

## DOWN SYNDROME PRENATAL EDUCATION

In July 2014, Pennsylvania became the seventh state after Virginia, Missouri, Massachusetts, Kentucky, Delaware, Maryland, and Louisiana to pass some form of Down syndrome prenatal education legislation. These laws are modeled after earlier, but unfunded, federal legislation.<sup>1</sup> The intent of these bills is to require that scientifically sound information and support services be provided to patients who receive a prenatal diagnosis of Down syndrome.

This legislation should be seen as an opportunity for Catholic-sponsored facilities to witness in a concrete way to the Catholic moral tradition in view of the inestimable value of all human life, including the weak and vulnerable, and the psychological harm of pregnancy termination, especially disability selective abortion, because this is usually a later term abortion that results in the death of an otherwise wanted child. With similar legislation pending in other states, Catholic-sponsored medical facilities have a chance to assess materials they may already have available that provide prenatal diagnosis and genetic counseling to women.

### Prenatal Diagnosis and Abortion

A poll published in 2013 in the *Journal of Intellectual and Developmental Disabilities* showed that almost one in four patients who had received a positive prenatal diagnosis for Down syndrome reported that their medical professional was *insistent* that they terminate their pregnancy.<sup>2</sup> A 1995 poll of members of the American College of Obstetricians and Gynecologists (ACOG) revealed that 63 percent believed abortion was a justifiable *treatment option* for fetal anomalies compatible with life.<sup>3</sup> These statistics reveal that the prevailing medical preference regarding prenatal diagnosis of Down syndrome is termination, and that preference is evident in the statistics that show a majority of women choose to terminate their pregnancy after diagnosis.<sup>4</sup>

The intent of Down syndrome prenatal education laws is to counteract the often negative and uninformed positions taken by health care workers toward disability, by ensuring that women who receive a prenatal diagnosis are accurately informed of the reality of giving birth to a child with Down syndrome, including—if not especially—the positive outcomes. They are also provided with information on important peer-support services.

### Down Syndrome Prenatal Education Laws Present an Opportunity

Emerging Down syndrome prenatal education laws provide a special opportunity for those working in pro-life ministry in states where these laws have not yet

been passed. Sample legislation is available at the Jérôme Lejeune Foundation's website, and also from the National Down Syndrome Society, for those who would like to initiate the legislative process in their own states.<sup>5</sup> As one family has reported, "Talking to parents of kids with [Down syndrome] and meeting beautiful children with [Down syndrome] helped us to be comforted that our son would be just like any other child."<sup>6</sup> Positive information alone can counteract the negative impression many families are given regarding the birth of a child with a disability.

The law passed in Louisiana (Act 352) is unique in that it requires that all resource materials not mention abortion as an option following a positive prenatal diagnosis.<sup>7</sup> Activists should evaluate their own state's tolerance for language that might be perceived as attempting to restrict abortion. The desire to explicitly exclude abortion in the wording of laws should not place at risk passage of legislation intended to positively inform and therefore reduce the incidence of abortion following prenatal diagnosis. Presenting the harmful effect of disability-selective abortion on families and the psychological health of women might better overcome the favorable view of abortion in some states and also discourage some who may consider leaving a Catholic health care facility to obtain a pregnancy termination elsewhere.

For those working in Catholic health care, Down syndrome prenatal education laws can serve to reinforce the beauty of human diversity and the inherent dignity of all persons regardless of disability. Materials should be selected that do not neglect the difficulties of raising a child with Down syndrome, but also present the statistical reality that families who have accepted into their lives a child with Down syndrome are almost uniformly happy. For example, Dr. Brian Skotko, codirector of the Down Syndrome Program at Massachusetts General Hospital, has published research showing that 99 percent of people with Down syndrome are happy with their lives, and 97 percent of brothers and sisters aged nine to eleven report that they love their sibling with Down syndrome.<sup>8</sup>

Most importantly, as Pope Francis has reminded us, "All life has inestimable value, even the weakest and most vulnerable, the sick, the old, the unborn and the poor, are masterpieces of God's creation, made in his own image, destined to live forever, and deserving of the utmost reverence and respect."<sup>9</sup> A prenatal diagnosis of Down syndrome provides those working in Catholic health care an opportunity to provide materials that comply with such laws, even if they have not yet been enacted. These materials offer consolation and hope to parents, and most importantly, witness to the human dignity of those conceived with a disability.

