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Selective Abortion of Fetuses with Non-Fatal Disabilities: Progress or Discrimination?

by Susan Agrawal

On the whole, I am pro-choice. I believe that it is up to an individual woman to choose whether or not she wishes to have a baby in the early weeks of her pregnancy. I recognize that others feel differently, and I respect their opinions.

But things get very murky for me when it comes to terminating a pregnancy later on because the mother is not carrying the particular baby she wants. For example, in China, Indian, Pakistan, and several other countries, sex-selective abortion is very popular when the fetus is found to be female. Most of us here in the United States regard this practice as barbaric, uneducated, and frankly “gendercide.” Nonetheless, it occurs with great frequency throughout the world, to the point that China and other countries now have way too many men and not enough women. Ratios of 130 boys to 100 girls in many areas are not uncommon.



But what about termination of fetuses with genetic or congenital anomalies, such as Down syndrome? Studies have shown that up to 90% of fetuses with Down syndrome are aborted.¹ Rates for spina bifida are similar in the US. These numbers may even

increase, since prenatal testing is now recommended for all mothers, and earlier testing is available, leading more mothers to know earlier on their pregnancies that their babies may have disabilities.

I understand that sometimes there are babies who have clearly fatal anomalies, and that ending these pregnancies is sometimes the best option for the mental health of the parents and to prevent potential suffering of the child. I am not talking about these pregnancies. I am talking about fetuses who may have Down syndrome, spina bifida, or another disability that is not fatal, and in some cases may not even be all that severe.

By the Numbers

Considering that a 2010 Gallup poll on the subject shows that 45% of Americans identify as pro-life, and 90% of fetuses with Down syndrome are being aborted, we have a problem.² It is clearly impossible that fetuses who have Down syndrome only occur in pro-choice mothers. Therefore, even people who identify as pro-life seem to change their opinions when confronted with a fetus who has a potential disability.

Two other Gallup polls from 2003 specifically asked adults about abortion of fetuses with mental, physical, and life-threatening conditions. In a January 2003 poll, 55% said abortion should be legal if the baby may be mentally impaired, and 56% said it should be legal if the baby may be physically impaired. A May 2003 poll also showed 38% believed abortion of a child with mental impairment--children without ANY medical conditions--should be legal even in the last three months of pregnancy. In comparison, only 10% in the January 2003 poll thought abortions of any kind should be legal in the last three months.

There is clearly a double standard here. It seems that a large number of people are pro-life only for babies who are thought to be “perfect.” Polling indicates that people not faced with this decision personally would still be more likely to support an abortion in this situation. Reality indicates that people actually faced with this decision almost universally choose abortion.

Making the Decision

Those of us who have children with disabilities know what blessings our children are. We see how they have important roles to us and in society, no matter how severe their limitations. But parents being confronted with the news that the baby they have dreamed about may not be the baby they expected are rightfully devastated that their fetus has an anomaly or disability. As we all know, acceptance of disability is a process, and one that can take some time. These parents barely have time to even process this news, let alone begin to accept it. They must make a decision immediately—usually within days or weeks—to proceed with the pregnancy or terminate.

Most turn to their doctors for advice, and their decisions are often influenced by how the doctor presents the news to the family. Unfortunately, a 2004 survey of obstetrics fellows found that 45% rated their education in delivering genetic diagnoses as “barely adequate or nonexistent.”³ Another survey of physicians showed that 37% actively tried to influence their patients’ decisions when facing a prenatal diagnosis of Down syndrome, with 13% emphasizing the negative aspects of Down syndrome and 10% encouraging termination.⁴ (It should be noted that some physicians argued the opposing viewpoint.) Most of these decisions are made based on limited information, often including dire predictions of pain, suffering, and dependence, that more likely than not are exaggerated. In addition, most doctors do not have hands-on experience personally caring for a child with a disability, and often make their recommendations based on abstract views of disability or their own moral or spiritual beliefs.

Progress or Discrimination?

