# Reflections on prenatal diagnostic testing

Sherry Wenger

Our second child, Elise, was born at Thanksgiving in 1998. I was thirty-nine years old and the pregnancy had been difficult. Within minutes of her birth, Curt and I were told that she had Down syndrome (DS), an assessment based on clinical features including her almond-shaped eyes, flat nasal bridge, and the single crease on each of her palms. A heart defect required surgery within a few months. Illnesses, feeding problems, and growth issues necessitated more hospitalizations. In addition to medical specialists, many therapists have worked with Elise. Despite intense challenges, she has thrived and has brought immense joy and meaning to our lives. God has been present in our journey. Now a relatively healthy preschooler, she is learning all the usual things, at her own relaxed pace, and we stand amazed as God uses her to work out his purposes.

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## "Did you know?"

Since Elise's birth I have been involved with a local DS parent support group and the local early intervention board. As a result, I have interacted with many families with children who have special needs. I am always interested in hearing their stories about when and how they learned they had a child with special needs. In the support group, when a new mom joins, the others ask, "Did you know?" The time of awareness is a pivotal point in the journey, and we identify each other according to whether we chose to know before the child's birth and why or why not.

At the usual time, during the second trimester of my pregnancy, my nurse midwife offered a standard prenatal screening test. Prenatal screening tests measure levels of substances in a small sample of maternal blood to indicate if the baby is at higher risk for neural tube defects such as spina bifida,[1] and chromosomal abnormalities, including Down syndrome. For several reasons I declined to be tested, as I had two years before when I was pregnant with our first daughter, Olivia. My convictions about the sanctity of life meant that I would not have an abortion even if I knew that my baby had a birth defect. As a nurse, I also knew that this test is not diagnostic and has a high false positive rate: many women who have abnormal levels of the substances measured will deliver healthy newborns. Several of my friends had abnormal test results and spent much of their pregnancies worrying; one even delayed bonding with her baby as a result.[2] Finally, the test could only give me the limited information that my risk of having a baby with one of these abnormalities was higher than usual, but I already knew that it was. At age forty, a woman's odds of having a child with DS are about one in a hundred, compared to one in a thousand at age thirty or lower.

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Finding out whether a fetus actually has one of the birth defects for which this test screens requires a further procedure, such as an amniocentesis or a biopsy of fetal tissue.[3] The initial screening test and the subsequent diagnostic test should not be thought of independently but as part of a protocol. The assumption built into the design of the testing is that if the results of screening indicate that the baby is at higher risk, then the mother will proceed with one of the diagnostic procedures. The second test will then determine whether the baby does in fact have one of these genetic or neural tube problems.

Prenatal screening is routine in many doctors' offices. With technology readily available to provide specific genetic and chromosomal information, it seems reasonable to start the process of checking to make sure the baby is developing as it should. After all, isn't testing just part of good prenatal care? However, some women are not adequately informed about the purpose of the screening test, and they are unclear about what to do with the results. Some choose to have the screen but refuse the diagnostic test, so they lack accurate and complete information. In other words, they may have just enough information to make them worry and not enough to reassure them. As a result, they spend their pregnancies in a heightened state of anxiety.

As is the case with most medical testing, the diagnostic tests have financial and other costs associated with them, as well as certain risks of harm. Unlike the simple screening test, both of the diagnostic procedures are invasive and entail a risk of miscarriage (approximately one in a hundred for biopsy, one in two to four hundred for amniocentesis). These and other risks should be weighed carefully against possible benefits. Additionally, women should ask themselves whether having the information will change something about how they proceed. If it won't, any cost or risk is unacceptable and makes proceeding inadvisable.

## Why would you choose to know?

As the possibilities in the world of technology increase, societal expectations change: people uncritically assume that if tests can give us information, we should avail ourselves of the opportunity to know. Information can indeed be liberating and empowering. It isn't always. Whether a couple should undergo prenatal screening and diagnostic testing is a matter for careful consideration.

