2013 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

HB 1305
January 22, 2013
Job #17534

[Signature]

Explanations or reason for introduction of bill/resolution:
Relating to the prohibition on abortions for sex selection or genetic abnormalities, definitions and provide a penalty.

Minutes:

Chairman Weisz: Opened the hearing on HB 1305.

Rep. Betty Grande: Introduced and sponsored the bill. (See Testimony #1)

9:22 Chairman Weisz: On the gender selection, how do you enforce it?

Rep. Grande: With sex selection, you are waiting quite a ways into a pregnancy to have that determination. You are looking at late term abortions for sex selection purposes only.

Chairman Weisz: If this bill passes won't the woman say it is for a sex selection?

Rep. Grande: Can we stop all of that? No, but I think the awareness of it is critical. You will never stop someone from lying or committing fraud.

Rep. Mooney: They can determine a sex through a simple procedure by a single cell early in term. Doesn't that bring it back to the statutes on the books right now on abortion? Sixteen weeks is the maximum.

Rep. Grande: If they can, then great.

Rep. Mooney: Do you have statistics that relate to United States as far as sex selection abortions?

Rep. Grande: I don't know if anyone else has brought that in. I'm not the expert on the statistics of that. I'm handing out other testimonies today and you may find some of that information available to you and if not we will look it up and produce it for the committee.

Rep. Mooney: Where are the 70-100% abnormalities comes into play as well.

Rep. Oversen: How does this affect patient privacy rights?

Rep. Grande: We would have in that conversation the physician would need to find out what the purpose of the abortion was and by law the physician would not be able to perform that abortion for that particular reason.

Rep. Oversen: Is that physician required to ask for that reason?


Rep. Oversen: How do we find out the physician has that information if they did the abortion?

Rep. Grande: I'm not the one who is going to determine the law and how it is implemented. You will have to discuss with the State's Attorney and Health Dept. as to how they are recording and dealing with the records. The Health Dept. is already dealing with the procedure of going through all records as abortions are performed. What we do for HIPPA requirements are blanked out.

Rep. Mooney: We will leave the enforcement with this our local law enforcement?

Rep. Grande: States attorneys are the law enforcement of laws. The statute itself tells them they are to enforce. Currently they pick and choose the ones they want to enforce.

17:02 William Schuh: Testified in support of the bill. (See Testimony #2)

25:44 Rep. Mooney: You said we would be state sanctioning abortion if not supporting the bill. Is it not another way to look at that it is not mandating to everybody one sensibility? To allow people to choose based on their needs?

Schuh: My point is this is a human being. When we start to say I want this and expect that and destroying the child in the womb on that basis, the child is becoming an object of our desire. People, who are allowed an easy out, take it. When you have early detections it creates fear. The incentives on fear base would push forward abortion. We can handle our children if they have disabilities and there is the help we need to do.

Rep. Mooney: I'll leave it lie there.

Chairman Weisz: Would you provide for the committee the quote you made?

Schuh: It will take a few days, but I will be happy to get it.

30:44 Stacey Pfliiger: Read Christopher Dobson's testimony in support of the bill. (See Testimony #2)

Rep. Oversen: Do you have any information on kids with Down syndrome as I'd like to see that?
Chairman Weisz: I believe that paper I asked for from Mr. Schuh also reflects that and should address that.

Stacey Pfliiger: I'll get both for you.

34:43 Tom Freier: From Family Alliance testified in support of the bill. The testimony that you have heard shares a great deal of what we know and what are concerns are. We respect life and specifically this bill deals with a couple of situations where that life is to be protected whether in the sex selection or genetic. We fully support this bill. ND Right to Life sent me written testimony he wanted me to share with you. I'd like to address the issue of enforcement of abortion. The enforcement takes place in the Dept. of Health. Regulations go through there. The State's Attorney could become involved in it if it was done in opposition or against the law. That issue would be resolved by the abortion facility physician's reports shared back with the Dept. of Health would be a means of determining whether or not this bill if it becomes law would be complied with.

OPPOSITION:

37:17 Renee Stromme: Executive Director of ND Women's Network testified in opposition of the bill. (See Testimony #3)

NEUTRAL

Roxanne Romanick: Here with the organization Designer Genes and we are a Down syndrome support network in the State of ND. We have over 200 individuals with Down syndrome and their families on our mailing list. I'm here to offer to provide any information you would like. No good studies at looking at the rates of statistics.

Beth Nodland: I'm supportive of bringing down the rates of termination for people who have genetic abnormalities. I'm grateful for the bill because it digs the bigger question. Why are 90% of these people choosing to terminate and it is not all pro-choice women. I have a child with Down syndrome and I have learned that one-third of the people are supportive, on-third say "It's good for you, but I couldn't do that", and one-third say, "We shouldn't have these children. I want to read to you some direct responses to me that I get on national forums "When we have a chance to improve ourselves, human beings, it is irresponsible to the point of being criminal not to terminate. Can anyone honestly say the world would not be a better place if every child was perfect? I recognize the catastrophic cognate of dissonant of having a disabled child requires you to view disability as a blessing, (Which I don't) and both you and me have my sincere sympathies." Another one says, "The difference with the downs is that it is preventable. The amniocentesis after 35 pretty much eliminates the potential. Yet for the people who refuse abortion should be made responsible for the lifelong up keep of these kids they will bring into the world. Since there is (inaudible) choice there is no excuse for blatant neglect or responsibility. Most other mental issues are not as clear as downs. Somethings are clearly identifiable as defects and downs is one of them. To not do our best to prevent such things is unconscionable". When you are a pregnant woman and you get this information, it is a hard choice. Another one is, "All is well and good for people who can afford to have this type of child, but for the people who do not have the resources the American taxpayer, pays and pays and pays and pays
until death do them part. If one chooses to have a baby with this defect and it is a defect plain and simple you should pay to send it to special schools and whatever medication or care it needs for its lifetime". The last one, "People with this dysfunctional down (my child) have learned to appreciate the qualities as they overlook the dependency of these beings. As long as financially cared for until their death, I see no problem to have them. The problem lies when the downs fall into the lap of society and then no one wants to pay for their sustenance". So the question is do we pay for their sustenance? Do we take care of the weakest among us? This bill is a big national conversation that needs to happen. What do we do as a people and what do we do to support people once they are born?

Chairman Weisz Closed the hearing on HB 1035.

Handed In Testimony

Christopher Dobson: ND Catholic Conference (See Testimony #4)

Paul Maloney: Right to Life (See Testimony #5)

Janne Myrdal, State Director for Concerned Women of America (See Testimony #6)

Information Handed In

(See Attachment #7)

Lori Scheck: (See Attachment #8)
2013 HOUSE STANDING COMMITTEE MINUTES

House Human Services Committee
Fort Union Room, State Capitol

HB 1305
February 5, 2013
Job #18323

☐ Conference Committee

Committee Clerk Signature

Explanation or reason for introduction of bill/resolution:

Relating to the prohibition to abortions for sex selection or genetic abnormalities, definitions and provide a penalty.

Minutes:

You may make reference to “attached testimony.”

Chairman Weisz: Let's look at HB 1305.

Rep. Oversen: I asked earlier how this is going to be enforced. This bill is not enforceable the way it is.

Chairman Weisz: I don't disagree. I don't know how you can enforce it.

Rep. Damschen: We don't let that always let that be the deciding factor in our in law making process. The argument was it would make a difference if it was against the law. I'm going to support it.

Rep. Mooney: I didn't see any reference to ND babies and I want what is best for ND. I'm opposed to the bill.


Rep. Oversen: I have a genetic abnormality of my spine. I have spina bifida. There are certain abnormalities where if one twin is not terminated the other won't make it either. There are no exceptions in the bill for cases like this. Because of that I can't support the bill.

Rep. Muscha: I'm very prolife, but am torn on how to vote for this.

Rep. Damschen: On the other bill I couldn't get the person testifying to tell when she thought life began. I don't think we would have this discussion about an individual that had been born. I believe life starts at conception so I will vote in favor of this bill.
Rep. Mooney: The Supreme Court has weighed in on when life begins will have to go to a much higher court than this one is. The interest groups that want that argument should pay for that themselves. Don't think ND should pay for it.

Rep. Damschen: It is not a fiscal note and there is always chance that it would pass. I don't think the assumption is correct that there will be a lawsuit for us to defend.

ROLL CALL VOTE: 10 y 2 n 1 absent

MOTION CARRIED

Bill Carrier: Rep. Laning
1. **State fiscal effect**: Identify the state fiscal effect and the fiscal effect on agency appropriations compared to funding levels and appropriations anticipated under current law.

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1 B. **County, city, school district and township fiscal effect**: Identify the fiscal effect on the appropriate political subdivision.

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2. **Bill and fiscal impact summary**: Provide a brief summary of the measure, including description of the provisions having fiscal impact (limited to 300 characters).

This bill prohibits a physician from performing an abortion with knowledge that the abortion is based on gender or genetic abnormality.

2 B. **Fiscal impact sections**: Identify and provide a brief description of the sections of the measure which have fiscal impact. Include any assumptions and comments relevant to the analysis.

Section 2 prohibits a physician from performing an abortion with knowledge that the abortion is based on gender or genetic abnormality. There is no fiscal impact.

3. **State fiscal effect detail**: For information shown under state fiscal effect in 1A, please:

A. **Revenues**: Explain the revenue amounts. Provide detail, when appropriate, for each revenue type and fund affected and any amounts included in the executive budget.

   Not applicable

B. **Expenditures**: Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.

   Not applicable

C. **Appropriations**: Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation is also included in the executive budget or relates to a continuing appropriation.

   Not applicable
Name: Kathy Roll
Agency: Office of Attorney General
Telephone: 701-328-3622
Date Prepared: 02/07/2013
2013 HOUSE STANDING COMMITTEE
ROLL CALL VOTES
BILL/RESOLUTION NO. 1305

House Human Services Committee

Check here for Conference Committee

Legislative Council Amendment Number

Action Taken: ☑ Do Pass ☐ Do Not Pass ☐ Amended ☐ Adopt Amendment
☐ Rerefer to Appropriations ☐ Reconsider

Motion Made By Rep. Laning Seconded By Rep. Looyseen

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Total (Yes) 10 No 2

Absent 1

Floor Assignment Rep Laning

If the vote is on an amendment, briefly indicate intent:
REPORT OF STANDING COMMITTEE

HB 1305: Human Services Committee (Rep. Weisz, Chairman) recommends DO PASS
(10 YEAS, 2 NAYS, 1 ABSENT AND NOT VOTING). HB 1305 was placed on the Eleventh order on the calendar.
2013 SENATE JUDICIARY

HB 1305
Relating to the prohibition on abortions for sex selection or genetic abnormalities

Senator David Hogue - Chairman

Rep. Betty Grande - Introduces the bill - Explains sex selection abortion and gives stats on how many girls are lost a year. She goes on to explain abortions because of Down’s syndrome and other genetic abnormalities. See written testimony plus multiple hand-outs (1). Senator Hogue asks why the woman in this instance is not outright forbidden to have the abortion if it is for these reasons. Rep. Grande replies that the physician needs to have made the diagnosis so they jointly know what the issue is. Senator Nelson asks how many abortions have been done in this state based on sex of the child. Rep. Grande replies they are no records currently for that.

Bill Schuh - See written testimony (2)

Anna Higgins - Director of the Center for Human Dignity, Family Research Council - See written testimony (3)

Beth Brown - Hands in testimony for Yanna Myrdahl - See (4)

David Prentice - Family Research Council - See written testimony (5)

Stacy Pfliiger - See written testimony (6)

Paul Maloney - Director of Right to Left - In support of the bill.

Dan Becker - National Field Director for Personhood USA - States the bill is of interest to people all over the nation.

Steve Cates - In support of the bill. States this is eugenics in every way.

Pastor Dave Motta - Fargo - In support. Need laws to protect the innocent.

Opposition
Dr. Alexandra Deufel - Biologist, Developmental Biology at Minot State University - See written testimony. (7)

Renee Stromme - Hands in testimony for Steven Morrison - Professor at the University of ND School of Law - See written testimony - (8)

Carel Two Eagle - See written testimony (9).

Neutral

Roxane Romanick - Designer Genes of ND - See written testimony (10)
Committee asks about the testing done, invasive or non-invasive. Ms. Romanick mentions a new test that has become available and is being used in ND. Mr. Schuh states there are many places that take care of these people.

Close the hearing on 1305
Committee work

Senator Grabinger proposes an amendment, 13.0351.0100. He explains that this amendment deletes the part of this bill about genetic abnormalities. He says he has no problem with the gender selection. He said he heard clear and convincing testimony in the hearing that to make some go through all the way to term with a fetus that will not survive is not right. Senator Sitte is upset that some people are called defective and believes we cannot judge who is going to live and who is not. She believes this bill lays the fundamental ground work. Senator Berry agrees and believes this is a good bill. The committee discusses the testing that is done and how the level of accuracy has increased. Senator Grabinger said it should be a doctor patient decision and believes this takes away any options for them.

Senator Grabinger moves a do pass on amendment 13.0351.0100
Senator Nelson seconded
Vote - 2 yes, 5 no
Amendment fails

Senator Berry moves a do pass
Senator Sitte seconded
Vote 4 yes, 3 no
Motion passes

Senator Sitte will carry
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Not applicable

B. **Expenditures:** Explain the expenditure amounts. Provide detail, when appropriate, for each agency, line item, and fund affected and the number of FTE positions affected.

Not applicable

C. **Appropriations:** Explain the appropriation amounts. Provide detail, when appropriate, for each agency and fund affected. Explain the relationship between the amounts shown for expenditures and appropriations. Indicate whether the appropriation is also included in the executive budget or relates to a continuing appropriation.

Not applicable
Date: 3-13-13
Roll Call Vote #: 1

2013 SENATE STANDING COMMITTEE
ROLL CALL VOTES
BILL/RESOLUTION NO. 1305

Senate JUDICIARY Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number 13-0351-000.

Action Taken: ☐ Do Pass ☐ Do Not Pass ☐ Amended ☒ Adopt Amendment

☐ Rerefer to Appropriations ☐ Reconsider

Motion Made By S. Grabinger, Seconded By S. Nelson

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Total (Yes) 2  No 5

Absent

Floor Assignment

If the vote is on an amendment, briefly indicate intent:
Date: 3-13-13
Roll Call Vote #: 3

2013 SENATE STANDING COMMITTEE
ROLL CALL VOTES
BILL/RESOLUTION NO. 1305

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Total (Yes) 4  No 3

Absent

Floor Assignment S Sitte

If the vote is on an amendment, briefly indicate intent:
REPORT OF STANDING COMMITTEE

HB 1305: Judiciary Committee (Sen. Hogue, Chairman) recommends DO PASS (4 YEAS, 3 NAYS, 0 ABSENT AND NOT VOTING). HB 1305 was placed on the Fourteenth order on the calendar.
2013 TESTIMONY

HB 1305
Mr. Chairman and Members of the Committee –


Sex-Selection Prohibition

As you are aware, sex-selection abortion is an abortion performed for the purpose of eliminating an unborn child of an undesired sex – usually female. It is described by scholars and civil rights advocates as an act of gender-based violence. Obviously, there are strong public policy reasons for banning such gender-based violence.

First, prohibiting sex-selection abortion affirms our policy of nondiscrimination. It is undisputed that women are a vital part of our society, possessing the same inherent human and civil rights as men. Indeed, federal and state laws prohibit the dissimilar treatment of males and females who are similarly situated, as well as sex discrimination in various contexts, including the provision of employment, education, housing, health insurance coverage, and even athletics. Yet, similar protection is not currently afforded to unborn female children in North Dakota. Allowing sex-selection abortion reinforces sex discrimination and has no place in civilized society.

Second, prohibiting sex-selection abortion is necessary to eliminate the drastic affects such abortions have on society. In 2011, author Mara Hvistendahl (vis-ten-dahl) reported in her book, Unnatural Selection, that 163 million girls are missing in the world because of sex-selection abortions. The problem is so severe in some countries that, in 2005, the United Nations Population Fund termed the practice “female infanticide”.

Sex-selection abortion results in an unnatural sex-ratio imbalance. Experts worldwide document that a significant sex-ratio imbalance in which males numerically predominate can be a cause of increased violence and militancy within society. Likewise, an unnatural sex-ratio imbalance gives rise to the commoditization of humans in the form of human trafficking, and consequential increases in kidnapping and other violent crime.