Inevitably, the concept of disability and the perceived value of a person’s life who has a disability come into play when making these decisions. Many people think that being dead—or not being born in this case—is better than being disabled. Those with disabilities and parents of children with disabilities strongly disagree. A recent study on attitudes of NICU staff and parents of children who are likely to have long term disabilities is telling: “Most health care workers ranked the most severe disability...as worse than death, whereas most parents of preterm infants ranked death as the worst outcome.”⁵ There is an entire group of people with disabilities called Not Dead Yet (<http://notdeadyetnewscommentary.blogspot.com/>), who specifically oppose the idea that being dead is better than being disabled, and fight against euthanasia of people with disabilities. The vast majority of people with disabilities view their lives as positive and worth living, and definitely not worse than death, especially when they are provided with appropriate medical, legal, and life services.

What does allowing—and in many cases encouraging—abortion of fetuses with disabilities say about disability in general? If a fetus with a disability is not worth carrying to term, by extension, the life of any person with a disability is not worth living. This devalues people with disabilities and views them as less worthwhile. On the other hand, the laws of our nation through the Americans with Disabilities Act and other pieces of legislation mandate nondiscrimination, acceptance, and the removal of prejudice against people with disabilities. How can these two very contradictory opinions exist? How can we legally advocate for nondiscrimination against people with disabilities, all the while encouraging mothers to not give birth to them in the first place because they are not as “worthy?”

Some have gone so far as to say that “choosing” to have a child with a disability—in other words, giving birth to the child that was conceived—is placing an undue burden on society. There have already been cases of insurers threatening to deny care to fetuses when they are known to carry defective genes or disabilities. For example, a Houston woman was initially told by her HMO that they would not pay for the birth of her second

child with cystic fibrosis because she knew in advance the child would carry the gene.⁶ Thoughts and policies such as these equate having a disability or medical condition with being a burden on society, a burden that some argue we should prevent if possible.



Nazi Propaganda against people with disabilities, 1938

“60000 Reichsmark; This is what this person suffering from hereditary defects costs the Community of Germans during his lifetime; Fellow Citizen, that is your money, too”

Which brings us to the land of eugenics, where designer babies are the norm, and misguided leaders such as Hitler feel empowered to choose who lives and who dies. Some disability activists feel that aborting fetuses with disabilities is a clear form of genocide, and that doing so will eventually minimize disability. While some may see this as progress, others recognize that eliminating people with disabilities inevitably destroys the rich fabric of diversity that currently makes up our society. Moreover, what happens to the small number of people who are born with disabilities when there are no longer services, specialists, or even antidiscrimination laws available?

Improving Attitudes and Services

In my opinion, the problem has little to do with moral views on abortion, and everything to do with the perception of disability in our culture, as well as the limited services that may be available for parents of children with disabilities. You can't help but feel for the young, single mother with limited resources who is about to give birth to a baby with Down syndrome in a country with no universal healthcare and poorly funded or unfunded special education services.

There is no doubt that having a baby with a disability is a difficult challenge. But the focus should not be on eliminating these children that so enrich our lives and the lives of

society as a whole. Instead, we need to advocate for improved services and care for these children after birth. If these children are given exceptional medical care, early intervention services, and family support, the so-called societally-inflicted “burden” of disability would disappear.

We also need to teach those around us of the great richness and meaning children with disabilities add to society. People with disabilities have made enormous contributions to society over time. Those of us who have learned to love our children as they are, and value the knowledge and positive change that their disabilities have brought to us, cannot even conceive of our lives without them. They are a gift to our society like any other child, and are important teachers about difference and possibility.

¹ Mansfield, C., Hopfer, S. and Marteau, T. M. Termination rates after prenatal diagnosis of Down syndrome, spina bifida, anencephaly, and Turner and Klinefelter syndromes: a systematic literature review. *Prenatal Diagnosis* 1999;19:808–12.

² <http://www.gallup.com/poll/1576/Abortion.aspx>

³ Skotko, B. G., Kishnani, P. S. and Capone, G. T. Prenatal diagnosis of Down syndrome: How best to deliver the news. *American Journal of Medical Genetics Part A*, 2009;149A:2361–7.

⁴ Skotko, 2362.

⁵ Hugh Simon Lam, *et al.* Attitudes Toward Neonatal Intensive Care Treatment of Preterm Infants With a High Risk of Developing Long-term Disabilities. *Pediatrics* 2009;123(6):1501-8.

⁶ Joseph P. Shapiro, *No Pity* (New York: Three Rivers Press, 1994): 281.