Disabilities

Austin, TX

FOR. This is a thorough, comprehensive bill to prevent discrimination against people with disabilities in an organ transplant. We appreciate the inclusion of access to supported decision making in the bill. We note also the bill is not a "free pass" for individuals with disabilities, which is appropriate; rather organ transplant decisions may factor into clinical factors that result from disability.

Mimi Barreras

Self

Magnolia, TX

Do you know what it is like to fill out endless paperwork for transplant and then sit across the table from a medical official you know has your child's life in their hands? I do. I know what it feels like being weighed for where you appear on that short list based upon insurance. I can't imagine the sorrow of being cut from that list based on my child's having Down Syndrome.

Do you know what it's like sitting in a doctor's office being told your child in utero has a trisomy like Down Syndrome? I do. I know the pressure to abort and the medical discrimination felt. I birthed that child. She's miraculously normal and works for a Texas State Rep. But I still remember that sorrow and how the medical community felt about a child with a chromosomal disorder.

As a parent who has faced transplant for a child, as a parent who has faced a trisomy birth, as an aunt of a child with Down Syndrome, it is atrociously unacceptable to me that an individual with Down Syndrome would not be considered at all for transplant. Every life has value. Transplant is already a very interesting and a bit of an unfair process, but discrimination based on a chromosome is no different than discrimination based on being born left handed, red headed, or minus an arm, not to mention race or gender.

Please, please close up any loopholes and make sure discrimination for transplant for individuals with Down Syndrome is not allowable in Texas.

Annette Kerr, Mrs

self

Magnolia, TX

as Aunt of child with Downs, she would deserve a chance for transplant just as any other person. She is still a life and deserves every chance at continuing life, sadly if another life was lost.

Ben Brown

Self- Retired

Fairview, TX

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March 9, 2021

Public Health Committee

Chair- Representative Stephanie Klick and Members of the Committee

Re: Support of HB 1119

HB 1119, which prohibits organ transplant discrimination on the basis of certain disabilities, is important not only for those with disabilities but for the citizens of Texas. Texas should be just as compassionate for individuals with disabilities as it is for all other residents. This bill will provide the necessary legal framework for access and compassionate care for those with disabilities.

This is personal to me and my family because I have a 12-year-old grandson with disabilities. I would like to think that should he need an organ transplant in the future, the laws of the State of Texas would include the legal framework for him to receive a transplant.

I urge you to support and vote for HB 1119 or its provisions as bills may be amended and consolidated by the Public Health Committee.

Yours truly,

Ben Brown  
Legislative and Campaign Activities Director  
Republican Club at Heritage Ranch  
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Linda Logan  
Texas Council for Developmental Disabilities  
Austin, TX

Thank you for reviewing my testimony on HB 119. 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.

TCDD would recommend the following modifications to the bill's language:

1. In §161.471(5), "supported decision making" needs to be defined consistent with Texas Estates Code §1357.002, as follows: (3) "Supported decision-making" means a process of supporting and accommodating an adult with a disability to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without impeding the self-determination of the adult.
2. 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 state law" would be more accurate.
3. A new term is needed to describe the items listed in (A) through (F) of the definition of "supported decision making." The items relate to health care provider requirements, not those for a supporter in a supported decision-making agreement.
4. If subparagraph (F) of (5) Supported decision making is retained anywhere 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...

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5. In §161.473(e), language that allows the health care provider to deny organ transplantation if it can be demonstrated that auxiliary aids and services would “fundamentally alter services provided or would impose an undue burden on the health care provider” should be deleted. This allowance is too broad to prevent the discriminatory refusal of services without defining “fundamentally” and “undue burden.”
6. Language is needed to clearly prohibit health care providers from assessing the individual’s “quality of life.” Health care providers should be limited to assessing the individual’s “quality of health.”
7. “Fast-track” procedures for challenging discrimination are needed ensure that people in urgent need of an organ transplant can obtain timely resolutions to their discrimination claims.