Third, Americans oppose sex-selection abortion. In a March 2006 Zogby International poll, 86 percent of Americans agreed that sex-selection abortion should be illegal. Likewise, the American medical community opposes sex-selection abortion. The American College of Obstetricians and Gynecologists (ACOG) has stated that sex selection abortion is inappropriate for family planning because sex-selection “ultimately supports sexist practices”. Likewise the American Society for Reproductive Medicine has stated that sex selection for family planning purposes is ethically problematic, inappropriate, and should be discouraged.
Finally, the lack of legal protection in this area underscores the need for North Dakota to enact this prohibition. Currently, only four states - Arizona, Illinois, Oklahoma and Pennsylvania – maintain prohibitions on sex-selection abortion. Importantly, none of these laws have ever been challenged in court.

**Down Syndrome & Genetic Abnormalities**

Turning to the issue of abortion for Down syndrome or genetic abnormalities, I want to emphasize a few points.

Various studies have found that between 70 to 100 percent of unborn children diagnosed with Down syndrome or a genetic abnormality are aborted. These are devastating percentages as persons with Down syndrome contribute to our culture and are a valuable part of our society. Many persons with Down syndrome are able to obtain an education, maintain employment and live with varying degrees of independence. As technology advances and as medical treatments and educational methods improve, persons with Down syndrome will increasingly be self-dependent and productive citizens.

Likewise, persons born with genetic abnormalities contribute to American society and are a valuable part of our lives. There are 4,000 known genetic abnormalities and these abnormalities manifest in varying ways and degrees. Many persons with such abnormalities are able to support themselves financially, earn an education, or live independently. Further, as technology advances and educational methods improve, many will increasingly become self-dependent.

Most importantly, persons born with Down syndrome or genetic abnormalities possess the same fundamental – and inalienable – rights as all other human beings, but they are being disproportionately targeted in the womb – and oftentimes based on inaccurate medical data.

Like a ban on sex-selection abortion, a ban on abortion performed solely because a child has Down syndrome or a genetic abnormality affirms a policy of nondiscrimination. State and federal law prohibit discrimination against persons with Down syndrome or genetic abnormalities. Unfortunately, the same protection is not currently afforded to such persons before they are born. North Dakota’s policy of nondiscrimination will be advanced by prohibiting the abortion of children with Down syndrome or genetic abnormalities.

Conclusion

In conclusion, I would like to thank the committee for the privilege of testifying on behalf of this important bill. House Bill 1305 fulfills a vital societal goal – treating women and persons with disabilities with respect and dignity.

Thank you.
TESTIMONY BEFORE THE SENATE JUDICIARY COMMITTEE
CONCERNING HOUSE BILL 1305

William Schuh

Tuesday, January 22, 2013

Chairman Weisz and Honorable Members of the House Human Services Committee, my name is Bill Schuh, and I am here as a private citizen and as the father of an adult disabled person to testify in favor of House Bill 1305. I also serve on the Board of Directors of Housing Industry Training (HIT), which is a major provider of services to the disabled in this area, although I hasten to point out that I do not, in my testimony, represent that Board or the Organization, neither of which have a position on this bill.

I ask you to vote Do Pass on this bill. HB 1305, in essence, forbids the practice of using genetic testing as a screening procedure for abortion on the basis of sex or or genetically defined disability.

One of the most dangerous human traits is our infinite ability to rationalize our own self interest when confronted with situations that may cause us perceived or feared inconvenience, or hardship. For this reason, to subject the definition and the protection of human life to a vague and sliding scale, subject to change based on human emotion, is a grave danger to any civilized society. History has shown that it is easy to ignore or even define away the humanity of others when they are inconvenient. It's even easier when the inconvenient people are silent or powerless and cannot resist their extermination.

My daughter, Ann Marie, has Down Syndrome. She is 26 years old. She lives with her parents and helps in the home, she works at a motel making beds and she peels potatoes for a delicatessen. She is good at what she does, she loves doing it, and she is proud. Annie has always been a source of love and happiness for all who have known her, her family, teachers, coaches, coworkers, and fellow students. Ann has aspirations like anyone else. She loves life, she values her privileges, and takes pride in her work, and she fears injury and death. Annie is simply a person with her own unique traits – like all of us.

Not long ago my sister, who has worked for 35 years as an intensive care and oncology nurse at Minneapolis Children's hospital, was introduced to a staff child development expert who works with disabled children. Marianne commented on what a joy it must be to work with Down children. The person bitterly replied, “what are are you talking about. There aren't any more Down children. They kill them all in the womb.”

The Annies are now being systematically exterminated before birth. A recent (1999) paper published in the journal “Prenatal Diagnosis, Vol. 18, Issue 9, pages 808-812 reviewing the literature on termination rates of pregnancies for various genetic traits detected using prenatal testing, reported that 91 to 93% of all Down babies detected are destroyed in their mothers' wombs. Numbers differed for other traits, like spinebifeda and Turners Syndrome. The lowest was Klinefelter syndrome, with a destruction rate of about 58%. Klinefelter is syndrome, which is the male chromosomal equivalent of Down syndrome, involves mainly some peculiarities of body shape, and not necessarily abnormal intellectual traits. Now it was one thing, and bad enough, that a mother, out of fear and with state sanction and lack of loving support, destroy the child in her womb. But it is another dangerous and socially degrading step, that genetic testing has been turned to the task of providing a quality product
through the detection and cold and rational liquidation of those having undesirable traits. In doing so we have crossed the border into eugenics, and have entered a territory that in other contexts has already in the last century cost the lives of millions already born. Selective killing of the undesirable – by race, by disability, by gender in not new.

The social ramifications of the test, select and slaughter mentality extend beyond the destruction of the child. The use of prenatal testing to screen and destroy the child based on genetic traits, creates an unreasonable fear for those who have not experienced the love and uniqueness of these special people. But now picture a young couple, a mother who wants more than anything to bear her child being pressured into an abortion by a frightened husband, or a father whose every instinct is to protect his child, helpless to stop his frightened wife from destroying the child. Now picture disrespect and bitterness, a broken marriage, and perhaps the effects of that bitterness, or that divorce on other children in the family, and on society. I know what I’m talking about here. I know what it means to be confronted with the reality of a child we did not expect. I know what it means to be afraid. But I also know about the love and special gifts that these people, and they are people, bring. Also, I know that for those faced with these challenges there is plenty of support. They are not alone.

Test, select and slaughter by gender or by traits classified as abnormalities, if it is allowed, is only the beginning of the eugenic selection that will evolve with growing genetic knowledge if it is allowed to take hold. The criteria of selection, and the limitations of who will be allowed to survive gestation, can be expected to expand as detection of genetic traits expands, and the “shopping cart” mentality toward children, the belief that a child is a property for me to “have” is legally sanctioned. Selective eugenics is a social poison, and a virtual pandora’s box, that should not be opened.

For those who would say, leave it up to the experts, the medical professionals, I would point out to the committee that medical science, for all the wonderful benefits it has bestowed upon human society, has not had an uncheckered ethical track record; that medical personnel, as such, are neither more nor less moral or ethical – or wise than others; and that without appropriate checks and limitations the profession has had its share of disastrous ethical failures, some of which which I could, but will not here enumerate. The more recent development of the process of test, select and slaughter is one of those failures. It is not unreasonable that the people of this state, in protecting human life, expect that the medical profession practice its skills without deliberate killing. I would urge the committee and the Legislature to protect all human life from deliberate unjust killing, and to reject any amendment that would allow the slaughter of unborn human beings simply for the purpose of selecting what they or someone else, thinks to be a better product.

Please vote Do Pass on House Bill 1305
Chairman Weisz and members of the committee, my name is Renee Stromme. I am Executive Director of the North Dakota Women's Network. We are a membership organization working to improve the lives of North Dakota women. It is the position of the North Dakota Women's Network that reproductive choices for women must be ensured.

*House Bill 1305 prohibits a physician from performing an abortion under criminal penalties if they think that their patient is making a decision based on sex or genetic abnormalities.* This is a dangerous intrusion on the doctor-patient relationship, and could strip nonjudgmental health care from women in need—including for a woman who has just received a complicated diagnosis during her pregnancy.

Abortion is a deeply personal and sometimes complex decision that must be left to a woman, her family, and her faith, with the counsel of her doctor or health care provider.

- Decisions about pregnancy are not for the government to make.
- This legislation intrudes on the doctor/patient relationship by requiring doctors to become investigators and patients their suspects.

This bill could have devastating consequences when a woman is experiencing medical complications.

- When a woman is experiencing a complicated pregnancy, including those that involve a fatal fetal anomaly, it is important that a woman and her doctor have every medical option available.
- Specific disorders such as anencephalic (no brain) syndrome are fatal and permit no normal development. The decision to carry out or terminate a fatal pregnancy belongs to the pregnant woman without interference from the government.
- HB 1305 does not include any exceptions for genetic disorders which may be fatal.

NDWN is asking for a do-not-pass recommendation on House Bill 1305. Thank you for allowing my testimony.

Renee Stromme  
Executive Director  
North Dakota Women’s Network  
1120 College Dr. Suite 100  
Bismarck, ND 58503  
701-223-6985  
renest@nwwomng.org
To: House Human Services  
From: Christopher T. Dodson, Executive Director  
Subject: House Bill 1305 - Prenatal Nondiscrimination Act  
Date: January 22, 2013

The North Dakota Catholic Conference supports House Bill 1305 to prohibit sex and disability discrimination in the womb.

House Bill 1305 furthers several important public interests that form the basis of a civil society. No matter where a person stands on abortion, we should, as a society, agree that abortion should never be used as a tool for sex-selection or the elimination of children with genetic abnormalities.

Sex-selection abortion has drastic effects on society. An estimated 163 million girls are missing in the world because of sex-selection abortions. The United Nations Population Fund has rightly called the practice “female infanticide.” Experts have noted that the unnatural sex-ratio balance resulting from the intentional termination of unborn females can contribute to increased violence, human trafficking, and kidnapping.

The problem of sex-selection abortion is not limited to other countries. Several studies have documented the practice of sex-selection abortions in the United States and Canada. One study followed pregnant women from a particular immigrant community and a shocking 89% of those carrying girls aborted during the study period. Understandably, four states have already banned sex-selection abortions. House Bill 1305 is a simple measure to affirm a policy of nondiscrimination based on sex.

Just as we should not tolerate abortion as a tool for sex discrimination, we should not tolerate abortion as a tool for discrimination against those with disabilities. In 1983 North Dakota became a leader when it passed its Human Rights Act and extended protection to persons with disabilities. The federal
government followed in 1990 with the Americans with Disabilities Act. That protection, however, does not extend to the womb.

In an estimated ninety percent of cases, a positive test for Down Syndrome leads to an abortion. Unborn children with other genetic abnormalities suffer a similar fate. This is a betrayal of our state and nation’s commitment to respecting the rights and dignity of persons with disabilities. If we truly believe that persons with Down Syndrome or other genetic abnormalities have the same fundamental rights as any other person, we cannot turn a blind eye to their intentional elimination prior to birth.

House Bill 1305 furthers respect for persons no matter what their sex or genetic condition. We urge a Do Pass recommendation.

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1 See Mara Hvistendahl, Unnatural Selection, PublicAffairs, 2011.

2 Puri S, Adams V, Ivey S, et al. “There is such a thing as too many daughters, but not too many sons”: a qualitative study of son preference and fetal sex selection among Indian immigrants in the United States. Soc Sci Med 2011;72:1169-76. [Study involving immigrant Indian women in the U.S. found that 40% had terminated pregnancies with female fetuses and 89% of the women carrying female fetuses in their current pregnancy pursued an abortion.]

Almond D, Edlund L. Son-biased sex ratios in the 2000 United States Census. Proc Natl Acad Sci U S A 2008;105:5681-2. [An analysis of 2000 Census data found clear evidence of sex-selective abortions in what the authors called “son-biased sex ratios,” that is, a higher ratio of boys to girls than would occur in nature.]


3 Arizona, Oklahoma, Illinois, Pennsylvania
The use of abortion as a means of sex selection is a major social problem in a number of Asian countries, including China and India. There are credible estimates that 160 million women and girls are missing from the world due to sex selection, and the figure may be even higher. Writing in the Fall 2011 issue of The New Atlantis, political economist Nicholas Eberstadt of the American Enterprise Institute observed, “In terms of its sheer toll in human numbers, sex-selective abortion has assumed a scale tantamount to a global war against baby girls.”

Multiple academic papers have put forward evidence that the practice of sex-selection by abortion is increasing in the United States, especially although not exclusively within communities of immigrants from Asia. For example, a study by researchers at the University of Connecticut, published in Prenatal Diagnosis in March 2011, concluded, “The male to female live birth sex ratio in the United States exceeded expected biological variation for third+ births to Chinese, Asian Indians and Koreans, strongly suggesting prenatal sex selection.”

In another powerful study published in 2011, Dr. Sunita Puri and three other researchers at the University of California interviewed “65 immigrant Indian women in the United States who had pursued fetal sex selection.” They wrote: “We found that 40% of the women interviewed had terminated prior pregnancies with female fetuses and that 89% of women carrying female fetuses in their current pregnancy pursued an abortion.” This study discusses in detail the multiple forms of pressure and outright coercion to which such women are often subjected: “Forty women (62%) described verbal abuse from their female in laws or husbands. . . . One-third of women described past physical abuse and neglect related specifically to their failing to produce a male child.” As a result, “women reported having multiple closely spaced pregnancies with terminations of female fetuses under pressure to have a male child.” (“‘There is such a thing as too many daughters, but not too many sons’,” Social Science & Medicine 72 (2011), 1169-1176)

Of course, pro-life Members will support this legislation. But it is to be hoped that even many Members who deem themselves “pro-choice” will recoil at the notion that “freedom of choice” must include even the choice to abort a little unborn girl, merely because she is a girl. Members who recently have embraced contrived political rhetoric asserting they are resisting a “war on women” must reflect on whether they wish to be recorded as being defenders of the escalating war on baby girls.

Paul Maloney
Mr. Chairman and members of the committee, my name is Janne Myrdal, and I am the State Director for Concerned Women for America (CWA) of North Dakota. CWA is the largest public policy women’s organization in the nation. We are here today on behalf of our North Dakota members, in support of this Prenatal Non-discrimination Act, HB1305.

Information that will shed greater understanding on the need for this legislation:
There are over 160 million “missing girls” in the world who were killed simply because they were girls. Condoning sex-selection abortion is discrimination, because it gives credence to the idea that women are less valuable than men. According to a 2006 Zogby poll, sex-selection abortions are opposed by over 86 percent of Americans. I would wager that number is even higher here in North Dakota. Condoning sex-selection abortions feeds into the idea that women are less valuable than men and are objects to be tossed aside. Sex-selection abortions have had devastating societal consequences around the world, consequences which could impact the country's stability, as a lack of girl children leads to an increase in kidnapping and sex trafficking. Sadly, sex-selection abortions aren't just a problem for other countries, they happen every day here in America. Pure and simple, these abortions are eugenics. It is astounding that in a country that prohibits discrimination on the basis of sex in various contexts, such as employment, education, and housing, it is legal to abort a child because she's/he's a girl or a boy.

(Because of gendercide, there are now approximately 37 million more males living in China than women. However, this is not an issue that only impacts countries like China. Sex-selection abortions are occurring here in the United States. According to a University of California Berkeley study which looked at 2000 Census data, there was a male bias, especially for third children, of U.S.-born children of Chinese, Korean, and Indian parents.)

Abortion on the basis of the unborn baby's gender is a problem recently highlighted by undercover videos released by Live Action showing a Planned Parenthood clinic staff member instructing a woman on how to obtain a late-term sex-selective abortion.

Every child deserves the right to live, regardless of its sex or genetic abnormalities or a potential genetic abnormality. Our Founding Fathers clearly delineated the right to life as one that is unalienable and endowed by our Creator. It is horrific that in America today babies are being killed on the basis of their sex or genetic abnormalities, or potential abnormalities.

An estimated 90 percent of pregnant women who are told that they may be carrying a child with Down syndrome choose to abort the baby. (This shocking statistic caused Concerned Women for America [CWA] to develop an educational brochure for expectant mothers and fathers. The brochure offers encouragement, a positive perspective, and a list of resources and support groups to help families learn more about their baby's opportunities. The brochure is available in English and Spanish and widely distributed at Ob/Gyn offices around the nation.)

When tests indicate the possibility of Down syndrome or other genetic disabilities, some physicians will place pressure on a pregnant woman to have an abortion. Many expectant parents feel overwhelmed by
such a prenatal diagnosis and may not understand that the test results can be inaccurate. They also may not understand the many opportunities and resources available today. The result is a 90 percent abortion rate often based on lack of information, a lack of connecting with the excellent support services that are available, and/or outright pressure to abort.

Some physicians and patients have outdated information regarding what life holds for a child with Down syndrome in the 21st century. Advances in medical technology have led to better management and understanding of Down syndrome or other genetic abnormalities, and many individuals with these diagnoses lead productive lives with rewarding personal relationships.

