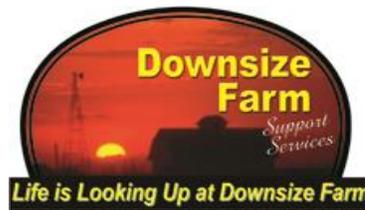


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Senate Bill 164

Senate Health, Human Services and Medicaid Committee

August 22, 2017

Chairman Burke, Vice Chairman Beagle, Ranking Member Tavares and members of the committee, thank you for allowing me to testify in favor of Senate Bill 164. My name is Bob Custer and I am the Executive Director of Downsize Farm, a Medicaid certified agency authorized to serve eligible Ohio citizens by the Ohio Department of Developmental Disabilities. On behalf of all the clients we serve, as well as my family, I am here to support this legislation.

Senate Bill 164, the Down Syndrome Non-Discrimination Act, is in effect, in my mind, the Down Syndrome Dignity Act. The active efforts of government to prevent the demographic discrimination of our citizens serves to identify, guard and nurture the cultural value of human dignity. Other testimony today will cite statistics with regard to the impact of genetic testing on the viability in our country of an unborn child carrying the Trisomy 21 chromosome disorder, known culturally as "Down Syndrome". I would like to testify about the experience of the birth of a child into our family with Down Syndrome.

Earlier this month my wife Midge and I watched reports of events in Charlottesville VA as factions raged over expressions of rights and symbols of discrimination related to genetic background. At least one person died. During the same broadcast, a report was given describing the "eradication of Down Syndrome" from the nation of Iceland, not through

genetic engineering, but through pre-natal testing and abortion. A woman in a white lab coat cited the statistic as a cultural values achievement and justified the abortive action as a reasonable and moral “quality of life” decision. Although couched in questioning concern, an interview with Governor Sarah Palin, the mother of a child with Down Syndrome, was the only countering opinion. I believe that the two reports have a common thread in question: A person’s rights and a person’s respect have a genetic basis...or as a principle: All people are not created equal...human dignity is based on genetic composition.

On February 5, 1994, our family experienced a moral eclipse. The sunlit hopes glowing around the birth of child was overshadowed by the report: “The doctor thinks Levi has Down Syndrome”. Up to that time, we knew very little about the condition and most of what we knew was not good. Quick research about the prognosis was not much better. As we instinctively embraced Levi with love, I battled internally with what the future would be like. Levi would be different than our other children, but as a dad, would I be able to value him as the others? Would I be proud of him or would I just have pity on him? The moral question I faced was the same question every person must answer. What gives any person dignity? Is it their appearance or potential productivity? Or is it the simple premise that “all people are created equal”...before they ever do a thing with their life. This life event took me a while to process...but I would have to make a choice. Because of Levi, I would now live and act and make decisions based on that premise. Like all other people, persons with disabilities have dignity, and I will guard it and I will nurture it and I will advocate for them. At Downsize Farm we identify, guard and nurture personal worth. At our farm, we grow dignity.

In 1864, Abraham Lincoln stated the same issue as the one that embroiled our country in a great civil war. He was dedicated to the proposition that “under God, all men are created equal”. His call was that those of us who remain should be dedicated to the same resolve lest we not endure as a nation. But now, as then, it is one thing to battle and enact legislation. It is another to feed our notion of “respect” as to our own value and those of others based on our genetic intellectual capacity or productive potential. On the basis we regard any one of our citizens, we regard them all. To quote Lincoln, this is an opportunity for “a new birth of freedom...and that the government of the people, by the people, for the people, shall not perish from the earth”.

Twelve years after the Gettysburg Address, Gen George Custer was killed in the Battle of Little Big Horn. After the Civil War that was committed to the emancipation of the slaves, ironically Custer was commissioned to deal with the savage Native Americans who were hindering the progress and quality of life in the West. “We will put them on reservations”. They did not go willingly. As a namesake, I researched Custer’s character. He held respect for the Native Americans...he loved the freedom of their lifestyle, difficult and different as it was. Custer justified his actions against them on the basis of quality of life: “If I were an Indian, I’d rather die than live on a reservation.” The contemporary cultural creed: “The only good Indian is a dead one”. Today, the resolve of SB164 is that we never allow ourselves to say the same about people who carry the genetic code of Down Syndrome.

Thank you for the opportunity to testify on SB164. I am happy to answer any questions you may have.