

November 14, 2017

Senate Bill 164

Senate Health, Human Services and Medicaid Committee

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Chairman Burke, Vice Chairman Beagle, Ranking Member Tavares, and members of the committee, thank you for allowing me to testify today in opposition to Senate Bill 164.

My name is Jane Gerhardt and I live in Cincinnati.

I am the parent of a 20 year old daughter with Down syndrome. Anne is a lovely young woman and we're extremely proud of her. Some of you may have seen her before. She had her 15 minutes of fame in a commercial with Urban Meyer and the State Treasurer, discussing the benefits of the Ohio STABLE Account. (I thank you for supporting STABLE in Ohio. To date, ## STABLE accounts have been opened – evidence of just how necessary that legislation was. )

I'm not here to talk about STABLE or Down syndrome. Because that's not really what this bill is about. This bill sends a very clear message, that some disabilities are more worthy of life than others and that one disability – Down syndrome- is the most worthy.

If passed, this committee's message is that individuals with Spina Bifida, Fragile X, achondroplasia, CF, osteogenesis imperfecta and every other genetically based disability, aren't worthy of protection. This bill creates a hierarchy of disabilities, with Down syndrome at the top, receiving state sanctioned protection, to the exclusion of all others.

What does this say to the prospective parent who receives a prenatal diagnosis of a non-protected, non-Down syndrome disability? Senate bill 164 disregards the potential lives of those with all other disabilities. I'm sure this is an unintended consequence but when you start making arbitrary decisions about which diagnoses deserve protections, you automatically make decisions about which do not, showing profound disrespect for these lives.

What is it that makes a person with Down syndrome so special? Or more special than one with achondroplasia? Or Fragile X? Nothing. Why do our elected officials feel it is their responsibility to make this judgment between disabilities? I'd venture to guess that if I spoke to each of you face to face, very few of you would tell me that you're comfortable judging on behalf of the State of Ohio which disability should be valued above others.

I'd submit that this has to do with stereotypes about the "loving" nature of people with Down syndrome, assuming they are all the same. Please know that these inaccurate and outdated stereotypes deny my daughter and all others of what makes them unique individuals, with the same

range of emotions as the rest of us, by turns ornery, snarky, sweet and pensive. Do you feel safe protecting this one disability because it's easy to recognize, to name and maybe to know?

While I stand before you speaking as a mom, I also work in the disability community and it's important for you to know that by singling out Down syndrome, this bill creates a wedge in the disability community, as it declares Down syndrome as the "better" disability, the one worth saving, against all other disabilities. I doubt this is the public policy outcome intended. When you start creating policy that impacts the disability community, it's really important to bring stakeholders to the table before drafting legislation.

There's a disability saying: Nothing About Us, Without Us. If this really is all about disability, then this is the wrong bill. If you really value these lives, wonderful. We have a whole lot of issues to talk about and I can't wait to speak to all of you about what's needed.

Thank you.