

Chair Derickson, Vice Chair Ginter, my ranking member Howse and distinguished members of the committee:

Thank you for the opportunity to testify.

My name is John Munnis, Jr. and I serve on the board of Democrats for Life of Ohio. I come before you today to ask you to support HB 135, the Down syndrome abortion ban. The following is as much my own personal testimony as that of a DFLO board member.

I was born with Spina Bifida back in 1964, when not all doctors would save us. Thankfully mine did save me. The nontreatment debate with respect to Spina Bifida (and Down syndrome too) continued into 1980s. In the early 1970s Dr. John Lorber published a paper advising against treating some babies with Spina Bifida. As someone who required a shunt at birth for the Hydrocephalus associated with Spina Bifida, I would not have been treated using Dr. Lorber's criteria

In the 1980s, there were the famous Baby Doe cases, the Baby Doe Down syndrome case and the Baby Jane Doe Spina Bifida case. In these cases, the parents were frightened into foregoing treatment by the gloom and doom they were led to expect for their children. In the Baby Jane Doe Spina Bifida case the girl's back eventually closed on its own. And at point the point the parents decided in favor of life saving shunt surgery for her Hydrocephalus that accompanied the Spina Bifida. That woman turned thirty not long ago and is a happy woman today. The doomsayers were wrong. I have included a 2013 New York Newsday article about the woman that was written at the time of her thirtieth birthday. We will never know if the famous Baby Doe Down syndrome baby would be happy today. That child died from the nontreatment decision.

It is scary to think that I was over eighteen years old when these nontreatment cases were being debated. This is personal to me.

As someone who spent more than my share of time in the hospital as a child, it troubles me to hear prospective hospitalizations as a reason for the need for abortion. Hospitals are not fun. I spent months in the hospital when I was five years old. But that does not mean I should not have been born.

But what about quality of life, one might ask? There are two ways of looking at quality of life – the medical model and the social model. I have included a sheet explaining the difference between the two. The medical model is the view of disability that doctors developed – consciously or not. Under the medical model, what will make problems of people with disabilities better is “curing the disabled person or making them seem as least disabled as possible.” The social model was developed of disability was developed by people with disabilities themselves. Under the social model of disability, “what will make the problems and issues people with disabilities have better is a change in society (like making things accessible for everyone).” Or making the world more inclusive. We should use the social model.

As a disability advocate I have personally advocated for a more accessible and inclusive world. I have advocated for the building of accessible homes. I have advocated for a more inclusive world for people with disabilities. (I know about the abuse and neglect at some of the institutions for people with

disabilities in the not-so-long-ago past.) For Down syndrome one thing we can do to promote quality of life is to promote inclusion in education. Research shows that students do better when mainstreamed with typical students – as opposed to being put in segregated environments. And, for all children with disabilities, this committee did the right thing by passing the disability expense savings account bill (ABLE Act) – Hb 155 Thank you. That will allow families to save for the needs of their children with disabilities. In closing, I would ask that we not give in to the cynical mentality that sees Down syndrome (and other conditions) as obvious evidence of the need for abortion. This Democrat believes we should have better answers. A better solution is to make the world that includes people with disabilities and supports families. That is better than the pessimistic view that their lives are not worth living. This is personal to me.

I respectfully ask the committee to vote in favor HB 135. Thank you for allowing me to testify.

John Munnis, Jr.
Democrats for Ohio board member
(Also a disability self-advocate)

Spina Bifida Family Support
 "Families Helping Families"
www.spinabifidasupport.com

Medical Model vs. Social Model

Even though people who have disabilities are very different, we are all different ages, races, and different kinds of disabilities, we still share a lot of things in common like a common history and common experiences of being discriminated against (being treated different because of our disability).

Adapted from Carol J. Gill, Chicago Institute of Disability Research

MEDICAL MODEL

1. Disability is a deficiency or abnormality.
2. Being disabled is negative.
3. Disability resides in the individual.
4. The remedy for disability-related problems is cure or normalization of the individual.
5. The agent of remedy is the professional.

Youth Friendly Version MEDICAL MODEL (How society views people with disabilities)

1. Disability is seen as something that could hold a person back. It is seen as something that a person should not want, that it makes people different in a bad way.
2. Disability is bad.
3. Disability is a personal problem-- the disability is in you, and it's your problem.
4. What will make problems people with disabilities have better is curing the disabled person or making them seem as least disabled as possible.
5. The only person who can help the disabled person fit in and be accepted in society is the professional.

SOCIAL MODEL

1. Disability is a difference.
2. Being disabled, in itself, is neutral.
3. Disability derives from interaction between the individual and society.
4. The remedy for disability related problems are a change in the interaction between the individual and society.
5. The agent of remedy can be the individual, an advocate, or anyone who affects the arrangements between the individual and society.

Youth Friendly Version SOCIAL MODEL (How the disability community sees themselves)

1. Disability is only a difference, like sex or race.
2. Being disabled is neither good or bad, it's just part of who you are.
3. Disability issues and problems come from the disabled person trying to function in an inaccessible society.
4. What will make the problems and issues people with disabilities have better is a change in society (like making things accessible for everyone).
5. That change can come from the person with a disability, an advocate, or anyone who wants people with disabilities to be equally included in society.

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