The National Down Syndrome Society explains, "Down syndrome occurs in one out of every 733 live births, and more than 350,000 people in the U.S. have this genetic condition. One of the most frequently occurring chromosomal abnormalities, Down syndrome affects people of all ages, races and economic levels. Today, individuals with Down syndrome are active participants in the educational, vocational, social and recreational aspects of our communities. In fact, there are more opportunities than ever before for individuals with Down syndrome to develop their abilities, discover their talents and realize their dreams."

It's a gross abuse of technology to allow parents to be able to kill their babies on the basis of sex or genetic abnormalities or a potential genetic abnormality. At the present time, America is the only advanced country that does not restrict sex-selection through law, and that must end today. Let's send a clear message from North Dakota that we will stand for the rights of all unborn children.

CWA of North Dakota strongly urges you to support HB1305 with a “Do Pass” vote.
Recent Congressional statements on similar legislation:

Franks (R-Arizona) stated:

"I am heartened that so many of my colleagues came together to, in an overwhelming majority, support the Prenatal Non-Discrimination Act. Though it did not secure the two-thirds majority necessary to pass under suspension rules, I am confident that this is not the end, but merely the opening salvo in ensuring the words, 'It's a girl,' are no longer a death sentence for so many unborn girls.

"I also note the sad and bitter irony that President Obama, who has disingenuously accused Republicans of a so-called 'war on women,' mustered a truly breathtaking display of hypocrisy in opposing a bill that would prevent aborting those little babies who have the 'nerve' to be little girls.

"Indeed, the same Democrats who are so frequently heralded as 'progressives' today refused to make the United States the very last civilized nation on Earth to outlaw aborting a little girl simply for being a little girl, even as the human family on Earth is today missing 200 million baby girls, thanks to the grisly practice the majority of my colleagues across the aisle couldn't find it in their hearts to condemn."

Congressman Chris Smith (R-New Jersey) stated:

“It is a sad day in America when the President of the United States endorses sex-selection abortion by opposing the Franks bill to outlaw this egregious assault on baby girls. Sex-selection abortion is cruel, it's discriminatory, and it's legal. It is violence against women. Most people in government are unaware that it is part of a deliberate plan of population control. This is the real war on women.”

Congressman Mike Kelly (R-Pennsylvania) stated:

“The House's failure to pass a federal ban against sex-selection abortion is a sad day for America and a frightening one for girls and women,” said Rep. Kelly. “If ever there were a war on women in this country, the practice of sex-selection abortion would be the ultimate pre-emptive strike, taking the lives of innocent baby girls simply because they are girls and not boys. That’s the most reprehensible form of gender discrimination imaginable, and it's a crime against girls and humanity that needs to be stopped.”

Congressman Diane Black (R-Tennessee) stated:

"Aborting a baby based upon their gender undermines one of our nation's founding principles that all human beings are created equal. United States law currently prohibits discrimination on the basis of gender. Abortion should be no exception. Victims of sex selection abortions are overwhelmingly female. This is a growing problem that needs to be addressed."

Congressman Steve Chabot (R-Ohio) stated:

"I am proud to cast my vote for the most innocent among us, the unborn children. I am sickened by the thought of parents aborting a child because of its sex, and I will do everything in my power to defend those who cannot defend themselves. Sex-selective abortions are becoming an international problem with terrible repercussions, and we must stop the discrimination from happening here in America. The
laws of our country go to great lengths to protect individuals from discrimination and unborn children cannot be abandoned."

Congressman Jean Schmidt (R-Ohio) stated:

“I’m disappointed. This is a bill that basically is about sex selection for abortion. Abortion is wrong at any level, but to condone someone wanting to end a life based solely on the sex of their child is horrendous. This is an assault on women. This is gendercide.”

Lila Rose, founder and president of Live Action, also issued the following statement:

“We applaud the brave leaders in Congress such as Rep. Trent Franks for leading the charge against the abhorrent practice of sex-selective abortion. The struggle to stop gendercide is a bipartisan issue—more Democrats voted in support of the ban than Republicans against—but the battle is far from over. We will continue to release the results of our national investigation into Planned Parenthood and other U.S. providers that are facilitating the brutal and lethal discrimination against girls in the womb. The public deserves to see the truth about how Planned Parenthood and their abortion industry allies, backed by the President, facilitate the late term targeting of girls, especially as we approach a historic election."

Penny Young Nance, Chief Executive Officer and President for Concerned Women for America, stated:

"This is the ultimate violence against women. There are more than 160 million 'missing girls' in the world, 'missing' because they were killed for one reason — they were girls. Condoning sex-selection abortions feeds into the idea that women are less valuable than men and are objects to be tossed aside. According to a 2006 Zogby poll, sex-selection abortions are opposed by more than 86 percent of Americans. Because of gendercide, there are now approximately 37 million more males living in China than women. Sex-selection abortions have devastating societal consequences which could impact the country's stability, such as increased kidnapping and sex trafficking. Sadly, sex-selection abortions aren't just a problem for other countries, they happen every day here in America. Every child deserves the right to live, regardless of its sex. Our Founding Fathers clearly delineated the right to life as one that is unalienable and endowed by our Creator. It is horrific that in America today babies are being killed on the basis of their sex or race."

Marjorie Dannenfelser, President of the nationwide pro-life group Susan B. Anthony List.

“Today President Obama and 168 absolutist members of Congress chose to stand with the abortion lobby rather than defend women from the lethal discrimination of sex-selective abortion. It strikes me as grossly hypocritical that President Obama and his allies lament the so-called ‘War on Women,’ and yet fail to defend those women most in need – unborn daughters and the mothers coerced into sex-selective abortion. Our President and the leaders of his party are now on the record as being diametrically opposed to an overwhelming majority – 80 percent – of American women who support a ban on sex-selective abortion. The SBA List plans to ensure that come November, women will remember who failed to stand up for them.”
Douglas Johnson, Legislative Director for National Right to Life Committee, stated

“We are heartened that a strong majority of House members voted to ban performing or coercing abortions for the purpose of eliminating unborn babies of an undesired sex – usually, girls. Shamefully, President Obama, and a minority of 168 House members, complied with the political demands of pro-abortion pressure groups, rather than defend the coerced women, and their unborn daughters, who are victimized by sex-selection abortions. We commend the House Republican leadership for bringing this bill to the floor today under the fast-track procedure. Today’s groundbreaking majority vote was a stepping stone to this bill ultimately becoming law – perhaps after the replacement of some of the lawmakers who today were unwilling to protect victimized women and their unborn daughters from sex-selection abortions, because they were more concerned with maintaining favor with the abortion industry, pro-abortion advocacy groups, and Hollywood donors.”
Sunita Puri, Vincanne Adams, Susan Ivey, Robert D. Nachtigall, “There is such a thing as too many daughters, but not too many sons”: A qualitative study of son preference and fetal sex selection among Indian immigrants in the United States,

Social Science & Medicine, Volume 72, Issue 7, April 2011, Pages 1169-1176, ISSN 0277-9536, 10.1016/j.socscimed.2011.01.027.

(http://www.sciencedirect.com/science/article/pii/S0277953611000700)

Abstract: In response to concerns from feminists, demographers, bioethicists, journalists, and health care professionals, the Indian government passed legislation in 1994 and 2003 prohibiting the use of sex selection technology and sex-selective abortion. In contrast, South Asian families immigrating to the United States find themselves in an environment where reproductive choice is protected by law and technologies enabling sex selection are readily available. Yet there has been little research exploring immigrant Indian women’s narratives about the pressure they face to have sons, the process of deciding to utilize sex selection technologies, and the physical and emotional health implications of both son preference and sex selection. We undertook semi-structured, in-depth interviews with 65 immigrant Indian women in the United States who had pursued fetal sex selection on the East and West coasts of the United States between September 2004 and December 2009. Women spoke of son preference and sex selection as separate though intimately related phenomena, and the major themes that arose during interviews included the sociocultural roots of son preference; women’s early socialization around the importance of sons; the different forms of pressure to have sons that women experienced from female in-laws and husbands; the spectrum of verbal and physical abuse that women faced when they did not have male children and/or when they found out they were carrying a female fetus; and the ambivalence with which women regarded their own experience of reproductive “choice.” We found that 40% of the women interviewed had terminated prior pregnancies with female fetuses and that 89% of women carrying female fetuses in their current pregnancy pursued an abortion. These narratives highlight the interaction between medical technology and the perpetuation of this specific form of violence against women in an immigrant context where women are both the assumed beneficiaries of reproductive choice while remaining highly vulnerable to family violence and reproductive coercion.

Keywords: USA; Gender; Reproductive technology; Sex selection; Son preference; South Asian women; Immigration and health; Reproductive decision making; Family violence; Reproductive coercion
Son-biased sex ratios in the 2000 United States Census

Douglas Almond* and Lena Edlund**

*Department of Economics, Columbia University, New York, NY 10025; and **National Bureau of Economic Research, 1050 Massachusetts Avenue, Cambridge, MA 02138

Edited by Ronald Lee, University of California, Berkeley, CA, and approved March 3, 2008 (received for review January 24, 2008)

We document male-biased sex ratios among U.S.-born children of Chinese, Korean, and Asian Indian parents in the 2000 U.S. Census. This male bias is particularly evident for third children: If there was no previous son, sons outnumbered daughters by 50%. By contrast, the sex ratios of eldest and younger children with an older brother were both within the range of the biologically normal, as were White offspring sex ratios (irrespective of the elder siblings’ sex). We interpret the found deviation in favor of sons to be evidence of sex selection, most likely at the prenatal stage.

Robustness. Similar results were obtained if we linked children to only mothers or only fathers. The found male bias at higher parity was true irrespective of the mother’s citizenship status (a possible marker of cultural assimilation and expectations regarding future dependence on children for old age support). If anything, mothers with citizenship had more male-biased offspring sex ratios, but the difference was not statistically significant.

Discussion

We document son-biased sex ratios at higher parities in a contemporary Western society. We interpret the found deviation in favor of sons to be evidence of sex selection, most likely at the prenatal stage. Since 2005, sexing through a blood test as early as 5 weeks after conception has been marketed directly to consumers in the U.S., raising the prospect of sex selection becoming more widely practiced in the near future.

Son-biased sex ratios were found despite the absence of many of the factors advanced to rationalize son bias in India, China, and Korea, such as China’s one-child policy, high dowry payments (India), patrilocal marriage patterns (all three countries) (11), or reliance on children for old age support and physical security.

Although the magnitude of the deviations we find for second and third children is comparable to that documented for India, China, and South Korea, the marriage market consequences for the U.S. are likely limited. Low fertility in the U.S. means that births are concentrated at lower parities, where sex ratios are closer to the biological norm. In addition, because Indians, 

Author contributions: D.A. and L.E. designed research, performed research, contributed new reagents/analytic tools, analyzed data, and wrote the paper.

The authors declare no conflict of interest.

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*To whom correspondence should be addressed. E-mail: le93@columbia.edu.

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Chinese, and Koreans make up <2% of the U.S. population, the effect on the breeding population sex ratio is small.

Finally, the male bias we find in the U.S. appears to be recent. In the 1990 U.S. Census, the tendency for males to follow females among Indians, Chinese, and Koreans is substantially muted.

Materials and Methods

We used the 2000 U.S. Census, 5% public use sample. We restricted the sample to families where both the mother’s and the father’s race was given as Chinese, Korean, or Indian, where either parent headed the household, and where all children were born in the United States (to ensure that the offspring sex composition was not the result of, for example, China’s one-child policy). We excluded families with adopted or step-children. To reduce the probability that there was an eldest child not in the household, we also restricted our sample to families where the oldest child was 12 years or younger. Focusing on parity one through three yielded an analysis sample of 18,557 children in 11,553 families.

We investigated the sex ratio of children by parity (as calculated by the age of children reported in the household) and sex of previous children. In the absence of manipulation, we expected the sex ratio at each parity and sex composition of older siblings to be random, with a mean of 1.05 at birth. Lower parity children were older, but were born to younger mothers, two factors known to exert small and roughly offsetting effects on the sex ratio. As for sex of previous children, there may have been a small tendency toward repeating the same sex (1, 12).

ACKNOWLEDGMENTS. We would like to thank Mac Brown, Janet Currie, Ronald Lee, and two anonymous referees for their comments. We also thank the Institute for Social and Economic Policy Research (ISERP) at Columbia University for financial support.

O Sister, Where Art Thou? The Role of Son Preference and Sex Choice: Evidence from Immigrants to Canada
Douglas Almond, Lena Edlund, and Kevin Milligan
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October 2009, Revised October 2010
JEL No. F22,J13,J61,Z12

ABSTRACT

Sex ratios at birth are above the biologically normal level in a number of Asian countries, notably India and China. Standard explanations include poverty and a cultural emphasis on male offspring. We study Asian immigrants to Canada using Census data, focussing on sex ratios across generations and religious groups. We find sex ratios to be normal at first parity, but rising with parity if there were no previous son. Since these immigrants are neither poor nor live in a society tolerant of sex discrimination/sex selection, our findings are more consistent with a preference for sons per se (and not for sons as a means to, e.g., old age support). Additionally, we uncover strong differences by religious affiliation that align with historical differences in doctrine concerning infanticide. Comparing across generations of Asian immigrants, we find fertility responds strongly to the sex composition of older children for first generation families. For the second generation, expression of son preference through the fertility channel is muted whereas sex selection seems to persist.

Douglas Almond
Department of Economics
Columbia University
International Affairs Building, MC 3308
420 West 118th Street
New York, NY 10027
and NBER
da2152@columbia.edu

Kevin Milligan
Department of Economics
University of British Columbia
#997-1873 East Mall
Vancouver, B.C.
CANADA V6T1Z1
and NBER
kevin.milligan@ubc.ca

Lena Edlund
Department of Economics
Columbia University
1002A IAB, MC 3308
420 West 118th Street
New York, NY 10027
and NBER
le93@columbia.edu
Are there missing girls in the United States?
Evidence from birth data*

by Jason Abrevaya†

February 2008

ABSTRACT

Gender selection, manifested by unusually high percentages of male births, has spread in parts of Asia since the introduction of ultrasound technology. This paper provides the first empirical evidence consistent with the occurrence of gender selection within the United States. Analysis of comprehensive birth data shows unusually high boy-birth percentages after 1980 among later children (most notably third and fourth children) born to Chinese and Asian Indian mothers. Moreover, using maternally linked data from California, Asian Indian mothers are found to be significantly more likely both to have a terminated pregnancy and to give birth to a son when they have previously only given birth to girls.

*The author is grateful to Jan Christensen, Karl Halfman, and Roxana Killian of the CDHS for their assistance during the data-acquisition process. The California natality data used in this paper can not be released due to a confidentiality agreement with the California Department of Health Services (CDHS). The federal natality data and Census data used in this paper were obtained from the Inter-University Consortium for Political and Social Research (ICPSR) and the National Bureau of Economic Research (NBER). Ken Chay, David Hummels, Jeffrey Kubik, Steve Levitt, and seminar participants at Georgia, Purdue, Oklahoma, and Syracuse provided helpful comments. Jack Barron provided invaluable computer assistance. Dudley Poston, Jr. kindly provided data on Chinese and South Korean male-to-female birth ratios. This paper is a revised version of Abrevaya (2005), which was based on fewer years of birth data and inadvertently included multiple births (e.g., twins) in some of the empirical analysis.

†Address: Department of Economics, University of Texas at Austin, Austin, TX 78712; e-mail: abre­vaya@eco.utexas.edu.
Termination Rates After Prenatal Diagnosis of Down Syndrome, Spina Bifida, Anencephaly, and Turner and Klinefelter Syndromes: A Systematic Literature Review

Caroline Mansfield, Suellen Hopfer and Theresa M. Marteau* on behalf of a European Concerted Action: DADA (Decision-making After the Diagnosis of a fetal Abnormality)

INTRODUCTION

Many studies have been published documenting termination rates following the diagnosis of different types of fetal abnormalities, but these have most often been single studies from single countries, often from just one centre. While there do exist a number of population-based registers recording termination rates across geographical regions within a country (such as The Northern Region Congenital Malformations Register, in the UK) or across countries (such as EUROCAT) these data rarely are published, thus precluding unbiased ascertainment of all registers. There has, to our knowledge, been no attempt to summarize published findings systematically. Variability across conditions has been shown in published series from single centres (e.g. Pryde et al. (1993)). Such comparisons could be made, termination rates were similar in the 1990s to those reported in the 1980s.

