Testimony on H.57 – An act relating to preserving the right to abortion House Human Services Committee

January 23, 2019

Eileen Haupt

vteileen@comcast.net

To Members of the Committee:

Thank you for the opportunity to come before you and testify in opposition to H.57: An act relating to preserving the right to abortion.

I oppose the legalization of abortion in general, but I am sharing my perspective as a mother of a child with Down syndrome. I am the mother of two daughters; the younger, named Sadie, has Down syndrome and is now 20. She is a special young lady and the joy of our lives!

I know that those of you on this board care about Social Justice and care about vulnerable individuals, such as those with disabilities. I am sure it is why you serve—not only in the legislature, but also in other ways, with other organizations—to improve the lives of Vermonters.

I want to share with you today the devastating effect that legalized abortion—the very procedure that the House is aiming to "preserve" by this proposed legislation—is having on the population of Down syndrome.

A study¹ by Dr. Brian Skotko of the Down Syndrome Clinic at Massachusetts General Hospital, and others, estimates that about one-third of the population of individuals with Down syndrome in the U.S. has been lost to abortion.

In that study, they refer to an earlier study² that estimates the rate of abortion of babies with Down syndrome to be approximately 67 percent in the United States. The rate varies among geographic areas and demographic groups. Geographically, the Northeast and Hawaii have the highest rates. I would expect Vermont would be included in that higher rate.

In Europe, the rates are even higher. In France, the abortion rate for babies prenatally diagnosed with Down syndrome is 77 percent. In the U.K., 90 percent; Denmark, 98 percent; and in Iceland, an unbelievable 100 percent of babies who are diagnosed prenatally with Down syndrome are aborted! (There may be a few here and there born because of inaccurate testing or the mother declines testing.) In Denmark and Iceland, a high number of mothers undergo prenatal testing (80-85 percent in Iceland, 90 percent in Denmark), so they are essentially "catching" most of the babies conceived with Down syndrome in those countries. There are not many who escape the net.

¹ Fact Sheet – People living with Down syndrome in the USA: Births and Population; Gert de Graaf, PhD, Frank Buckley, and Brian Skotko, MD, MPP: <u>https://dsuri.net/us-population-factsheet</u>

² Prenatal diagnosis of Down syndrome: a systematic review of termination rates (1995-2011); Natoli JL1,

Ackerman DL, McDermott S, Edwards JG.: https://www.ncbi.nlm.nih.gov/pubmed/22418958

In 2017, "CBSN: On Assignment" produced a show that investigated the eradication of babies with Down syndrome in Iceland. ³ This is an issue that has garnered international attention.

When abortion is allowed for **any** reason with no restrictions, it is also allowed for **discriminatory** reasons, such as to eradicate babies with Down syndrome.

Of course, in order to abort based on disability, the disability must be detected. This is why prenatal testing was developed. And if I am not mistaken, the primary reason for the development of amniocentesis was to detect Down syndrome specifically. Prenatal testing is routinely performed on pregnant mothers to detect whether their babies have Down syndrome, as well as other genetic conditions.

Without going into too much detail, I will just say that advances in new non-invasive prenatal screening tests (NIPS), along with the current policy recommended by the American College of Obstetricians and Gynecologists (ACOG), that ALL pregnant mothers be offered prenatal testing (previously offered only to older women, 35 and over), has led to many more babies with Down syndrome being detected in the womb than ever before. Statistics tell us that when they are detected, almost three-quarters of them will be aborted.

In the United States, prior to these fairly recent changes, most babies with Down were left undetected, and therefore, born. About 80 percent of babies with Down syndrome were born to mothers under 35 years of age. There is great concern that many of those babies that would have been undetected previously will now be prenatally diagnosed, and therefore, aborted. We are heading in the same direction as Europe.

All of this new non-invasive testing, alone, is completely harmless to babies with Down syndrome. Testing merely gives information. It is the legality of abortion that is threatening their lives and drastically reducing the Down syndrome population.

This routine practice of screening for babies with Down syndrome so that they can be aborted is nothing short of discrimination. For a state that prides itself on respect, tolerance, and equality, it is unconscionable that we allow this.

The situation is so alarming, that there is a trend among other states—North Dakota, Ohio, Indiana, and Louisiana, so far—to enact bans on aborting babies specifically for the reason of having Down syndrome, other disabilities, or for the sex of the baby.⁴ Other states, such as Pennsylvania and Utah, considered bills, though the bills were ultimately not passed into law. All but the North Dakota law have been challenged in court.

³ What kind of society do you want to live in?": Inside the country where Down syndrome is disappearing: <u>https://www.cbsnews.com/news/down-syndrome-iceland/</u> (Video)

⁴ Overview of Legislation and Litigation Involving Protections Against Down Syndrome Discrimination Abortion; Amanda Stirone, J.D.: <u>https://lozierinstitute.org/overview-legislation-litigation-involving-protections-against-down-syndrome-discrimination-abortion/</u>

Indiana's law, prohibits a baby from being aborted solely based on "race, color, national origin, ancestry, sex, or diagnosis or potential diagnosis of the fetus having Down syndrome or any other disability." It was challenged by Planned Parenthood and was subsequently blocked by the 7th Circuit Court of Appeals. Indiana's Attorney General has petitioned the U.S. Supreme Court to review the state's 2016 law. This review been relisted to this coming Friday. This law that seeks to ban the discriminatory practice of aborting babies based on a disability or the wrong sex, might very well go to the U.S. Supreme Court.

So while other states are trending toward protecting unborn babies with disabilities and babies of an undesired sex, this state seems to be moving backwards by preserving in law no restrictions whatsoever.

In the late 1950's, a renowned French researcher and physician, Dr. Jerome Lejeune, discovered that an extra 21st chromosome is what caused Down syndrome. He was horrified when the medical field used his discovery to detect unborn babies with Down syndrome, so that they could be aborted.

Just a few decades ago, when parents were told their newborns had Down syndrome, they were advised to put them in institutions, to forget they were born. I am old enough to remember Geraldo Rivera's investigative expose on ABC Eyewitness News in the early 1970s, on the Willowbrook Institution on Staten Island, New York.⁵ Though I was only about 12, that report disturbed me greatly. Fortunately, circumstances were beginning to improve around that time for newborn babies with Down syndrome. It became acceptable for parents to keep their babies to be raised at home.

So just when things were looking up for this special population of people, along comes prenatal testing and legal abortion to, again, ruin their lives. Or rather, to take them.

There has never been a better time, in the history of the world, for a baby with Down syndrome to be born: More understanding and awareness of the genetic condition, more advanced medical technology to treat health issues, more inclusive education, more understanding about their potential, and so much more. But because of legalized abortion, almost three-quarters of those prenatally diagnosed never get the chance in life that is rightfully theirs.

I believe that future generations of Americans are going to look back on these past few decades and wonder how we ever allowed abortion to be legal, just as we look back now and wonder how we could have tolerated slavery, and right here in our own state, instituted involuntary sterilizations. If this legislature passes this legislation, I believe you will be on the wrong side of history.

Rather than advance this legislation, I would request that, instead, you introduce legislation, like Indiana's, that would prohibit the prenatal discrimination of babies with Down syndrome in the womb.

I'd like to end with a quote from Dr. Jerome Lejeune: "The quality of a civilization can be measured by the respect it has for its weakest members. There is no other criterion."

Thank you very much for your time today.

⁵ Willowbrook: The Last Great Disgrace: <u>http://index.geraldo.com/folio/willowbrook</u>