We do not know how many might receive a prenatal diagnosis from a Catholic provider and then go to a non-Catholic facility for an abortion. The requirement to provide positive printed material and a connection to various peer supports might help keep those individuals in the Catholic system, where they can learn to welcome their child as a unique gift from God, a cherished member



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of their family, and a welcome addition to the broader human community.

### Available Down Syndrome Prenatal Education Resources

Currently there are two resources widely available for distribution to families who have received a prenatal diagnosis of Down syndrome. *Understanding a Down Syndrome Diagnosis* is a small and visually beautiful booklet from the National Center for Prenatal and Postnatal Down Syndrome Resources at the University of Kentucky.<sup>10</sup> With text in English and Spanish, it was prepared with the assistance of representatives from the National Society of Genetic Counselors, ACOG, the National Down Syndrome Society, and the National Down Syndrome Congress. It benefits from being a peer-reviewed resource, but critics fault the publication for its mention of abortion as a "safe option" many families make. To its credit, the booklet points out that depression and symptoms of post-traumatic stress can be associated with the choice to terminate, and it intentionally places the option to give a child up for adoption on the opposing page.

In 2012, the Global Down Syndrome Foundation and the National Down Syndrome Congress collaborated to publish a small pamphlet that omits termination as an option.<sup>11</sup> A second edition of this resource is now in development.

Resources currently available fulfill the legal requirement for balanced and factual information, but fail to affirm the beauty of human diversity as expressed in disability and genetic difference as understood in the Catholic tradition. Emerging Down syndrome prenatal education laws present those working in Catholic health care with an opportunity to develop their own materials that affirm the invaluable worth of all human life and at the same time

prepare families to welcome into their homes the unique gift of a child with Down syndrome.

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- <sup>1</sup> In 2007, the late Senator Ted Kennedy and Senator Sam Brownback introduced the Prenatally and Postnatally Diagnosed Conditions Awareness Act that was passed and signed into law by President George W. Bush on October 8, 2008. The Kennedy-Brownback bill was never funded due to a disagreement between pro-life and pro-choice legislators over how the topic of abortion would be addressed. Individual states have begun to promote legislation with the same intent, i.e., to provide positive information and support to women receiving a prenatal diagnosis of Down syndrome.
- <sup>2</sup> Briana S. Nelson Goff et al., "Receiving the Initial Down Syndrome Diagnosis: A Comparison of Prenatal and Postnatal Parent Group Experiences," *Journal of Intellectual and Developmental Disabilities* 51.6 (December 2013): 446-457.
- <sup>3</sup> Denis Cavanagh et al., "Changing Attitudes of American Ob/Gyns on Legal Abortion," *The Female Patient* 20 (May 1995).
- <sup>4</sup> Abortion statistics following prenatal diagnosis of Down syndrome are unclear. See Mark Bradford, "Improving Joyful Lives: Society's Response to Difference and Disability," *Charlotte Lozier Institute American Reports Series* 8 (June 2014): 13-15, <http://www.lozierinstitute.org/downsyndrome/>.
- <sup>5</sup> "Protections for Those Prenatally Diagnosed with Down Syndrome," accessed July 18, 2014, <http://lejeuneusa.org/node/600#.U8kkNJRdVnZ>.
- <sup>6</sup> Nelson Goff et al., "Receiving the Initial Down Syndrome Diagnosis," 453.
- <sup>7</sup> Louisiana Act 352 (passed May 30, 2014), available at <http://www.legis.la.gov/Legis/BillInfo.aspx?i=225378>.
- <sup>8</sup> Brian G. Skotko, Susan P. Levine, and Richard Goldstein, "Self-Perceptions from People with Down Syndrome," *American Journal of Medical Genetics* 155A.10 (October 2011): 2360-2369.
- <sup>9</sup> Francis, Message to Catholics Taking Part in the Annual Day for Life in Britain and Ireland (July 28, 2013).
- <sup>10</sup> This can be found at [www.lettercase.org](http://www.lettercase.org).
- <sup>11</sup> This is available in print and can be found at [www.downsyndrometest.org](http://www.downsyndrometest.org).

