

Written Testimony in Support of H.B. 135

Dennis M. Sullivan, MD, MA (Ethics), FACS
Professor of Pharmacy Practice
Director, Center for Bioethics
Cedarville University, Cedarville, Ohio
May 19, 2015

1. Good afternoon, Mr. Chairman and members of this distinguished Committee. My name is Dr. Dennis Michael Sullivan. I am a citizen of the state of Ohio and I reside in Beavercreek, Ohio, where I have lived since 1997. I am pleased to give my expert opinion before this committee in support of H.B. 135, and will specifically address the ethical concerns at stake in the matter of abortion for genetic disabilities.
2. I am a physician and have been licensed to practice medicine since 1978, and in the State of Ohio since 1980. My medical degree is from Case Western Reserve University in Cleveland, Ohio, and I have specialty training in general surgery. I was board certified by the American Board of Surgery, and am a Fellow of the American College of Surgeons. I practiced medicine in the U.S. Army and internationally for 12 years. Since 1996, I have served on the teaching faculty of Cedarville University and I have taught human biology, including advanced anatomy and human embryology. During this time, I have received additional graduate training in bioethics and philosophy, and I now also teach moral philosophy and medical ethics. Since 2006, I have been Director of Cedarville University's Center for Bioethics. I currently serve on the faculty of the School of Pharmacy.
3. Ladies and gentlemen, this modern era has often been named the "Biotech Century," and for good reason. Since the completion of the Human Genome Project in 2003, we have

come to understand the mysteries of our human genetic code to a degree never before thought possible. And with that understanding comes the promise of new treatments for disease and for the relief of much human suffering. It is an exciting time to practice and to teach medicine.

4. Unfortunately, with all this understanding come some unrealistic expectations. Our society has seemed to increasingly embrace perfectionism as its ideal. There are deep ethical implications to all of this.
5. One major domain for ethical concern is that of genetic testing. How reliable and useful is the information obtained, and for what will it be used? In the unborn, prenatal genetic screening may take place by amniocentesis, a sterile technique where a needle is passed directly into the amniotic cavity surrounding the fetus in the uterus. Cells found in the withdrawn fluid are then tested for genetic anomalies. This procedure cannot be performed before the twelfth week of pregnancy, and itself carries a 0.5% risk of miscarriage. Chorionic villus sampling (CVS) is an alternative procedure involving a tissue sample obtained through a transcervical catheter and ultrasound guidance. This can be performed earlier than amniocentesis (about 8 weeks), but carries an increased risk of miscarriage (1-2%). Frequently, prenatal testing is used as a justification for induced abortion if certain genetic abnormalities are found, such as Down syndrome.
6. The perfecting of humanity is an important argument for the practice of selective abortion, based on the elimination of undesirable traits. Society runs the risk of creating superior and inferior subclasses of humanity. Such a program could lead our society to embrace a philosophy that some persons are desirable and others are dispensable.

7. When I tell my students that we have all been down this road before, I am often met with blank stares and disbelief. They are simply too young to realize the great cost we have paid as a nation to combat the evils of discrimination. I relate to them the history of eugenics, beginning with the forced sterilization of prisoners at the turn of the last century, in order to eliminate certain supposed genetic traits that could affect their morals.
8. But of course this story becomes more and more disturbing, as we see how our society has responded to individuals with mental retardation and other cognitive disabilities, calling them by the vague and unscientific term “feeble-minded.” By the late 1920s, over 30 states had eugenics laws permitting sterilization of the mentally disabled. In the end, over 50,000 Americans were sterilized against their will, with some of the laws used as a blueprint for the much more egregious abuses in Nazi Germany.
9. My students are disturbed and often in tears when they hear about these violations of human dignity in the past, but they are even more troubled when they realize that we are about to commit many of the same mistakes today. The modern practice of eugenics is more subtle than the era surrounding World War I, mostly because it involves a hidden and under-protected category of our population: namely, the unborn.
10. It is well established that the prenatal diagnosis of genetic abnormalities leads to a high rate of abortion. And the top of the list for such genetic discrimination is Down Syndrome.
11. Down Syndrome is the most common chromosomal abnormality today, affecting one in every 691 babies. There are about 400,000 people living with Down Syndrome in the United States. This condition occurs when a child has a partial or complete extra copy of

the 21st chromosome. This is often called Trisomy 21, since there are three copies of the 21st chromosome instead of just two. Chromosomes are tiny packets of DNA, our genetic blueprint, present in the nucleus of every body cell. In Down Syndrome, the extra genetic material leads to a small stature and other physical characteristics, and may lead to cognitive disabilities as well, usually mild.¹

12. The National Down Syndrome Society has said this:

People with Down syndrome have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia, and thyroid conditions. Many of these conditions are now treatable, so most people with Down syndrome lead healthy lives. . .