KEY WORDS: Down syndrome; Klinefelter syndrome; spina bifida; anencephaly; Turner syndrome; prenatal diagnosis; termination

The aims of this systematic literature review are to estimate termination rates after prenatal diagnosis of one of five conditions: Down syndrome, spina bifida, anencephaly, and Turner and Klinefelter syndromes, and to determine the extent to which rates vary across conditions and with year of publication. Papers were included if they reported (i) numbers of prenatally diagnosed conditions that were terminated, (ii) at least five cases diagnosed with one of the five specified conditions, and (iii) were published between 1980 and 1998. 20 papers were found which met the inclusion criteria. Termination rates varied across conditions. They were highest following a prenatal diagnosis of Down syndrome (92 per cent; CI: 91 per cent to 93 per cent) and lowest following diagnosis of Klinefelter syndrome (58 per cent; CI: 50 per cent to 66 per cent). Where comparisons could be made, termination rates were similar in the 1990s to those reported in the 1980s.

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series, however, rarely provide sufficiently large sample sizes to enable reliable estimations of termination rates. Data pooled across studies could also be used to examine the extent to which termination rates for particular conditions may be changing over time.

The aims of this systematic literature review are to describe termination rates for five conditions: Down syndrome, spina bifida, anencephaly, and Turner and Klinefelter syndromes, and to determine the extent to which they vary across conditions and year of publication. The conditions were chosen to comprise the more common prenatally diagnosed conditions, and to reflect a range in terms of severity and type of disability, ranging from a lethal condition (anencephaly) to one compatible with an average life expectancy (Klinefelter syndrome). They also ranged in terms of public awareness of the condition, from conditions that much of the public are familiar with, such as Down syndrome, to ones that are largely unfamiliar, such as Klinefelter syndrome.

METHOD

Selection criteria

Papers were included in the systematic review if they met the following criteria:

(i) The number of women who had been diagnosed with a fetal abnormality and the number of these women who terminated their pregnancies were both reported.

(ii) The fetal abnormality was one of the following five: (i) Down syndrome; (ii) spina bifida, (iii) anencephaly; (iv) Turner syndrome or (v) Klinefelter syndrome.

(iii) A minimum of five cases involving a particular diagnosis were reported.

Search strategy

The following strategies were used:

(i) searching computerized databases of psychINFO, Medline and Bath Information and Data Services (BIDS) Embase using the following MeSH headings: abortion, prenatal diagnosis, chromosome abnormalities and neural tube defects;

(ii) references drawn from previously obtained papers;

(iii) consultation with health professionals in the UK, Europe and the US with known expertise in the area under review.

Data extraction

Data relating to termination rates were transferred onto a data extraction sheet. Agreement concerning termination rates was reached in all cases by two raters (CM and SH or TMM).

Statistical analyses

Chi-square tests were used to test for associations between termination rates and (i) condition diagnosed, and (ii) year of publication.

RESULTS

20 papers were identified which met the inclusion criteria. Details of each of these are presented in the Appendix. Altogether, these papers included 37 data sets from 11 different countries.

Condition

Termination rates varied across conditions (Chi square=269; df=4; p<0.0001). The largest proportion of pregnancies was terminated for Down syndrome; the smallest proportion of pregnancies was terminated for Klinefelter syndrome (Table 1).

Time

The number of papers published in each year was insufficient to allow analysis based upon annual rates. Rates in papers published in the 1980s were therefore compared with those published in the 1990s (Table 2). Statistical comparisons were not made for neural tube defects given that confidence intervals could not be calculated for this condition from papers published in the 1980s. For Down syndrome and Turner and Klinefelter syndromes there was no difference in the rates of termination in 1980 compared with series reported in the 1990s.

DISCUSSION

Termination rates varied across conditions. They were highest following a prenatal diagnosis of Down syndrome and lowest following diagnosis of Klinefelter syndrome. Where comparisons could be made, termination rates were similar in the 1990s compared with those reported in the 1980s.

Before discussing the possible explanations for these findings, it is necessary to consider what termination rates reflect. It seems likely that they reflect a myriad of factors which may differ for different conditions, including the way tests are initially offered and to whom. They will also reflect values of the women undergoing tests as well as those of the health professionals providing any counselling. Thus, high rates might reflect thorough counselling and systematic decision-making before a diagnostic test is undergone, with all those not inclined to terminate a pregnancy affected by the condition being tested for, declining...
### Table 1—Systematic literature review based on 20 studies of trisomy 21, spina bifida, anencephaly and sex chromosome anomalies

<table>
<thead>
<tr>
<th>Study number</th>
<th>Year of study</th>
<th>Total numbers terminating</th>
<th>Country</th>
<th>Total percentage terminating</th>
<th>Confidence intervals</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1998</td>
<td>4438/4824</td>
<td>UK</td>
<td>92%</td>
<td>92%-93%</td>
</tr>
<tr>
<td>3</td>
<td>1992</td>
<td>6/6</td>
<td>New Zealand</td>
<td>100%</td>
<td>-</td>
</tr>
<tr>
<td>10</td>
<td>1995</td>
<td>76/76</td>
<td>France</td>
<td>100%</td>
<td>-</td>
</tr>
<tr>
<td>13</td>
<td>1990</td>
<td>5/5</td>
<td>UK (NI)</td>
<td>100%</td>
<td>-</td>
</tr>
<tr>
<td>20</td>
<td>1992</td>
<td>4/5</td>
<td>Singapore</td>
<td>80%</td>
<td>62%-98%</td>
</tr>
<tr>
<td>2</td>
<td>1985</td>
<td>42/43</td>
<td>US</td>
<td>98%</td>
<td>96%-100%</td>
</tr>
<tr>
<td>19</td>
<td>1988</td>
<td>13/15</td>
<td>US</td>
<td>87%</td>
<td>76%-96%</td>
</tr>
<tr>
<td>17</td>
<td>1982</td>
<td>14/14</td>
<td>UK</td>
<td>100%</td>
<td>-</td>
</tr>
<tr>
<td>18</td>
<td>1990</td>
<td>20/28</td>
<td>France</td>
<td>71%</td>
<td>62%-80%</td>
</tr>
<tr>
<td>5</td>
<td>1980</td>
<td>18/19</td>
<td>US</td>
<td>95%</td>
<td>90%-100%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4636/5035</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Trisomy 21</td>
<td>7</td>
<td>1991</td>
<td>UK</td>
<td>61%</td>
<td>57%-65%</td>
</tr>
<tr>
<td>7</td>
<td>1991</td>
<td>16/208</td>
<td>Belgium</td>
<td>20%</td>
<td>2%-38%</td>
</tr>
<tr>
<td>7</td>
<td>1991</td>
<td>38/60</td>
<td>France</td>
<td>63%</td>
<td>53%-73%</td>
</tr>
<tr>
<td>7</td>
<td>1991</td>
<td>4/5</td>
<td>Italy</td>
<td>80%</td>
<td>62%-98%</td>
</tr>
<tr>
<td>11</td>
<td>1987</td>
<td>6/6</td>
<td>US</td>
<td>100%</td>
<td>-</td>
</tr>
<tr>
<td>15</td>
<td>1995</td>
<td>9/9</td>
<td>US</td>
<td>100%</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1317/204</td>
<td></td>
<td></td>
<td>61%-67%</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>7</td>
<td>1991</td>
<td>UK</td>
<td>78%</td>
<td>75%-81%</td>
</tr>
<tr>
<td>7</td>
<td>1991</td>
<td>15/16</td>
<td>Belgium</td>
<td>94%</td>
<td>88%-100%</td>
</tr>
<tr>
<td>7</td>
<td>1991</td>
<td>4/5</td>
<td>Denmark</td>
<td>80%</td>
<td>62%-98%</td>
</tr>
<tr>
<td>7</td>
<td>1991</td>
<td>9/16</td>
<td>Holland</td>
<td>56%</td>
<td>44%-68%</td>
</tr>
<tr>
<td>7</td>
<td>1991</td>
<td>82/87</td>
<td>France</td>
<td>94%</td>
<td>92%-97%</td>
</tr>
<tr>
<td>7</td>
<td>1991</td>
<td>15/15</td>
<td>Italy</td>
<td>100%</td>
<td>-</td>
</tr>
<tr>
<td>15</td>
<td>1995</td>
<td>18/18</td>
<td>US</td>
<td>100%</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td></td>
<td>30617/165</td>
<td></td>
<td></td>
<td>84%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>82%-86%</td>
</tr>
<tr>
<td>Anencephaly</td>
<td>4</td>
<td>1989</td>
<td>UK</td>
<td>71%</td>
<td>54%-88%</td>
</tr>
<tr>
<td>9</td>
<td>1987</td>
<td>6/6</td>
<td>UK and Finland</td>
<td>100%</td>
<td>-</td>
</tr>
<tr>
<td>16</td>
<td>1989</td>
<td>4/9</td>
<td>US</td>
<td>44%</td>
<td>27%-61%</td>
</tr>
<tr>
<td>19</td>
<td>1988</td>
<td>35/47</td>
<td>US</td>
<td>74%</td>
<td>68%-80%</td>
</tr>
<tr>
<td>8</td>
<td>1996</td>
<td>71/100</td>
<td>Denmark</td>
<td>71%</td>
<td>66%-76%</td>
</tr>
<tr>
<td>14</td>
<td>1984</td>
<td>5/7</td>
<td>Denmark</td>
<td>71%</td>
<td>54%-88%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1261176</td>
<td></td>
<td></td>
<td>72%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>69%-75%</td>
</tr>
<tr>
<td>Turner syndrome</td>
<td>2</td>
<td>1985</td>
<td>UK</td>
<td>63%</td>
<td>46%-80%</td>
</tr>
<tr>
<td>4</td>
<td>1989</td>
<td>4/11</td>
<td>UK</td>
<td>36%</td>
<td>22%-51%</td>
</tr>
<tr>
<td>9</td>
<td>1987</td>
<td>10/15</td>
<td>UK and Finland</td>
<td>67%</td>
<td>55%-79%</td>
</tr>
<tr>
<td>16</td>
<td>1989</td>
<td>34/75</td>
<td>US</td>
<td>45%</td>
<td>39%-51%</td>
</tr>
<tr>
<td>19</td>
<td>1988</td>
<td>3/5</td>
<td>US</td>
<td>60%</td>
<td>38%-82%</td>
</tr>
<tr>
<td>6</td>
<td>1982</td>
<td>3/5</td>
<td>Australia</td>
<td>60%</td>
<td>38%-82%</td>
</tr>
<tr>
<td>12</td>
<td>1984</td>
<td>23/25</td>
<td>Germany</td>
<td>92%</td>
<td>87%-97%</td>
</tr>
<tr>
<td>14</td>
<td>1984</td>
<td>9/12</td>
<td>Denmark</td>
<td>75%</td>
<td>63%-88%</td>
</tr>
</tbody>
</table>

*See Appendix.

Testing. Alternatively, they may reflect directive counselling from health professionals putting pressure on women to undergo a termination. Clearly the results of this review cannot address this. It is, however, important to avoid evaluating rates that are high or low as good or bad.

The results of this review confirm results from smaller series in showing that termination rates vary across conditions (Pryde et al., 1993; Drugan et al., 1990; Hassed et al., 1993). The high rates for Down syndrome reflect the negative attitudes towards giving birth to a child with serious cognitive impairments (Faden et al., 1987; Drake et al., 1996). The lower rates for Klinefelter syndrome reflect the greater tolerance for giving birth to a child with relatively minor physical and cognitive impairments and the fact that this is a chance finding. There is a greater range of severity amongst spina bifida and Turner syndrome than for Down and Klinefelter syndromes. As severity of these diagnoses was not reliably reported in published series, it is difficult to comment upon how terminations may reflect severity of the diagnosed condition. In addition
Table 2—Termination rates (95 per cent CI) following prenatal diagnosis by year of publication

<table>
<thead>
<tr>
<th>Year</th>
<th>Down Syndrome</th>
<th>Spina Bifida</th>
<th>Anencephaly</th>
<th>Turner Syndrome</th>
<th>Klinefelter Syndrome</th>
</tr>
</thead>
<tbody>
<tr>
<td>1980s (study numbers: 2, 4, 5, 6, 9, 11, 12, 14, 16, 17, 19)*</td>
<td>87/91</td>
<td>9/9</td>
<td>0/0</td>
<td>55/76</td>
<td>91/156</td>
</tr>
<tr>
<td>Termination rates (95 per cent CI)</td>
<td>96% (92–100%)</td>
<td>100%</td>
<td>0%</td>
<td>72% (62–82%)</td>
<td>58% (50–66%)</td>
</tr>
<tr>
<td>1990s (study numbers: 1, 3, 7, 8, 10, 13, 15, 18, 20)*</td>
<td>4549/4944</td>
<td>139/208</td>
<td>306/365</td>
<td>71/100</td>
<td>0/0</td>
</tr>
<tr>
<td>Termination rates (95 per cent CI)</td>
<td>92% (91–93%)</td>
<td>67% (61–73%)</td>
<td>84% (80–88%)</td>
<td>71% (62–80%)</td>
<td>0%</td>
</tr>
</tbody>
</table>

*See Appendix.

...to severity, many other factors seem to affect decisions about whether or not to continue with a pregnancy affected by a fetal abnormality (Marteau and Mansfield, 1998). These include timing of diagnosis as well as the information parents receive about the diagnosed condition.

The data in this review suggest that termination rates have remained stable over the past 18 years. Fears have been expressed that increasingly widespread prenatal testing for fetal abnormalities may result in a lower tolerance of disability resulting in higher termination rates (Stacey, 1996). The results of this review suggest that, over a relatively short time period, these fears may be unfounded.

The strength of conclusions that can be made on the basis of this review are weakened by the sample sizes both in relation to the number of series that have been published and the relatively small numbers of cases reported in many of the papers. This makes it difficult to determine how much variability there is in termination rates within conditions across different centres within the same country and across countries. The strength of conclusion is further weakened by little or no information being provided on the representativeness of the women included in the series of prenatal diagnoses. While acknowledging these weaknesses, this review provides good estimates of termination rates following the diagnosis of more commonly diagnosed conditions. More precise estimates and fuller explanations for these will come from publication of existing registers containing large unselected series of prenatal diagnosis and outcomes.

APPENDIX. STUDIES IN THE SYSTEMATIC REVIEW

2. Benn P, Hsu L, Carlson A, Tannenbaum H. 1985. The centralized prenatal genetics screening pro-
This work was conducted as part of a concerted action: Decision-Making After the Diagnosis of a Fetal Abnormality (DADA), funded from the BioMed II programme of the European Union. Theresa Marteau is supported by the Wellcome Trust.

REFERENCES


A Normal Life
By Lori Scheck

The morning is as hectic as ever. I am scrambling eggs and warming one of last night’s dinner rolls for my son’s breakfast. He is getting his shoes and socks on. It isn’t easy because he would rather be playing his video game. We have to be ready for school early this morning so we can review words for his spelling test one last time. After I help him clean his glasses (because he has a much higher tolerance level for smudge than I do) and comb his hair (because I happen to believe that a part should actually look like a straight line) he grabs his backpack, his snack and his water bottle, and rushes out to catch the school bus. My son is Stephen. He is 13 years old, he attends a local middle school and he has Down syndrome.

Stephen is the last of my husband’s and my four children, the first three being what we would consider “normal.” Having gone through the infant, toddler, elementary and middle school stages with our first three children, we had a pretty good idea of what they entail. What we experienced with our special needs child was very much the same as the first three. We laughed at his first smile and first giggles. He crawled like a GI Joe Army man for the longest time. We celebrated his first steps, first words, and first day in preschool. Yes, we had to wait longer for those accomplishments to come to pass, but they all did. In fact, the waiting made the accomplishment cause for greater celebration than with the first three kids. We learned to enjoy every little thing in his life. Our life with Stephen has been much more normal than it has been “special.”

I was 33 when Stephen was born, not yet the age where a mom is considered high risk for giving birth to a child with Down syndrome. Because I had enjoyed three healthy, successful pregnancies before, I had no doubt that this one would be the same. Thirteen years ago the AFP blood test, which is given early in the second trimester to try to discern the presence of birth defects, was fairly new and I did not know a lot about it. When offered the test I refused as I knew that, regardless of the outcome, I would continue the pregnancy and bring this child into the world. It wasn’t until after Stephen was born that the suggestion that our new baby had a disability was even presented to my husband and me. I was glad to have it that way. It removed pre-birth anxiety from my experience. It also allowed me to cope with the diagnosis as I cradled a beautiful baby in my arms... much easier than trying to cradle a test result and sonogram picture.

