

## **Standing up for Children and Parents**

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What value do we, as a society, place on the lives of the mentally disabled?

This question has been brought into focus in recent weeks with John McCain's choice of Sarah Palin as his running mate.

As most of the world now knows, Governor Palin's 5-month-old son, Trig, has Down syndrome. When the Governor and her husband Todd were told last December that the child she was expecting in May would be born with Down syndrome, they knew that ending the pregnancy was never an option for them. After all, why would it be? "We understand," she was quoted as saying at the time, "that every innocent [unborn] life has wonderful potential."

According to reputable studies, between 80 and 90 percent of the children diagnosed with Down syndrome in the United States this year won't make it into this world, simply because they have a positive genetic test in prenatal screening – a test which can be wrong, by the way.

America is poorer because of this. To deny children with disabilities a chance at life will make us more insensitive, callous, and jaded and will take away from the diversity of American life. *Roe v. Wade* has made it not only possible but Constitutional to deny that fundamental right to life to a whole class of people, simply because of their genetic makeup. We are poorer without them, without their amazing gifts, and without their wonderful, unconditional love.

The day after their son Trig was born, the Palins released the following statement: "Trig is beautiful and already adored by us. We know through early testing he would face special challenges, and we feel privileged that God would entrust us with this gift and allow us unspeakable joy as he entered our lives. We have faith that every baby is created for good purpose and has potential to make this world a better place. We are truly blessed."

In an e-mail to friends the day Trig was born, Governor Palin wrote "Many people will express sympathy, but you don't want or need that, because Trig will be a joy...Children are the most precious and promising ingredient in this mixed-up world...Trig is no different, except he has one extra chromosome."

Sadly, for many in the medical community, these special children do not hold the same value. They argue that these children are a burden on their parents and on society, and this is why they recommend that their lives be terminated before they have a chance to begin. This "eugenics mentality" is behind much of the recent push to expand prenatal testing, with the argument that it is better for everyone to weed out these lives before they are born than to bear the emotional and financial cost of taking care of them after they are born.

Sometimes, this eugenics mentality is explicit. According to the Los Angeles Times, "a senior Canadian doctor is now expressing concerns that such a prominent public role model as the

governor of Alaska and potential vice president of the United States completing a Down syndrome pregnancy may prompt other women to make the same decision against abortion...thereby reducing the number of abortions.”

The article goes on to quote Dr. Andre Lalonde, executive vice president of the Society of Obstetricians and Gynecologists in Ottawa, saying that he worries that Palin’s decision may cause abortions to decline as other women in Canada and elsewhere opt to follow suit.

“Lalonde says his primary concern is that women have the....choice of abortion and that greater public awareness of women making choices like Palin to complete a pregnancy and give birth to their genetically-abnormal baby could be detrimental and confusing to the women and their families.”

“The worry is that this will have an implication for abortion issues in Canada,” Lalonde is quoted as saying.

Sometimes, the push to weed out these lives is more subtle. Recently, the American College of Obstetricians and Gynecologists put out new recommendations that all pregnant women, not just those over 40 as previously recommended, should be screened to determine whether the baby they are carrying has Down syndrome. The College makes the argument that it is more responsible to inform parents of their options beforehand so that they can decide whether or not to let the baby live.

This recommendation codifies a practice that has become all too common: direct or indirect pressure applied to parents by the medical establishment to end the unborn life of children with disabilities, because these children are, supposedly, too much of a burden for their parents to bear.

The irony is that if children with Down syndrome make it out of the womb, their prospects in life are brighter than ever. Children and adults with Down syndrome are often the centerpieces of their families. They have amazing gifts and are full of affection. Many adults with Down syndrome have jobs, live independently, and make valuable contributions to the communities in which they live.

We now understand that with early intervention and access to proper therapies, individuals with Down syndrome can achieve a level of health and intellectual development not dreamed of even a decade ago. And yet, their prospects of being born are dimmer than ever, largely because of misconceptions that the medical community itself is actively fostering.

This situation needs to be addressed. On September 23, the Senate passed a bill, that I co-sponsored with Senator Kennedy, designed to provide additional information and support to parents who receive a diagnosis of Down syndrome or other prenatally diagnosed condition.

Known as the Prenatally and Postnatally Diagnosed Conditions Awareness Act, our bill meets an undeniable need: providing support and balanced information to parents in a tough position.

Even before the recent recommendations, screening for Down syndrome and other conditions is becoming more routine. More and more mothers are receiving these diagnoses about their developing child, and we as a society can do a much better job of providing them with some practical help and resources.

Specifically, our legislation would establish a national registry of families willing to adopt newborns with Down syndrome or other prenatally diagnosed conditions. It also calls for the expansion of national and local peer-support programs and the establishment of a telephone hotline and website accessible to families.

Make no mistake: our bill is a first step. Much more needs to be done for families in these situations. One of the most difficult and vulnerable moments in the life of an expectant mother is when she learns she is going to have a child with a disability or medical condition. Access to the best support and information about the condition can make all the difference to a woman and her family.

Hopefully, our bill is the start of something new: real help for families, deepened respect for the value of every life, especially those with disabilities, and one step closer to the kind of America we all know is possible.

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