Making a good decision about whether to have prenatal testing requires clarity about its purposes. One clear purpose is to identify the presence of a chromosomal or genetic problem, to gain information. One could argue that a possible benefit of declining testing is the bliss of ignorance, an innocence and freedom from interference with one's hopes and dreams for one's child. In the absence of disappointing information, a woman can concentrate wholly on developing the emotional bond necessary for caring for her baby. She is free to enjoy this special time in their life together.

Alternatively, a possible reason to know before the birth is to prepare oneself intellectually and psychologically to receive and care appropriately for a child with special needs. Many couples use the time before their baby arrives to learn about the disability, to set up the supports they need, and to begin grieving the loss of the "perfect" baby they had expected. Several of my friends who knew about their baby's disability before birth say the knowledge made the pregnancy difficult, but they were grateful for the opportunity to grieve and prepare so that they were emotionally ready when the baby arrived.

For other people the psychological costs of knowing their baby has a disability may be substantial and may seriously impair the bonding process. Some families recognize that they do not want to parent a child with a disability, or do not have the resources (financial, emotional, or other) to care for a child with special needs, and they choose to place their baby in adoption. Knowing before the child's birth allows time for adoption procedures, which can be lengthy. It also reduces the need for foster care, which delays bonding between the infant and the adoptive parents. Many families want to adopt babies with special needs; in the case of babies with DS, there are national waiting lists.

In certain circumstances, other preparations may also be warranted. Prenatal testing could identify a serious medical condition that may affect the way the delivery is handled. For example, the presence of spina bifida may mean that delivery by Caesarean section is safer for the baby. Forty or fifty percent of babies born with DS have heart defects. Some of these defects are so severe that if untreated they will cause death soon after birth. Elise's defect was serious enough that we were referred out of state for consultation. When her diagnosis was confirmed, she was scheduled for surgery within two weeks. During the seven hours of her surgery we sat in the hospital waiting room with a potpourri of people from many parts of the world. Later I learned that these families had traveled to this hospital to entrust their babies to the care of a particular cardiovascular surgeon. Some of these children were alive because, as a result of prenatal diagnostic testing, they were born in a medical center that provided such specialty care. In such circumstances, the result of not knowing could be more serious than merely missing an opportunity to prepare oneself; it could cost the baby's life.

Some women opt for prenatal diagnostic testing to enhance their reproductive choices. Many decide to have an abortion when they learn that the fetus has a chromosomal defect. One study estimates that nearly 90 percent of such fetuses are aborted.[4] Noreen and Samuel Glover point out that the laws governing abortion are different (in some states, quite dramatically) for fetuses diagnosed with DS than for normal fetuses. “Ordinarily, the stage of fetal development is an essential factor in whether a woman carrying a healthy fetus can obtain a legal abortion. However, if the fetus has DS, a woman may obtain a ‘therapeutic’ or ‘medically necessary’ abortion much later, even after viability.”[5] The authors note that although the public is about evenly divided between those who support and those who oppose abortion, the numbers shift dramatically when the fetus has a defect. Even people “who otherwise describe themselves as pro-life advocates may make an exception in the case of a fetus with a disability. In one case, as many as 78% expressed a belief that abortions should be legal.”[6]

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I believe this approach is discriminatory. Many people seem unable to recognize that a person is more than an individual trait, more than their disability. A person with Down syndrome has other traits, gifts that can contribute to society and enrich our world. A *Hastings Center Report* contends that “prenatal testing depends on a misunderstanding of what life with a disability is like for children with disabilities and their families.”[7] Because our society sees life with disability as a less than worthy existence, and because it seems “unfair” to allow a child to “suffer,” many people believe abortion is best for both baby and family. Some physicians discourage women from continuing their pregnancy after a positive diagnostic test, even suggesting that it is irresponsible to bring a child with a serious anomaly into the world.

Yet professionals lack consensus on what constitutes a serious anomaly.[8] People assume that those “with disabilities lead lives of relentless agony and frustration and that most marriages break up under the strain of having a child with a disability.”[9] Some marriages do break up, but research does not support the claim that most do. In fact, many marriages thrive as a result of personal growth from the experience of caring for a child with special needs.