Our family has learned much from having Stephen in our world. Not only did we learn various terminologies and developmental strategies, we learned a lot about ourselves. If our kids are smart or beautiful, athletic or talented in some way, we tend to feel this enormous sense of pride--as though we had anything at all to do with them having those characteristics. The converse is true as well. If they are retarded or handicapped or in some way don’t measure up to the standard of our culture, then we feel embarrassment or shame. Both thoughts are ridiculous. Our children’s talents, abilities or disabilities are gifts from God. We have no control over such things. We do, however, have control over our attitude and response to these circumstances.
Our culture has created an environment where it’s okay to abort a child if he or she, for some reason, will not “measure up,” or will be hard to care for. Who sets the standard for whether or not someone is worth bringing into the world? I’ll be the first to tell you that special needs children are not the only ones who are hard work and sometimes bring frustration. My older children have done their fair share of that as well. All children, normal, handicapped, able and disabled, can be a source of joy and pride as well as heartache and frustration.

The medical profession is not a fortune teller. It cannot guarantee a child’s future outcome. Doctors may be able to tell you about the baby’s genetic code, but they cannot determine his character or happiness quotient. I wonder if the parents of young people who shoot their classmates at school would have chosen abortion if they could have known about their child’s outcome in advance. That’s part of the adventure of parenting. There are no guarantees.

When I hear about people who have aborted such a child because they didn’t want him to have to “live a life like that,” I am incredulous. How someone comes to the conclusion that not allowing a child to live at all is somehow better than living as a special needs child is beyond comprehension. Aborting a disabled child removes the option of looking at the glass as half empty or half full. Abortion takes the glass and heaves it over the side of a cliff while the pieces shatter on the rocks below. While it may eliminate the disappointment, sorrow and frustration, it also eliminates the hope, joy and pride of accomplishment that child can bring. What a travesty. What arrogance. What right do we have to destroy that little person because he doesn’t measure up to someone’s standard? If the choice were left up to the child, I am confident he or she would choose life. I know my son would.

Lori Scheck is the daughter of Beverly LaHaye, CWA’s founder and chairman.
Mr. Chairman and Members of the Committee –


Sex-Selection Prohibition

As you are aware, sex-selection abortion is an abortion performed for the purpose of eliminating an unborn child of an undesired sex – usually female. It is described by scholars and civil rights advocates as an act of gender-based violence. Obviously, there are strong public policy reasons for banning such gender-based violence.

First, prohibiting sex-selection abortion affirms our policy of nondiscrimination. It is undisputed that women are a vital part of our society, possessing the same inherent human and civil rights as men. Indeed, federal and state laws prohibit the dissimilar treatment of males and females who are similarly situated, as well as sex discrimination in various contexts, including the provision of employment, education, housing, health insurance coverage, and even athletics. Yet, similar protection is not currently afforded to unborn female children in North Dakota. Allowing sex-selection abortion reinforces sex discrimination and has no place in civilized society.

Second, prohibiting sex-selection abortion is necessary to eliminate the drastic affects such abortions have on society. In 2011, author Mara Hvistendahl (vis-тен-дahl) reported in her book, Unnatural Selection, that 163 million girls are missing in the world because of sex-selection abortions. The problem is so severe in some countries that, in 2005, the United Nations Population Fund termed the practice “female infanticide”.

Sex-selection abortion results in an unnatural sex-ratio imbalance. Experts-worldwide document that a significant sex-ratio imbalance in which males numerically predominate can be a cause of increased violence and militancy within society. Likewise, an unnatural sex-ratio imbalance gives rise to the commoditization of humans in the form of human trafficking, and consequential increases in kidnapping and other violent crime.

Third, Americans oppose sex-selection abortion. In a March 2006 Zogby International poll, 86 percent of Americans agreed that sex-selection abortion should be illegal. Likewise, the American medical community opposes sex-selection abortion. The American College of Obstetricians and Gynecologists (ACOG) has stated that sex selection abortion is inappropriate for family planning because sex-selection “ultimately supports sexist practices”. Likewise the American Society for Reproductive Medicine has stated that sex selection for family planning purposes is ethnically problematic, inappropriate, and should be discouraged.
Finally, the lack of legal protection in this area underscores the need for North Dakota to enact this prohibition. Currently, only four states - Arizona, Illinois, Oklahoma and Pennsylvania - maintain prohibitions on sex-selection abortion. Importantly, none of these laws have ever been challenged in court.

**Down Syndrome & Genetic Abnormalities**

Turning to the issue of abortion for Down syndrome or genetic abnormalities, I want to emphasize a few points.

Various studies have found that between 70 to 100 percent of unborn children diagnosed with Down syndrome or a genetic abnormality are aborted. These are devastating percentages as persons with Down syndrome contribute to our culture and are a valuable part of our society. Many persons with Down syndrome are able to obtain an education, maintain employment and live with varying degrees of independence. As technology advances and as medical treatments and educational methods improve, persons with Down syndrome will increasingly be self-dependent and productive citizens.

Likewise, persons born with genetic abnormalities contribute to American society and are a valuable part of our lives. There are 4,000 known genetic abnormalities and these abnormalities manifest in varying ways and degrees. Many persons with such abnormalities are able to support themselves financially, earn an education, or live independently. Further, as technology advances and educational methods improve, many will increasingly become self-dependent.

Most importantly, persons born with Down syndrome or genetic abnormalities possess the same fundamental – and inalienable – rights as all other human beings, but they are being disproportionately targeted in the womb – and oftentimes based on inaccurate medical data.

Like a ban on sex-selection abortion, a ban on abortion performed solely because a child has Down syndrome or a genetic abnormality affirms a policy of nondiscrimination. State and federal law prohibit discrimination against persons with Down syndrome or genetic abnormalities. Unfortunately, the same protection is not currently afforded to such persons before they are born. North Dakota’s policy of nondiscrimination will be advanced by prohibiting the abortion of children with Down syndrome or genetic abnormalities.

**Conclusion**

In conclusion, I would like to thank the committee for the privilege of testifying on behalf of this important bill. House Bill 1305 fulfills a vital societal goal – treating women and persons with disabilities with respect and dignity.

Thank you.
When you live with a chronically ill child, certain words and phrases become a permanent part of your lexicon. One of my least favorite is "quality of life", where we attempt to ascertain the value of another human's existence.

We heard that phrase for the first time in 1999, as we fought to stay pregnant with our tiny son. "Even if he's born alive," they said, "which is unlikely, he'll have no quality of life." The words were spoken kindly, by well-meaning people, but they were like a sledgehammer to my heart. What did it all mean? And what was going to happen to us, to our baby? 4 days later, hours past the "viable" mark, our 24 week baby was born alive. He was 1 lb, 5 oz, and he was very, very sick.

One night during his first week, they told us to go back to our hotel and wait. "We'll call you if, when it's time to say goodbye."

His tiny body was wracked with seizures, his brain a mass of blood and cerebrospinal fluid. We sobbed our way back to our room and lay fully clothed on the beds, waiting. We woke up that way the next morning and realized he had passed the test, he had lived through the impossible.

Upon arriving near his incubator, a doctor pulled us aside and strongly suggested that we "let him go." "You have to start thinking about quality of life," he told us, frustrated with our youth and our seeming naiveté. I remember feeling so small and shaken, standing in front of this man and his dire predictions, and hearing my husband say to him, "All I want is for him to be able to smile at me. That's all I want."

So we decided to hang on, to fight for that smile.

He's 13 now, and his smile is infectious. He celebrates every day. Our quality of life is immeasurably greater because of our little Richy. Some would argue that we should have let go, back in 1999. It's been an uphill battle, but it's been worth it. I'd let our little guy battle anyone's assertion that his life lacks quality, and he's nonverbal. His face says it all.

following 15 minute clip is from our radio interview on The Grayson Alex Show, where I tell a little bit more of our story.
Boy Now 11 Survives Doctor's Suggestion to Let Him Die | LifeNews.com

Listen to our excerpt from the Grayson Alex Show.

To listen to that episode in its entirety, go to the show's podcast.

LifeNews Note: Jess Clark divides her time between writing, breaking up fights over Buzz Lightyear, and traveling with a missionary rock and roll band. She and her husband Richy have 3 biological children and recently adopted their 4th. reprinted with permission from Bound4Life’s blog.

High school senior and member of the local varsity basketball team Matt Thorson had been more of a cheerleader than a player, but all that changed in one very special moment of a very special game.

Thorson was born with Down Syndrome, but his condition has never stopped him from reaching his goals. He's been involved with the Finley-Sharon/Hope-Page basketball team since grade school, and he's showed up for every practice and never missed a game since becoming a member of the team his freshman year.

On the varsity team, Thorson has always done more sitting then playing, and he's okay with that, but on February 1st with a 90 seconds left on the clock, Matt was put into the game.

"He missed his first to opportunities, and on his third try from about the middle of the court there -- right about the volley ball attack line -- he let one go and hit nothing but net," coach Rob Ressler recalls with pride. "The crowd went crazy."

Swish! 3 points, the first of Thorson's varsity career. It's a moment neither he nor his teammates nor their fans
A Normal Life

By Lori Scheck

The morning is as hectic as ever. I am scrambling eggs and warming one of last night’s dinner rolls for my son’s breakfast. He is getting his shoes and socks on. It isn’t easy because he would rather be playing his video game. We have to be ready for school early this morning so we can review words for his spelling test one last time. After I help him clean his glasses (because he has a much higher tolerance level for smudge than I do) and comb his hair (because I happen to believe that a part should actually look like a straight line) he grabs his backpack, his snack and his water bottle, and rushes out to catch the school bus. My son is Stephen. He is 13 years old, he attends a local middle school and he has Down syndrome.

Stephen is the last of my husband’s and my four children, the first three being what we would consider “normal.” Having gone through the infant, toddler, elementary and middle school stages with our first three children, we had a pretty good idea of what they entail. What we experienced with our special needs child was very much the same as the first three. We laughed at his first smile and first giggles. He crawled like a GI Joe Army man for the longest time. We celebrated his first steps, first words, and first day in preschool. Yes, we had to wait longer for those accomplishments to come to pass, but they all did. In fact, the waiting made the accomplishment cause for greater celebration than with the first three kids. We learned to enjoy every little thing in his life. Our life with Stephen has been much more normal than it has been “special.”

I was 33 when Stephen was born, not yet the age where a mom is considered high risk for giving birth to a child with Down syndrome. Because I had enjoyed three healthy, successful pregnancies before, I had no doubt that this one would be the same. Thirteen years ago the AFP blood test, which is given early in the second trimester to try to discern the presence of birth defects, was fairly new and I did not know a lot about it. When offered the test I refused as I knew that, regardless of the outcome, I would continue the pregnancy and bring this child into the world. It wasn’t until after Stephen was born that the suggestion that our new baby had a disability was even presented to my husband and me. I was glad to have it that way. It removed pre-birth anxiety from my experience. It also allowed me to cope with the diagnosis as I cradled a beautiful baby in my arms... much easier than trying to cradle a test result and sonogram picture.

Our family has learned much from having Stephen in our world. Not only did we learn various terminologies and developmental strategies, we learned a lot about ourselves. If our kids are smart or beautiful, athletic or talented in some way, we tend to feel this enormous sense of pride--as though we had anything at all to do with them having those characteristics. The converse is true as well. If they are retarded or handicapped or in some way don’t measure up to the standard of our culture, then we feel embarrassment or shame. Both thoughts are ridiculous. Our children’s talents, abilities or disabilities are gifts from God. We have no control over such things. We do, however, have control over our attitude and response to these circumstances.
Our culture has created an environment where it's okay to abort a child if he or she, for some reason, will not “measure up,” or will be hard to care for. Who sets the standard for whether or not someone is worth bringing into the world? I'll be the first to tell you that special needs children are not the only ones who are hard work and sometimes bring frustration. My older children have done their fair share of that as well. All children, normal, handicapped, able and disabled, can be a source of joy and pride as well as heartache and frustration.

The medical profession is not a fortune teller. It cannot guarantee a child’s future outcome. Doctors may be able to tell you about the baby’s genetic code, but they cannot determine his character or happiness quotient. I wonder if the parents of young people who shoot their classmates at school would have chosen abortion if they could have known about their child’s outcome in advance. That’s part of the adventure of parenting. There are no guarantees.

When I hear about people who have aborted such a child because they didn’t want him to have to “live a life like that,” I am incredulous. How someone comes to the conclusion that not allowing a child to live at all is somehow better than living as a special needs child is beyond comprehension. Aborting a disabled child removes the option of looking at the glass as half empty or half full. Abortion takes the glass and heaves it over the side of a cliff while the pieces shatter on the rocks below. While it may eliminate the disappointment, sorrow and frustration, it also eliminates the hope, joy and pride of accomplishment that child can bring. What a travesty. What arrogance. What right do we have to destroy that little person because he doesn’t measure up to someone’s standard? If the choice were left up to the child, I am confident he or she would choose life. I know my son would.

Lori Scheck is the daughter of Beverly LaHaye, CWA’s founder and chairman.
A few years back, Crystal Kelley was looking to enter into a surrogacy agreement. But when she finally found a family and promised to have the couple’s baby, she had no idea that legal drama and an epic battle over the morality of abortion would ensue.

In entering into the initial pregnancy agreement, Kelley’s motives were pure. Considering that she was an unemployed, single mother, she needed the $22,000 she would earn from being a surrogate. But Kelley was also hoping to help a family struggling with fertility issues. At the time, she was 29 and had suffered two miscarriages of her own. So — she could relate.

When Kelley finally found and then met with a couple in need from Vernon, Conn., she was impressed with the way they treated their three children. So, she agreed to have their fourth child. And as CNN notes, the story started out quite favorably:

The couple had conceived their children through in-vitro fertilization and had two frozen embryos left over. Doctors thawed them out and on October 8, 2011, put them in Kelley’s uterus.

About 10 days later, a blood test showed she was pregnant — one of the embryos had taken.

Kelley and the parents were thrilled, and over the next few weeks, the mother was attentive and caring. When Kelley had morning sickness the mother called every day to see how she was feeling. She gave Kelley and Kelley’s daughters Christmas presents. When Kelley couldn’t make rent, the mother made sure she got her monthly surrogate fee a few days early.

But the situation changed after Kelley had a routine ultrasound around the five-month point and medical professionals struggled to see the baby’s heartbeat. After having a more robust examination, the surrogate received a frantic phone call from the mother who was paying her to have the child.

“There’s something wrong with the baby. What are we going to do?” Kelley recalled the woman telling her in an interview with CNN. “She was frantic. She was panicking.

Later, Kelley heard more details from the midwife — that the child’s ultrasound showed a cyst on her brain, a serious heart defect and a cleft lip and palate. Doctors were also not able to see a stomach or spleen. Follow-up appointments exposed severe health issues that would require surgeries and a plethora of medical attention once the child was born.

Kelley remembers doctors saying that the child would only have about a 25 percent chance of having a normal life.

Here’s where the situation became contentious. The family decided that termination would be best, but Kelley fervently disagreed. As the two parties discussed the horrific situation, the family begged her to reconsider her view that the pregnancy should continue.

“They were both visibly upset. The mother was crying,” Kelley recalled in her CNN interview. “They said they didn’t want to bring a baby into the world only for that child to suffer...They said I should try to be God-like and have mercy on the child and let her go.”
She remembers delivering a pointed response to the family.

“I told them that they had chosen me to carry and protect this child, and that was exactly what I was going to do,” Kelley continued. “I told them it wasn’t their decision to play God.”

What happened next can only be described in one word: Chaos.

Rita Kron, a representative at Surrogacy International, told Kelley that the parents were refusing to be the legal guardians if the surrogate decided to continue on with the pregnancy. The family then offered up $10,000 if Kelley was willing to abort the baby. She was faced with a tough decision, as she didn’t want another child of her own.

Surrogate Crystal Kelley (Photo Credit: CNN)

The surrogate, in a weak moment, almost considered the parents’ offer. She was desperate for money and countered at $15,000, almost immediately regretting doing so. Kelley had always been against abortion and, despite the family’s later refusal to pay that increased sum, she decided she couldn’t have gone through with it anyway.

CNN recaps what happened next, as the family resorted to legal avenues to try and prevent the pregnancy from concluding:

On February 22, 2012, six days after the fateful ultrasound, Kelley received a letter. The parents had hired a lawyer.

“You are obligated to terminate this pregnancy immediately,” wrote Douglas Fishman, an attorney in West Hartford, Connecticut. “You have squandered precious time.”

On March 5, Kelley would be 24 weeks pregnant, and after that, she couldn’t legally abort the pregnancy, he said.

TIME IS OF THE ESSENCE,” he wrote.

Fishman reminded Kelley that she’d signed a contract, agreeing to “abortion in case of severe fetus abnormality.” The contract did not define what constituted such an abnormality.

Kelley decided she needed a lawyer and after getting advice, she was told that she wasn’t legally bound to have an abortion. But the problems didn’t end there; they intensified. When it was evident that she wasn’t willing to abort, the family said that it would assert its right to take the baby after birth and immediately put her into Connecticut’s foster care system.

