

March 6, 2025

Senate Committee on Public Health and Welfare

Support for HB 2307

Chairwoman Gossage & Members of the Committee:

I am Lola Kernell, the Advocacy Coordinator for the Kansas Council on Developmental Disabilities and a peacemaker. Most importantly, I am a proud member of the disability community and a 20-year-old with Down syndrome.

I also attend college at JCCC, and work for the Chiefs and the Royals as a greeter in a fancy suite. Just last week, I wrapped up acting in a world-premier musical called *Just Ask*, based on a book written by Supreme Court Justice Sonia Sotomayor about people with disabilities. (I even got to meet her twice and moderate a panel with her last fall!)

As you know, KCDD's mission is to empower individuals with intellectual and developmental disabilities (I/DD) and their families to lead systems change, build capacity, and advocate for inclusive, integrated, accessible communities where everyone belongs and thrives. You all probably know our small but mighty team of Whit Downing, myself, Allyson McCain, and Sara Hart Weir at KCDD.

On behalf of KCDD, I would like to express our strong support for **HB 2307** - *Prenatal and Postnatal Diagnosed Conditions Awareness* bill. This legislation is critical because it ensures that parents receive not just medical facts, but also evidence-based information about the prenatal and postnatal conditions of their child. Parents deserve information that celebrates the life of their baby and offers hope, not just a focus on challenges.

This bill is deeply personal to me. When my mother was advised to undergo amniocentesis during her pregnancy, she was not given information about the risks—particularly the risk of miscarriage. When she asked, the healthcare counselor said, "Yes, there are risks, but there is a greater risk of having a child with a disability." What?? This comparison does not make sense at all. There is no rational way to compare the tragic loss of a pregnancy with the idea of having a child who is living, breathing, and capable of bringing joy and purpose to the world. My mother had already endured multiple miscarriages, and this simplistic comparison only added to her anxiety without providing the accurate information she deserved. While amniocentesis is an important tool, it is not the right choice for every situation.

When I was born, I was diagnosed with Down syndrome. However, that diagnosis did not come through a professional conversation. Instead, while my mom was still in surgery from a C-section, a nurse casually announced that I had features consistent with Down syndrome. At this point, my father nearly passed out and was taken to the ER.

Years later, many doctors continued to make assumptions about my abilities. One even expressed surprise when I was able to read, saying, "She can read?" Clearly, this doctor had outdated information about Down syndrome.

Today, thanks to early intervention, I can confidently say that I can read and write, work, learn French (parlez-vous français, mes amis), and even tackle algebra (although it's not my favorite). Most importantly, I am happy, successful, and thriving in my life. The message here is simple: parents should never be offered limited, outdated, or incomplete information about disabilities.

When my parents sought information and support, they found it by connecting with other families, joining peer and disability support groups, and researching current resources. These support networks offered invaluable opportunities to share stories of hope, growth, and success, alongside medical challenges. Medical tests may identify certain conditions, but they cannot measure the value each individual brings to the world.

KCDD is committed to ensuring that HB2307 is implemented in a way that truly supports families. Parents deserve real, hopeful information about the possibilities for their children, not just medical diagnoses and statistics. HB 2307 would create a hotline and local peer support groups, connecting families to one another and to resources that can help them navigate their journey. It would also require healthcare providers to follow clear guidelines to share supportive, accurate information with parents. We can't think of a better home than KCDD, where myself and my colleagues who have lived experience can ensure the bill is implemented.

Please support this bill so that people like me know that we matter and so that parents can access the information they need to understand and celebrate their children's unique abilities. When I was in high school, I was fully included and made a difference in others' lives. I was even voted "Most Likely to Brighten Someone's Day." People with disabilities are kind, compassionate individuals who work hard to accomplish their goals.

We have so much to offer, and that's why the message of this bill is so important: every child, regardless of their abilities, deserves to be celebrated for who they are and the contributions they can make to their community and society.

This is what the world needs now—love, kindness, and people who brighten each other's days.

Thank you for your time and for considering this important legislation. I strongly urge you to support HB 2307 to ensure that all parents have access to the supportive and hopeful information they need, and that people like me know we matter.

Sara and I will stand for questions at the appropriate time.

Sincerely, *Lola Kernell*

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