All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses.¹

13. So these individuals can lead healthy and fulfilling lives. Just ask my friend Mr. Edwin Vance, who is present with me in this hearing room. His son Justin has Down Syndrome. Justin is 33 years old, and enjoys his life and relates well to his family and friends. Justin is a permanent part-time employee of the Goodwill Store in Xenia, where he has recently received a positive job review. I have come to expect a big hug from Justin when I visit the Vance household. He loves to tell me about his recent projects and about his love for the Cincinnati Reds and, of course, the Ohio State Buckeyes.

14. Despite all this, a recent systematic review of 24 studies revealed that Down Syndrome is a significant reason for women to terminate their pregnancies, with between 61% and 91% choosing abortion when Trisomy 21 is discovered on a prenatal test.² These kinds of numbers led commentator George F. Will, himself a father of a child with Down Syndrome, to describe the recent increase in prenatal testing as a “Search and Destroy Mission” against babies with this condition.³

15. This is just eugenics, and it is blatant discrimination. In my opinion, physicians are a major part of the problem. What is it about mild cognitive disabilities that makes doctors so uneasy? Certainly Down Syndrome is not a life-threatening condition, though sometimes it is characterized in that way. In my teaching of medical ethics, I often point out that health care professionals are the least qualified to determine the quality of life of their patients. The patients themselves and their families often have a markedly more optimistic view. When asked about their life satisfaction in a recent study, the overwhelming majority of individuals with Down Syndrome were happy with their lives, and the overwhelming majority of parents and families were happy with them, 99% and 97% respectively.⁴ How is it, then, that physicians often recommend pregnancy termination when Trisomy 21 is detected?
16. It is my professional and personal position, based on science, philosophy, and my view of human flourishing, that protectable human life begins at the moment of conception, and extends to the grave. I am also very aware that some in this hearing room disagree with my opinion. I hope that sometime we can have a mutual and meaningful conversation about these matters, but that discussion is not for today.
17. I am also aware that the abortion debate is a highly contentious area in our civil discourse, one that causes great emotion in sorting out the rights of the unborn v. the rights of mothers dealing with an unwanted or unexpected pregnancy. This too is a conversation for another time.
18. However, it is highly relevant to our purposes today how we will protect the disadvantaged and vulnerable among us, and how we will prevent genetic discrimination among those who currently have no voice. Seven other states ban abortion for gender

selection, and one other state bans abortion for genetic abnormalities.⁵ What we are proposing with this statute is rather simple: to protect unborn individuals with Down Syndrome from being killed simply because they have this condition. Anything else is discriminatory. Failure to protect these innocent unborn children is simply eugenics, and it is morally wrong.

19. I urge that you pass H.B. 135, and I thank you for the opportunity to testify before this distinguished committee.

References:

1. National_Down_Syndrome_Society. Down Syndrome Facts. 2015; <http://www.ndss.org/Down-Syndrome/Down-Syndrome-Facts/>.
2. Natoli JL, Ackerman DL, McDermott S, Edwards JG. Prenatal diagnosis of Down syndrome: a systematic review of termination rates (1995–2011). *Prenatal Diagnosis*. 2012;32(2):142-153.
3. Will GF. Golly, What Did Jon Do? *Time Magazine* 1/28/2007.
4. Skotko BG, Levine SP, Goldstein R. Self-perceptions from people with Down syndrome. *American Journal of Medical Genetics Part A*. 2011;155(10):2360-2369.
5. Guttmacher_Institute. Abortion Bans in Cases of Sex or Race Selection or Genetic Anomaly. 2015; http://www.guttmacher.org/statecenter/spibs/spib_SRSGAAB.pdf.