Unable to imagine such a scenario for the child, Kelley worked with her lawyer and found a loophole. If she moved to Michigan, she would escape Connecticut law that viewed the birth parents as the rightful guardians; in Michigan, she would be considered the baby’s mother. So, in April, at seven months, she left with her daughters to live in Ann Arbor.

“Once I realized that I was going to be the only person really fighting for her, that Mama bear instinct kicked in, and there was no way I was giving up without a fight,” Kelley told CNN.

In addition to the laws that protected her and designated her the parent, Kelley also chose the state because of its stellar medical care. After researching the baby’s condition, she found that the C.S. Mott Children’s Hospital at the University of Michigan had an excellent pediatric heart program.
The single mother inevitably decided, though she had an urge to keep the child, that the baby would be better off in someone else's care. She found a couple to adopt, but, alas, the legal drama continued. Despite not hearing from the biological parents in quite some time, Kelley found out that they had filed in the Connecticut Superior Court asking that they have their names printed on the baby's birth certificate.

They also dropped a bombshell — that the mother's eggs weren't used and that an anonymous egg donor offered up the real maternal DNA (this further complicated the case). When the child was born on June 25, the battle over who would be considered the parent continued, CNN reports.

In the end, a deal was struck and the family allowed the child to be adopted so long as they were permitted to visit her. The request was granted and they have since seen the child.

While her health problems were more severe than previously expected, the baby (known as Baby S.) is seen as a blessing to the family that adopted her. She has a long road ahead of her and she may not survive required surgeries. And even if she does, there's a 50 percent chance she won't walk or talk or use her hands normally. But the adoptive family showers her with love.

“S. wakes up every single morning with an infectious smile. She greets her world with a constant sense of enthusiasm,” the adoptive mother told CNN via email. “Ultimately, we hold onto a faith that in providing S. with love, opportunity, encouragement, she will be the one to show us what is possible for her life and what she is capable of achieving.”

As for Kelley, she has her supporters and detractors. While some hail her as a hero, others see her as a villain who carried on with a pregnancy that they believe should have been terminated. What do you think? Read the entire story here and let us know in the comments section.

(H/T: CNN)
Brave Mother Refuses Doctors’ Advice to Abort Her Baby — And Here’s What Happened Next

Feb. 15, 2013 12:00pm Billy Hallowell

Coming on the heels of this week’s horrifically tragic death of a New York woman who suffered a ruptured uterus following a late-term abortion, there’s an inspirational story to share — one that, ironically, also involves abortion. In 2011, doctors told Jade Clarke of Yorkshire, England, that her baby wouldn’t survive if she continued with her pregnancy. But rather than complying with medical professionals’ advice that she terminate, she forged on.

After she delivered the child, a baby boy named Riley, doctors soon realized that their assessments were wrong. But despite the infant’s survival, the road hasn’t been easy. He spent the majority of his first 17 months in the hospital, with doctors this week finally permitting him to go home with Jade and the baby’s father, Rikki. While he was born in Sept. 2011 and went home a few weeks after his birth, Riley returned to receive medical care in December of that year and received in-patient medical care until this past Wednesday.

In addition to being born with his heart on the wrong side of his body, the child also had disconnected valves and twisted bowels, the Daily Mail reports. But his 22-year-old mother, determined to keep the child, battled alongside doctors to save her son’s life.

"Doctors told me time and time again that Riley would have no chance, and I should consider an abortion," Jade said. "But he’s an angel sent from above. He’s my first child and I just felt I wanted to keep him."

Even though he’s been released by the hospital, Riley continues to have health challenges. Doctors claim he may never walk; he has a tracheostomy that is attached to a ventilator and a kidney that is not properly formed.

Jade and Rikki are full-time caretakers for the child, but despite the hurdles they are overjoyed that he is now home and that they will have more time to spend with him.

“He’s such a happy chappy. He loves Tigger from Winnie the Pooh and is always bouncing about,” she said, going on to say that the challenges are entirely worth it. “He needs watching constantly as sometimes he tries to pull out his tubes. It’s challenging but I wouldn’t have it any other way.”

(HIT: Daily Mail)
Abortion Death Shows Women Pressured to Abort Disabled Babies

by Micaiah Bilger | LifeNews.com | 2/20/13 2:23 PM

The tragic abortion death of Jennifer Morbelli and her 8-month-old baby girl has brought new attention to the issue of aborting babies with disabilities.

According to reports, Morbelli and her husband were looking forward to the birth of their baby girl. Then, doctors discovered problems with the baby's brain. The couple decided to have a late-term abortion. Sadly, both mother and child died as a result of the procedure.

While we don't know the details about the Morbelli family's situation, we do know that many families feel pressured into having abortions when their baby has a disability.

Peter Saunders, a pro-life doctor from the UK, relates the concerns he heard from families and advocates during a government inquiry about abortion and people with disabilities:

"First, there seemed to be very little support or information available for families who wanted to keep their babies, as opposed to having them aborted.

"Second, there was a strong presumption from doctors that parents with disabled children would choose to have them aborted.

"Third, there was a huge amount of subtle or direct pressure placed on parents who decided not to abort. They were repeatedly asked to reconsider their decisions and treated like pariahs -- in short they were discriminated against."

Fortunately, many parents are now sharing their stories about raising a child with a disability and encouraging others to do the same. Check out some of their stories:

• Doctors said Riley had no chance of survival and urged his parents to abort him. They refused. Riley was born with several serious medical issues, but he fought for his life. Read the rest of his incredible story here.
• Adeline was given a one-in-ten chance of surviving birth after being diagnosed with multiple birth defects. After her parents were pressured by doctors to abort her, they decided to get a second opinion. Find out what happened [here](http://www.lifenews.com/2013/02/20/abortion-death-shows-women-p...).
• Benedict lived for only 24 hours after he was born. But his mother made the most of the short time she had to spend with him. Read more [here](#).
• Chloe was born with Down Syndrome in 2003. Today, she and her dad are on a mission to teach the world about the abilities of people with Down Syndrome. Read more [here](#) about her incredible life.

These stories remind us of why there is always a reason to choose life!
Chairman Hogue and Honorable Members of the Senate Judiciary Committee, my name is Bill Schuh,
and I am here as the father of an adult disabled person to testify in favor of House Bill 1305. I am also
a member of the Board of Directors of Housing Industry Training (HIT), which is a major provider of
services to the disabled in this area, although I hasten to point out that I do not, in my testimony,
represent that Board or the Organization, neither of which have a position on this bill.

I ask you to vote Do Pass on this bill. HB 1305, in essence, forbids the practice of using genetic testing
as a screening procedure for abortion on the basis of sex or or genetically defined disability.

One of the most dangerous human traits is our infinite ability to rationalize our own self interest when
confronted with situations that may cause us perceived or feared inconvenience, or hardship. For this
reason, to subject the definition and the protection of human life to a vague and sliding scale, subject to
change based on human emotion, is a grave danger to any civilized society. History has shown that it
is easy to ignore or even define away the humanity of others when they are inconvenient. It's even
easier when the inconvenient people are silent or powerless and cannot resist their extermination.

My daughter, Ann Marie, has Down Syndrome. She is 26 years old. She lives with her parents and
helps in the home, she works at a motel making beds and she peels potatoes for institutions. She is
good at what she does, she loves doing it, and she is proud. Annie has always been a source of love
and happiness for all who have known her, her family, teachers, coaches, coworkers, and fellow
students. Ann has aspirations like anyone else. She loves life, she values her privileges, and takes
pride in her work, and she fears injury and death. Annie is simply a person with her own unique traits —
like all of us.

Not long ago my sister, who has worked for 35 years as an intensive care and oncology nurse at
Minneapolis Children's hospital, was introduced to a staff child development expert who works with
disabled children. Marianne commented on what a joy it must be to work with Down children. The
person bitterly replied, “what are you talking about. There aren't any more Down children. They
kill them all in the womb.”

The Annies are now being systematically exterminated before birth. A recent paper published in
the journal "Prenatal Diagnosis, Vol. 18, Issue 9, pages 808-812 (1999) reviewing the literature on
termination rates of pregnancies for various genetic traits detected using prenatal testing, reported that
91 to 93% of all Down babies detected are destroyed in their mothers' wombs. Numbers differed for
other traits, like spina bifida and Turner's Syndrome. The lowest was Klinefelter syndrome, with a
destruction rate of about 58%. Klinefelter syndrome, which is the male chromosomal equivalent of
Down syndrome, involves mainly some peculiarities of body shape, and not necessarily abnormal
intellectual traits. Now it was one thing, and bad enough, that a mother, out of fear and with state
sanction and lack of loving support, destroy the child in her womb. But it is another dangerous and
socially degrading step, that in a perverse and further dehumanizing twist the medical profession has
turned its genetic testing ability to the task of providing a quality product through the detection and
cold and rational liquidation of those having undesirable traits. In doing so we have crossed the border
into eugenics, and have entered a territory that in other contexts has already in the last century cost the
lives of millions already born. Selective killing of the undesirable – by race, by disability, by gender is
not new.

The ramifications of the test, select and slaughter mentality extend beyond the destruction of the child,
into the destruction of families. The use of prenatal testing to screen and destroy the child based on his
or her genetic traits, creates an unreasonable fear for those who have not experienced the love and
uniqueness of these special people. But now picture a young couple, a mother who wants more than
anything to bear her child being pressured into an abortion by a frightened husband, or a father whose
every instinct is to protect his child, helpless to stop his frightened wife from destroying the child.
Now picture disrespect and bitterness, a broken marriage, and perhaps the effects of that bitterness, or
that divorce on other children in the family, and on society. I know what I'm talking about here. I
know what it means to be confronted with the reality of a child we did not expect. I know what it
means to be afraid. But I also know about the love and special gifts that these people, and they are
people, bring.

I know that for those faced with these challenges there is plenty of support. A previous objection to
this bill is that parents would voluntarily bear these children if there were sufficient government
funding to help meet the needs of these children. Nonsense. There is free early childhood education,
parental support groups, social security disability support, medicaid support, home visit support,
excellent special education programs in our schools, adult training, work and support programs like
Pride Inc. and HIT, volunteer athletic programs like special olympics which do a wonderful job, and we
are even offered free supervision for the opportunity to have a night out. The reason is not money. It is
fear. We all fear the unknown, and we all find a change in our life's plans inconvenient. But the option
to select and kill to maintain those plans is a social tragedy that stains our state and our nation.

Finally, healthy societies need the representation of many human traits. Narrow selection of human
traits determined by preference can cause severe imbalances and strange and harmful social
configurations. In societies like China, which have forced abortion to limit population, preference for
males has caused the murder and abandonment of girl babies, which eventually has caused an
imbalance in the male to female ratio. This, in turn, has caused a situation in which young man cannot
find brides – one of the most simple of human needs. Again, in turn, this has caused kidnapping and
trafficking in women – more abuse of women. One need not have the tyranny of forced abortion to
create skewed societies. It is very possible for a society that has arrogated the right and ability to
"screen and glean" human beings as a matter of individual choice to twist itself into a sorrowful mess.

Test, select and slaughter by gender or by traits classified as abnormalities, if it is allowed, is only
the beginning of the eugenic selection that will evolve with growing genetic knowledge if it is
allowed to take hold. The criteria of selection, and the limitations of who will be allowed to
survive gestation, can be expected to expand as detection of genetic traits expands, and the
"shopping cart" mentality toward children, the belief that a child is a property for me to "have"
is legally sanctioned. Selective eugenics is a social poison, and a virtual pandora's box, that should
not be opened.
I would point out to the committee that medical science, for all the wonderful benefits it has bestowed upon human society, has not had an uncheckered ethical track record; that medical personnel, as such, are neither more nor less moral or ethical – or wise than others; and that without appropriate checks and limitations the profession has had its share of disastrous ethical failures, some of which which I could, but will not here enumerate. The more recent assertion of the right to test, select and slaughter is one of those failures. It is not unreasonable that the people of this state, in protecting human life, expect that the medical profession practice its skills without deliberate killing. I would urge the committee and the Senate to protect all human life from deliberate unjust killing, and to reject any amendment that would allow the slaughter of unborn human beings simply for the purpose of selecting what they or someone else, thinks to be a better product.

Please vote Do Pass on House Bill 1305
Mr. Chairman and honorable members of the committee, thank you for giving me the opportunity to testify before you today. My name is Anna Higgins. I am the Director of the Center for Human Dignity at the Family Research Council, a Christian public policy organization that since 1983 has promoted and defended human life, religious liberty, and family values in the United States. We represent more than 1.5 million people from Evangelical, Catholic, and other Christian denominations around the country. I speak today as a representative of Americans who support the sanctity of all human life, no matter the stage of development. Fundamentally, we believe that life begins at conception and that this life is worthy of respect and equality under the law.

**Humanity of the Unborn:**

The denial of basic human rights of the unborn has become an indefensible position. It is indisputable that an unborn child is a unique person from conception to birth. It is a foundational principle of western thought that life is a fundamental right given to all men by their Creator. It was this principle that guided our founding fathers to declare in our country’s first foundational document, that all men are created equal and endowed by their Creator with unalienable rights, among which, predominant is the right to life. Liberty and the pursuit of happiness are of no consequence unless a person is first
afforded the most fundamental of all rights, life. As Thomas Jefferson noted, "The God that gave us life, gave us liberty at the same time."

Previous to Roe v. Wade, the most egregious violation of civil rights handed down by the Supreme Court was Dred Scott v. Sanford in which the Court determined that a slave was not a person but rather property. This decision was rectified by the 14th amendment which guaranteed due process and equal protection to all persons. This rights of due process and equal protection are violated when groups of people are singled out for disparate treatment based on inherent qualities like race, gender and disability.

**Discrimination:**

Sex selective abortion and abortion for reasons of genetic abnormality single out a specific demographic to be discriminated against based solely on inherent characteristics. It is illegal to discriminate against a person based on gender and disability outside the womb. Additionally, pre-born humans are protected by myriad of civil and criminal state laws. Thus, it follows that the prohibition on discrimination should be applied to pre-born persons as well.

**Sex Selection:**

The vast majority of sex selective abortions are performed on females due to preference for male children in many cultures. For example, there are 117 boys born for every 100 girls born in China because of this idea of "son preference," according to Women’s Rights Without Frontiers. This practice has been rightly condemned by United Nations

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and United States officials; however, the act of gender selective abortion is also practiced in the United States. Recently the non-profit pro-life group, Live Action exposed the hidden gendercide agenda in the abortion industry by conducting a sting operation in which they recorded various abortion clinic workers expressing support for gender-based abortion.

"The Supreme Court has made it clear that States have a compelling interest in eliminating discrimination against women and minorities." Additionally the Casey Court in upholding Roe made it clear that States have an interest in protecting the life and health of the mother and fetus from the outset of pregnancy. Thus, it is reasonable for the State of North Dakota to implement a regulation that protects a certain class of citizens from discrimination based on gender.

**Genetic Abnormalities:**

The Americans With Disabilities Act (ADA), enacted in 1990, is a civil rights law that prohibits discrimination against persons with a disability defined as, "...a physical or

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3 Steven H. Aden, Vice President/Senior Counsel, Human Life Issues, Alliance Defense Fund. Hearing of the House Judiciary Committee, Subcommittee on the Constitution Regarding H.R. 3541, the Prenatal Nondiscrimination Act, December 6, 2011, “In 2008, researchers Douglas Almond and Lena Edlund of Columbia University analyzed year-2000 census data to document male-biased sex ratios among U.S.-born children of certain Asian and South Asian populations. These researchers concluded that the demonstrated deviation from the norm in favor of sons was “evidence of sex selection, most likely at the prenatal stage.” This “Son Preference” was true regardless of the absence in the United States of many factors used to rationalize son bias in other countries (e.g., high dowry payments, patrilocal marriage patterns, and China’s one-child policy) and was irrespective of the mother’s citizenship status; “[i]f anything,” they noted, “mothers with citizenship had more male-biased offspring sex ratios,” although the difference was not considered statistically significant." (footnotes omitted).

4 http://www.liveaction.org/.

5 Id., citing, See, e.g., Roberts v. United States Jaycees, 468 U.S. 609 (1984); Board of Directors of Rotary Intern. v. Rotary Club of Duarte, 481 U.S. 537 (1987); Miller v. Johnson, 515 U.S. 900, 920 (1995) ("There is a ‘significant state interest in eradicating the effects of past racial discrimination.’").

6 505 U.S. at 846.
mental impairment that substantially limits a major life activity." However, pre-born persons with disabilities enjoy no such protections. For example, persons with Down Syndrome are rightly protected against discrimination in areas like employment, public accommodation, and transportation. However, over 90% of children diagnosed with Down Syndrome prior to birth are aborted.\footnote{http://abcnews.go.com/Health/w_ParentingResource/down-syndrome-births-drop-us-women-abort/story?id=8960803} This statistic is appalling. One way to ensure that persons with disabilities are truly treated equally in our society is to protect them in the womb as well as outside the womb. Allowing discrimination against those with disabilities inside the womb while protecting those outside the womb is arbitrarily prejudicial.

Again, the legal standard for this protection is the fact that the State has an interest in protecting life from the outset of pregnancy. Requiring that the same laws that protect people from gender, race and disability discrimination after birth are applied pre-birth is commonsense. These abortions are purely elective and involve no threat to the life or health of the mother. The restrictions do not place an undue burden in the path of the mother because they are based on common practices of anti-discrimination policy.

**Conclusion:**

Whereas after birth, a person is protected from discrimination based on gender, race, and disability, legal abortion and the denial of basic protections to human beings at very early stages of development asks us to discriminate against a person based on his gender and disability status prior to birth is indefensible. This position is incompatible with a Constitution and a society that places such high value on the rights of an individual. It is
particularly troubling to deny these rights to those persons who do not have a way to speak for themselves but rather rely on those in power for protection.

As President Obama recently reminded us, "This is our first task, caring for our children. It's our first job. If we don't get that right, we don't get anything right. That's how, as a society, we will be judged." A law that protects pre-born minorities and those who have been exposed to historical discrimination is an appropriate and humane course for any state to take.
March 12, 2013

Mr. Chairman and members of the committee, my name is Janne Myrdal, and I am the State Director for Concerned Women for America (CWA) of North Dakota. CWA is the largest public policy women’s organization in the nation. We are here today on behalf of our North Dakota members, in support of this Prenatal Non-discrimination Act, HB1305.

Information that will shed greater understanding on the need for this legislation:
There are over 160 million “missing girls” in the world who were killed simply because they were girls. Condoning sex-selection abortion is discrimination, because it gives credence to the idea that women are less valuable than men. According to a 2006 Zogby poll, sex-selection abortions are opposed by over 86 percent of Americans. I would wager that number is even higher here in North Dakota. Condoning sex-selection abortions feeds into the idea that women are less valuable than men and are objects to be tossed aside. Sex-selection abortions have had devastating societal consequences around the world, consequences which could impact the country’s stability, as a lack of girl children leads to an increase in kidnapping and sex trafficking. Sadly, sex-selection abortions aren’t just a problem for other countries, they happen every day here in America. Pure and simple, these abortions are eugenics. It is astounding that in a country that prohibits discrimination on the basis of sex in various contexts, such as employment, education, and housing, it is legal to abort a child because she’s/he’s a girl or a boy.

(Because of gendercide, there are now approximately 37 million more males living in China than women. However, this is not an issue that only impacts countries like China. Sex-selection abortions are occurring here in the United States. According to a University of California Berkeley study which looked at 2000 Census data, there was a male bias, especially for third children, of U.S.–born children of Chinese, Korean, and Indian parents.)

Abortion on the basis of the unborn baby’s gender is a problem recently highlighted by undercover videos released by Live Action showing a Planned Parenthood clinic staff member instructing a woman on how to obtain a late-term sex-selective abortion.

Every child deserves the right to live, regardless of its sex or genetic abnormalities or a potential genetic abnormality. Our Founding Fathers clearly delineated the right to life as one that is unalienable and endowed by our Creator. It is horrific that in America today babies are being killed on the basis of their sex or genetic abnormalities, or potential abnormalities.
An estimated 90 percent of pregnant women who are told that they may be carrying a child with Down syndrome choose to abort the baby. (This shocking statistic caused Concerned Women for America [CWA] to develop an educational brochure for expectant mothers and fathers. The brochure offers encouragement, a positive perspective, and a list of resources and support groups to help families learn more about their baby’s opportunities. The brochure is available in English and Spanish and widely distributed at Ob/Gyn offices around the nation.)

When tests indicate the possibility of Down syndrome or other genetic disabilities, some physicians will place pressure on a pregnant woman to have an abortion. Many expectant parents feel overwhelmed by such a prenatal diagnosis and may not understand that the test results can be inaccurate. They also may not understand the many opportunities and resources available today. The result is a 90 percent abortion rate often based on lack of information, a lack of connecting with the excellent support services that are available, and/or outright pressure to abort.

Some physicians and patients have outdated information regarding what life holds for a child with Down syndrome in the 21st century. Advances in medical technology have led to better management and understanding of Down syndrome or other genetic abnormalities, and many individuals with these diagnoses lead productive lives with rewarding personal relationships.

The National Down Syndrome Society explains, "Down syndrome occurs in one out of every 733 live births, and more than 350,000 people in the U.S. have this genetic condition. One of the most frequently occurring chromosomal abnormalities, Down syndrome affects people of all ages, races and economic levels. Today, individuals with Down syndrome are active participants in the educational, vocational, social and recreational aspects of our communities. In fact, there are more opportunities than ever before for individuals with Down syndrome to develop their abilities, discover their talents and realize their dreams."

It’s a gross abuse of technology to allow parents to be able to kill their babies on the basis of sex or genetic abnormalities or a potential genetic abnormality. At the present time, America is the only advanced country that does not restrict sex-selection through law, and that must end today. Let’s send a clear message from North Dakota that we will stand for the rights of all unborn children.

CWA of North Dakota strongly urges you to support HB1305 with a “Do Pass” vote.
Recent Congressional statements on similar legislation:

Franks (R-Arizona) stated:

"I am heartened that so many of my colleagues came together to, in an overwhelming majority, support the Prenatal Non-Discrimination Act. Though it did not secure the two-thirds majority necessary to pass under suspension rules, I am confident that this is not the end, but merely the opening salvo in ensuring the words, 'it's a girl,' are no longer a death sentence for so many unborn girls.

"I also note the sad and bitter irony that President Obama, who has disingenuously accused Republicans of a so-called 'war on women,' mustered a truly breathtaking display of hypocrisy in opposing a bill that would prevent aborting those little babies who have the 'nerve' to be little girls.

"Indeed, the same Democrats who are so frequently heralded as 'progressives' today refused to make the United States the very last civilized nation on Earth to outlaw aborting a little girl simply for being a little girl, even as the human family on Earth is today missing 200 million baby girls, thanks to the grisly practice the majority of my colleagues across the aisle couldn't find it in their hearts to condemn."

Congressman Chris Smith (R-New Jersey) stated:

"It is a sad day in America when the President of the United States endorses sex-selection abortion by opposing the Franks bill to outlaw this egregious assault on baby girls. Sex-selection abortion is cruel, it’s discriminatory, and it’s legal. It is violence against women. Most people in government are unaware that it is part of a deliberate plan of population control. This is the real war on women."

Congressman Mike Kelly (R-Pennsylvania) stated:

"The House’s failure to pass a federal ban against sex-selection abortion is a sad day for America and a frightening one for girls and women," said Rep. Kelly. "If ever there were a war on women in this country, the practice of sex-selection abortion would be the ultimate pre-emptive strike, taking the lives of innocent baby girls simply because they are girls and not boys. That’s the most reprehensible form of gender discrimination imaginable, and it’s a crime against girls and humanity that needs to be stopped."

Congressman Diane Black (R-Tennessee) stated:

"Aborting a baby based upon their gender undermines one of our nation's founding principles that all human beings are created equal. United States law currently prohibits discrimination on the basis of gender. Abortion should be no exception. Victims of sex selection abortions are overwhelmingly female. This is a growing problem that needs to be addressed."
Congressman Steve Chabot (R-Ohio) stated:

"I am proud to cast my vote for the most innocent among us, the unborn children. I am sickened by the thought of parents aborting a child because of its sex, and I will do everything in my power to defend those who cannot defend themselves. Sex-selective abortions are becoming an international problem with terrible repercussions, and we must stop the discrimination from happening here in America. The laws of our country go to great lengths to protect individuals from discrimination and unborn children cannot be abandoned."

Congressman Jean Schmidt (R-Ohio) stated:

"I'm disappointed. This is a bill that basically is about sex selection for abortion. Abortion is wrong at any level, but to condone someone wanting to end a life based solely on the sex of their child is horrendous. This is an assault on women. This is gendercide."

Lila Rose, founder and president of Live Action, also issued the following statement:

"We applaud the brave leaders in Congress such as Rep. Trent Franks for leading the charge against the abhorrent practice of sex-selective abortion. The struggle to stop gendercide is a bipartisan issue—more Democrats voted in support of the ban than Republicans against—but the battle is far from over. We will continue to release the results of our national investigation into Planned Parenthood and other U.S. providers that are facilitating the brutal and lethal discrimination against girls in the womb. The public deserves to see the truth about how Planned Parenthood and their abortion industry allies, backed by the President, facilitate the late term targeting of girls, especially as we approach a historic election."

Penny Young Nance, Chief Executive Officer and President for Concerned Women for America, stated:

"This is the ultimate violence against women. There are more than 160 million 'missing girls' in the world, 'missing' because they were killed for one reason — they were girls. Condoning sex-selection abortions feeds into the idea that women are less valuable than men and are objects to be tossed aside. According to a 2006 Zogby poll, sex-selection abortions are opposed by more than 86 percent of Americans. Because of gendercide, there are now approximately 37 million more males living in China than women. Sex-selection abortions have devastating societal consequences which could impact the country's stability, such as increased kidnapping and sex trafficking. Sadly, sex-selection abortions aren't just a problem for other countries, they happen every day here in America. Every child deserves the right to live, regardless of its sex. Our Founding Fathers clearly delineated the right to life as one that is unalienable and endowed by our Creator. It is horrific that in America today babies are being killed on the basis of their sex or race"
Marjorie Dannenfelser, President of the nationwide pro-life group Susan B. Anthony List.

“Today President Obama and 168 absolutist members of Congress chose to stand with the abortion lobby rather than defend women from the lethal discrimination of sex-selective abortion. It strikes me as grossly hypocritical that President Obama and his allies lament the so-called ‘War on Women,’ and yet fail to defend those women most in need – unborn daughters and the mothers coerced into sex-selective abortion. Our President and the leaders of his party are now on the record as being diametrically opposed to an overwhelming majority – 80 percent – of American women who support a ban on sex-selective abortion. The SBA List plans to ensure that come November, women will remember who failed to stand up for them.”

Douglas Johnson, Legislative Director for National Right to Life Committee, stated

“We are heartened that a strong majority of House members voted to ban performing or coercing abortions for the purpose of eliminating unborn babies of an undesired sex – usually, girls. Shamefully, President Obama, and a minority of 168 House members, complied with the political demands of pro-abortion pressure groups, rather than defend the coerced women, and their unborn daughters, who are victimized by sex-selection abortions. We commend the House Republican leadership for bringing this bill to the floor today under the fast-track procedure. Today’s groundbreaking majority vote was a stepping stone to this bill ultimately becoming law – perhaps after the replacement of some of the lawmakers who today were unwilling to protect victimized women and their unborn daughters from sex-selection abortions, because they were more concerned with maintaining favor with the abortion industry, pro-abortion advocacy groups, and Hollywood donors.”
To the Distinguished Chair, Ranking Member and Honored Members of the Committee.

I am a cell biologist, currently working for a think tank in Washington, D.C. and as an adjunct professor at a local university. Previously I spent 20 years as Professor of Life Sciences at Indiana State University and Adjunct Professor of Medical & Molecular Genetics at Indiana University School of Medicine. Prior to that I was a faculty member in the Department of Obstetrics, Gynecology and Reproductive Sciences, University of Texas Medical School at Houston. I have done federally-funded laboratory research, lectured, and advised on these subjects extensively, in the U.S. and internationally. I’ve taught embryology, developmental biology, molecular biology and biochemistry for over 30 years to medical and nursing students, as well as undergraduate and graduate students.

I am testifying in SUPPORT of HB 1305, the bill to prenatal discrimination, by prohibiting abortion based on sex selection or genetic abnormality.

This bill deals with preventing discrimination based on gender, or based on genetic differences, in pre-born human beings. While it might seem to some people that this is a straightforward and logical protection that is unnecessary, there is ample evidence for the need of such protection.

Gender in humans is determined by the sex chromosomes, X and Y, within an individual’s cells. If you have two X chromosomes (XX) you are female, if XY you are male. This genetic composition is determined at the moment of conception. Likewise genetic abnormalities, such as Down’s syndrome in which an individual has an additional chromosome 21, are determined at conception when the sperm and egg fuse to form the zygote, the single-celled human organism.

**Eugenics** is the term given to attempts to control human heredity. In the past, such attempts have included efforts at selective breeding of “high quality” individuals, selective sterilization of others to prevent offspring, and even infanticide. Today we see eugenic attempts at what some have termed “gendercide”, usually selecting for boys and against girls, in the womb or as embryos in the laboratory.

There is ample evidence to show that this gender selection occurs in some countries such as China and India. One group has documented that the three deadliest words in the world are “It’s a girl.” Globally it is estimated that there are between 160 million and 200 million missing girls, due to sex selection abortion.

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2 It’s a girl, http://www.itsagirlmovie.com/

But this problem also occurs in the United States and in Canada. There are a number of studies that now document similar sex-selection abortions taking place in the U.S. and in Canada. As in other countries, the targets are primarily girls, selected against for birth.

In terms of selection against genetic abnormality, the best documented case involves selection against babies diagnosed in utero with Down’s syndrome. Studies show that such pre-born children are aborted at a rate of 95-98%. Similar rates of selection against life are seen for babies diagnosed in the womb with other genetic conditions. Again, this is simply a modern version of eugenic selection.

This bill would provide necessary, distinct protections for developing human beings, preventing discrimination based on gender or genetic composition. Thank you for the opportunity to contribute to the discussion on this important issue.

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5 Mansfield C et al. Termination rates after prenatal diagnosis of Down syndrome, spina bifida, anencephaly, and Turner and Klinefelter syndromes: a systematic literature review, Prenatal Diagnosis 19, 808, 1999; Britt DW et al., Determinants of parental decisions after the prenatal diagnosis of Down syndrome: Bringing in context, American Journal of Medical Genetics 93, 410, 1999
To: Senate Judiciary  
Subject: House Bill 1305 - Prenatal Nondiscrimination Act  
Date: March 12, 2013  

The North Dakota Catholic Conference supports House Bill 1305 to prohibit sex and disability discrimination in the womb.

House Bill 1305 furthers several important public interests that form the basis of a civil society. No matter where a person stands on abortion, we should, as a society, agree that abortion should never be used as a tool for sex-selection or the elimination of children with genetic abnormalities.

Sex-selection abortion has drastic effects on society. An estimated 163 million girls are missing in the world because of sex-selection abortions. The United Nations Population Fund has rightly called the practice “female infanticide.” Experts have noted that the unnatural sex-ratio balance resulting from the intentional termination of unborn females can contribute to increased violence, human trafficking, and kidnapping.

The problem of sex-selection abortion is not limited to other countries. Several studies have documented the practice of sex-selection abortions in the United States and Canada. One study followed pregnant women from a particular immigrant community and a shocking 89% of those carrying girls aborted during the study period. Understandably, four states have already banned sex-selection abortions. House Bill 1305 is a simple measure to affirm a policy of nondiscrimination based on sex.

Just as we should not tolerate abortion as a tool for sex discrimination, we should not tolerate abortion as a tool for discrimination against those with disabilities. In 1983 North Dakota became a leader when it passed its Human Rights Act and extended protection to persons with disabilities. The federal government followed in 1990 with the Americans with Disabilities Act. That protection, however, does not extend to the womb.
In an estimated ninety percent of cases, a positive test for Down Syndrome leads to an abortion. Unborn children with other genetic abnormalities suffer a similar fate. This is a betrayal of our state and nation's commitment to respecting the rights and dignity of persons with disabilities. If we truly believe that persons with Down Syndrome or other genetic abnormalities have the same fundamental rights as any other person, we cannot turn a blind eye to their intentional elimination prior to birth.

House Bill 1305 furthers respect for persons no matter what their sex or genetic condition. We urge a Do Pass recommendation.

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2 Puri S, Adams V, Ivey S, et al. "There is such a thing as too many daughters, but not too many sons": a qualitative study of son preference and fetal sex selection among Indian immigrants in the United States. *Soc Sci Med* 2011;72:1169-76. [Study involving immigrant Indian women in the U.S. found that 40% had terminated pregnancies with female fetuses and 89% of the women carrying female fetuses in their current pregnancy pursued an abortion.]


3 Arizona, Oklahoma, Illinois, Pennsylvania
Good morning – My name is Alexandra Deufel. I am a Biologist, live in Ward Co., and teach Developmental Biology at Minot State University.

I am here today to urge you to give a “Do Not Pass” to this bill (HB 1305).

I could speak about this bill as a taxpayer: I certainly do not want my taxes to pay for a doomed lawsuit to defend this unconstitutional bill.

I could speak about this bill as a woman: I am certainly deeply offended that a number of representatives and senators in this esteemed body feel they have the right to treat me like a child who cannot make decisions about her own body.

I could speak to you as a religious moderate: I do not believe that religious fundamentalists, even if they may be in the majority in this state, should be allowed to force their interpretation of morality and God's will on the entire population of this state.

I am here today to appeal to your human decency and compassion.

This bill, if it became law, would prohibit abortion for the sole reason to eliminate a child of a certain undesirable sex. Is abortion for sex selection really a problem in ND? Do you really believe there are families in this state, who, after having 4 or 5 girls, will abort any subsequent girls because they want a male heir to take over the farm? While this practice does exist in some parts of the world, it is certainly not part of ND culture. I can only speculate why this language is part of the bill: to challenge Roe v Wade at the national level and to shame women by asking them to justify why they need an abortion.

The part of the bill that I find particularly appalling, however, is the prohibition of abortion of fetuses with genetic abnormalities. Media images of happy, smiling individuals with Down syndrome may give the impression that giving birth to and raising a child with genetic developmental malformations is not all that bad. Down syndrome is, however, a relatively mild developmental abnormality, although many of those taking care of an individual with Down syndrome might disagree.

While many people think of Down syndrome when genetic malformations are discussed, there are many other developmental malformations that are much more severe.

Let me just talk about a few examples.

Patau syndrome is the result of an extra copy of chromosome 13. Individuals have close set eyes that in some fuse into one, split irises, missing skin on scalp, severely malformed brains resulting in severe intellectual deficits, extra fingers and toes that are clenched and other skeletal malformations, severe heart defects (mostly incomplete division of the heart into four chambers) etc. etc. Most die before birth or within the first year of life.

Edwards syndrome is the result of an extra copy of chromosome 18. Individuals have holes in their iris, split abdominal muscles resulting in hernias, heart defects as in Patau syndrome, severe kidney malformations, many other physical malformations. Most die before birth or within the first week of life.
Anencephaly is a condition in which the brain never forms. The brain and skull are absent to various degrees, although a malformed face tends to form. This usually causes death within hours or days, if not before birth.

Sirenomelia is a defect of the lower body that results from a malformed umbilical cord. The legs are fused and there are severe malformations of the lower abdominal organs. E.g. absence of rectum and anus so that the large intestine just ends in body cavity, absence of bladder, malformed kidneys etc. The severity of this one is quite variable.

I could go on, but I think I probably made my point. Down syndrome is just one of many things that can go wrong during development. And while it is sad that so many fetuses with Down Syndrome are aborted, can we really legislate for every case? Is it prohibited to abort for Down syndrome but not for the others? Down is also variable in its individual effects. Is it prohibited to abort a Down syndrome fetus unless it has a particularly severe heart defect, and then it is ok?

We don't live in a world that is black and white. There are many gray areas and state legislatures cannot legislate for every eventuality. Do you really want to force every set of parents who gets the diagnosis of Down syndrome or any other malformation to carry the pregnancy to term? What happens to the child after it is born to parents who are not ready for this? Who takes care of him? How will he be treated?

And think about the severity of some of the developmental abnormalities I highlighted today. How cruel to force parents to carry a doomed pregnancy to term just watch their baby die! How cruel is it to force a mother to carry her doomed baby until it dies in the womb and the delivery of the dead fetus has to be induced before she becomes septic! A diagnosis of such a syndrome is devastating news for any family. This bill twists a knife in that wound. Families need to be able to make their own decision, together with their doctors, and consulting their own conscience and their own God, to continue such a pregnancy or not. Not every family is emotionally ready for this.

Forcing parents to give birth to severely malformed babies is extremely cruel and unkind, and I would say un-Christian. Have a heart and give this bill a "do not pass".
Sirenomelia – stillborn

Anencephaly
Patau syndrome

Edwards syndrome
My name is Steven R. Morrison, and I am an assistant professor at the University of North Dakota School of Law, where I teach Constitutional Law and Criminal Procedure courses. I am providing this written testimony in opposition to HB 1305 (the “gender-gene bill”) and HB 1456 (the “heartbeat bill”), because I believe both bills are patently unconstitutional. My testimony reflects my views alone, and not necessarily those of the UND School of Law, UND, or any other individual or entity.

Like many North Dakotans, I believe that an abortion is an unwelcome and traumatic, but sometimes necessary, medical procedure. Those women who have obtained abortions certainly know better than I the thoughts and feelings that accompany the decision to abort. Indeed, as a male I hesitate to wade into what I believe is a debate concerning a woman’s right—and hers alone—to choose what she will do with her own body. I do, however, have experience as a professor of constitutional law, and so my comments are based on that experience.

It is my opinion that the gender-gene bill and heartbeat bills are patently unconstitutional. If either of these bills passes, opponents will immediately initiate legal challenges, courts will quickly issue injunctions to temporarily halt their enforcement, and those and appellate courts will strike the laws down without hesitation. By passing these bills, the North Dakota legislature will succeed only in forcing taxpayers to pay for what would ultimately be losing cases.

As this committee knows, the United States Supreme Court decided Roe v. Wade in 1973, holding that states could not restrict abortions during the first trimester, could restrict them only for the health of the woman in the second, and could restrict them unless doing so would threaten the woman’s health in the third. The Court in Planned Parenthood v. Casey, in 1992, permitted regulations on abortions that did not create an “undue burden,” but it upheld the Roe structure of rights.

The gender-gene bill now before this committee would prohibit all abortions based on a particular motivation at any stage of a pregnancy. This would amount to the most obvious undue burden—absolute prohibition. It would also prohibit abortions during the first and second trimesters, which Roe and Casey clearly do not allow.

The heartbeat bill pending before this committee is also clearly unconstitutional. Heartbeats are generally detectable in a human embryo at around six weeks of gestation. This bill would, therefore, extend the prohibition on abortions throughout the second trimester and well into the first trimester. There is no question that the law set forth in Roe and Casey does not allow such a prohibition.
I hope that the committee believes me when I say that I hope for the day when no woman finds herself seeking an abortion. I am not a religious person, nor do I purport to know when life begins. I understand, however, that the decision to obtain an abortion is fraught, and one that any woman does not hope to face.

I also know that many people of good will think that life begins at conception and that abortion is therefore murder. They naturally would like to see the procedure end, and they are engaging and will continue to engage in the ongoing national debate regarding this issue. One way that they are doing so is by engaging the legislative process to present bills that inform women of abortion’s possible consequences, require waiting periods, and so forth. My opinion of the substantive merit of these bills and their drafters’ motivation is irrelevant. What matters from a constitutional standpoint is that many of these bills may be limited or nuanced enough to be constitutional. As such, they stand a chance of being upheld in a court.

The gender-gene bill and the heartbeat bill stand no such chance. They are, certainly, an expression of many people’s interest in seeing abortion outlawed, but they will have no effect because they are patently unconstitutional. All they will do is force the state, at taxpayers’ expense, to mount unsuccessful legal defenses. However important the abortion debate is—and it is important—these bills will accomplish nothing, and this committee should quash them both.
Testimony of Rev. Carel Two-Eagle regarding HB 1305 and HB 1456 Before Senate Judiciary Committee on 03/12/2013; Senator Hogue, Chair

Hanh Mr. Chairman and members of the Committee. I spoke this morning without notes, so this is a synopsis of what I said, so you may have it in writing. Thank you for your forbearance.

In re HB 1305 - I head a non-denominational, non-sectarian, non-Christian Church. I am a Pipe Carrier, therefore I have a specific prayer, called an obaghi – a sacred commitment – which focuses my life and the Ch'annunpa (Holy Pipe) I Keep & Carry. I am the woman who Dances The Four Winds – a prayer to heal the Sacred Hoop, which we all know is seriously damaged.

People come to me for a wide variety of help, but in the matter of the Ch'annunpa, they come for spiritual help. I intercede for them with the spirits, and quite a number of people have come to me because they are the parents of genetically defective children. These 'children' are currently all adults, but they need care for their entire lives. The parents want me to ask the spirits to find suitable caretakers for the 'children', after the parents have died. 2 of these people are white; the rest are Native. There is very little drug or alcohol use in their backgrounds, so these defective 'children' just had unlucky genetic draws.

Also – every one of these people cannot function in an institutional setting. Schools have invariably thrown these children out ( ! ). For these people, schools & other institutional settings are prisons and they cannot function in them.

One young man comes to mind who cannot talk. He communicates with gestures and by means of a computer. He is bright, in specific ways. But his frustration level is such that he cannot function alone. When his frustrations become overwhelming for him, he becomes violent. He is nearly 6 ft tall & in good physical condition. Currently, the only person who has ever been able to calm him is his father. What will happen to this young man when his father dies? He is one case of many in my experience - & that of others.

One of my sisters has a Masters in Intellectual Development & Special Education. She prays constantly to be able to work herself out of a job! Partly, because the people who have these people before her – she teaches at high school – do nothing with them. They treat their situation as a fancy babysitting job. When she was told she was getting an 18-year-old freshman who was not yet potty-trained, she drew a line. She said – to both the school & to me – "I have a Master's degree in Special Education! I will not change diapers on an adult male & call it teaching! I will quit first." That student went elsewhere - & my sister has had enough – she is looking for a job in some other field, after over 10 years in this one. She is universally seen as “excellent” at her work. She seems to be the only one.
During my Sun Dance, I gave over 800 pieces of my flesh to convince the Spirits of my seriousness in my obaghi. I’m sure none of you have done anything even remotely like that.

And I wonder – will any of you go out & change the diapers on adult males who are genetically defective? Particularly when they are 20.. or 30.. or 40 years of age? I doubt it.

In re HB 1456 – I had 2 pregnancies where the babies were deemed dead from the initial joining of the egg & the sperm. In the first case, the gynecologist told me this & then said, “You will go to 4 – 5 months, the tissue will become septic, and you will spontaneously abort.” I asked him if that didn’t mean that my life was literally at risk & he said, “Yes. But that’s a risk you take on when you spread your legs.” I was married at the time, and he knew it. A year later, he did not have his license to practice medicine – I did not take his attitude well, & I protected other women from such a vicious attitude. I’m proud of that.

But I prayed on the matter of 2 out of 2 being dead from the start & asked the Spirits “Why me? Why were they dead from the start? What am I supposed to learn from this?” They answered me, & quickly (!). They told me, “A woman’s body functions like a factory. When an egg & sperm unite, it automatically makes another body. But that body does not become a live human unless or until a spirit/soul chooses to take up residence in it.”

None of you is qualified or trained to carry the responsibility for another person’s soul. I am. It is a murderously difficult and wearing job. So I believe you should consider this carefully before you rush to pass bills such as these & the others that have come up on this subject, because you are spiritually responsible for the suffering you promote when you pass such a bill as these. That is not conjecture, that is fact.

Moreover, I believe that all such bills violate the 13th and 14th amendments to the US Constitution. The 13th amendment states that involuntary servitude is illegal; & believe me when I say that when you force people to birth such children, you sentence them to a lifetime of involuntary servitude.

The 14th amendment speaks about depriving citizens of life, liberty, and the pursuit of happiness. When you pass bills such as these, you definitely deprive the involved citizens of their choice of lives insofar as how they would live it, of their liberty because they are never free again to make any plan except around the ‘child’ you sentence them to birth, and of the pursuit of happiness – even something so small as owning a home is now beyond them, because of the cost of keeping such people alive once they’ve been forced onto their parents, and I’m sure there are more facets than these to consider.

Thank you for hearing me in a good way now. And for recommending DO NOT PASS on all bills such as these. Mitakuye ohasin – all (are) my relatives. And yours, too. You have a built-in responsibility to your relatives.
Chairman Hogue and Members of the Senate Judiciary Committee:

My name is Roxane Romanick and I live in Bismarck, ND. Today I am testifying on behalf of Designer Genes of North Dakota, Inc. Designer Genes is a Down syndrome support organization consisting of 200 individuals with Down syndrome and families from across the state of North Dakota (www.designergenesnd.com).

One of Designer Genes’ main programming areas is to provide support to all families who need information about what a diagnosis of Down syndrome means to their unborn or newborn child and their family. We provide balanced, accurate, and up-to-date information to families and to the medical profession about what it means to live with a diagnosis of Down syndrome in North Dakota and the United States. We remain neutral on the content of this bill; however we appreciate the discussions that this bill stimulates regarding the discrimination of individuals with Down syndrome and other disabilities and the need for support to families with prenatal diagnoses.

During the hearing in the House Human Services Committee on HB 1305, there were many questions about the accuracy of termination rates in instances of prenatal diagnosis of Down syndrome that was used in various testimonies. The most current study was published in the February, 2012 volume of Prenatal Diagnosis by researchers Natoli, Ackerman, McDermott, and Edwards. They reviewed studies on pregnancy termination following a prenatal diagnosis of Down syndrome in specific states. Twenty-four studies were selected and based on the how the studies were conducted, the rate ranged from 50% - 85%. The authors report that it appears that the rate of termination has decreased over the years. A reference to this study can be found at: http://www.ncbi.nlm.nih.gov/pubmed/22418958.

While the issue of providing support to parents with new babies (born and unborn) with a diagnosis of Down syndrome has always been a priority in the Down syndrome field, the advancement of new prenatal testing has increased the urgency to partner with the medical community to support families. The new prenatal testing, referred to as Non-Invasive Prenatal Test (NIPT), currently is being used as a screening tool but has the potential to replace invasive procedures such as amniocentesis to actually diagnosis Down syndrome as well as Trisomy 13 and Trisomy 18. The NIPT can be used to detect a diagnosis as early as ten weeks into a woman’s pregnancy. Currently there is no other screening or diagnostic tool that can provide some type of information that early in a woman’s pregnancy. Since 2007, it has been the position of the American Congress of Obstetrics and Gynecology to recommend prenatal testing to all mothers. See Practice Bulletin 77: http://www.ncbi.nlm.nih.gov/pubmed/17197615 and Practice Bulletin 88: http://www.ncbi.nlm.nih.gov/pubmed/18055749.

The Down syndrome field has been making many advances in preparing information that is balanced, accurate, and up-to-date to assist physicians, geneticists, and genetic counselors in their work with new parents. The National Center for Prenatal and Postnatal Down Syndrome Resources (http://downsyndromediagnosis.org/) based at the University of Kentucky produces written and online
materials that are available for parents who are pregnant with a baby with Down syndrome or have had a baby with Down syndrome. Some of their materials were developed in direct collaboration with the American Congress of Obstetrics and Gynecology, the American College of Medical Genetics, and the National Society of Genetic Counselors. The Global Down Syndrome Foundation and the National Down Syndrome Congress have recently published materials to help women understand the meaning of the diagnostic tests and screening tools that are being used to provide women with more information about their babies (www.downsyndrometest.org). In 2008, Congress passed the Prenatally and Postnatally Diagnosed Conditions Awareness Act (United States Public Law 110-374). This law seeks to improve opportunities for parents and pregnant women to anticipate and understand the likely life course of children born with Down syndrome and other (unspecified) conditions. In 2012, the state of Massachusetts also created a state statute to support parents who are experiencing a prenatal diagnosis of Down syndrome. A similar bill passed unanimously in the Kentucky state assembly this year and is awaiting the signature by Kentucky’s governor. In December, 2011, Designer Genes of North Dakota, Family Voices of North Dakota, and Pathfinder Parent Center trained 22 parent mentors to support prospective parents with prenatal diagnosis. This project, called Project Carson, has supported 33 North Dakota families since launching.

A survey of women who made the decision to terminate a pregnancy indicated that the most selected reason for terminating was being uncertain about their ability to support a child with a disability. (http://www.ncbi.nlm.nih.gov/pubmed/?term=brookes+women's+voices). Right now your peers in both chambers are considering bills that greatly impact how we decrease discrimination, provide access, and support individuals with disabilities in our community. I can personally attest as a parent to a thirteen year old daughter with Down syndrome that there continues to be barriers to being fully included in our communities and that sometimes accessing what she needs to be successful is very difficult. I urge you to think beyond this bill and make North Dakota the very place where raising a child and/or supporting an adult with Down syndrome is not difficult. Let’s make sure that new parents are supported before their baby is born and after. This is the message that we want to be able to take to families when they are learning about what an extra chromosome will do and how they will support the child that they are bringing into the world.

Thank you for your time and I welcome any questions.

Roxane Romanick
Designer Genes of North Dakota
Board President
830 Longhorn Dr.
Bismarck, ND 58503
701-391-7421
romanick@bis.midco.net