According to the National Down Syndrome Congress's "Position Statement on Prenatal Testing and Eugenics: Families' Rights and Needs,"[10] couples should be given information that presents the disability from the perspective of a person with it. They need information on community-based service programs and financial assistance programs as well as on special needs adoptions. And they need a summary of major laws protecting the civil rights of people with disabilities. One physician at the New England Medical Center reports that in her practice couples expecting a baby with DS are introduced to families who are raising infants, children, and young adults with DS, so they can be as fully informed as possible. In her practice, "only 62 percent of women who discover they are carrying a fetus with Down syndrome decide to have abortions."[11] Obviously, education plays a crucial role in the choices people make; unfortunately, there is far too little of this kind of education.

## It takes a church community . . .

I believe that the issues surrounding prenatal testing are best addressed in the context of a faith community that respects the worth of every human life. In addition to aiding couples in discernment about prenatal testing, pastors and congregations have much to offer people who are expecting and caring for children with special needs. I believe it takes a church community to successfully raise our children. Prayers, companionship, openness to and acceptance of people with disabilities—these are important gifts to families facing challenges and are also potential sources of blessing for congregations.

When a woman learns that the baby she is carrying has a chromosomal or genetic defect, she and her partner will likely grieve the loss of hopes and dreams, and they may need help to move through the grief process toward a place of acceptance. People's responses vary: some will get through this stage more easily; others will circle back to it again throughout their lives. Some will struggle intensely with faith and will need help to deal with anger toward God. Many will experience denial, sadness, grief, isolation, panic, and guilt.[12] Pastors and church families can offer patience, understanding, and a willingness to walk with couples. Pastors must be ready to give support and sensitive counsel, recognizing that the marriage relationship may be strained, especially if the wife and husband disagree about having diagnostic testing or respond differently to the results.

Knowing their congregation will be there with acceptance and support can ease the way for couples facing the birth of a child with special needs. A church sends a positive message to such couples when it is attuned to needs of those who are disabled and is willing to journey with families. Important help can come in the form of caring teams, respite care, and special provisions for nursery care and Sunday school. Pastors and congregations need to be aware of overt or covert messages they may be sending that indicate a lack of support for or intolerance of those with special needs in the church. Ministering to those among us with special needs is an important mission of the church, and it can begin even before the baby is born, through careful examination of attitudes, policies, programs, and facilities in our congregations.

The words we use are powerful and can reflect whether and how we value others. Sometimes words intended to encourage or comfort may offend. Even some Scripture passages may be used in hurtful or confusing ways. It is usually unhelpful to try to explain why God would allow a child to have a disability. Equally unhelpful are statements that suggest the couple must be special to have been assigned the challenge of parenting a child with a disability; also problematic are comments that special children are gifts from God. All children are precious gifts from God. Pastors and congregations can play a key role in conveying this message.

Since Elise's birth we have been surrounded by the supportive and encouraging words of friends and family, and we accepted and loved her from the start. We were full of joy, not grief, when she was born. We never heard condolences; people did not offer platitudes suggesting that her disability was a test of our faith, a punishment for our sin, a lesson we needed to learn, or God's plan intended for our good. We were aware of God's presence with us from the beginning, giving us courage, strength, and wisdom to accept the unexpected news about Elise. As a result we saw her as a gift, just as her older sister was a gift, though her challenges and journey through life are undoubtedly different.

When Elise was two years old, we attended a weekend reunion with friends. One evening we were in a large room. A man was lying in the back of the room on a cot. Because of a serious degenerative disease, he was in pain. Many young children played near him, but it was Elise who noticed him and went to his side. As she patted him, stroked him, and gently mumbled to him, he was moved to tears. She was the only child who had reached out to him that weekend. Through her care, God touched this man's heart in a way that none of the rest of us could.

At its best, the church embraces each new life as precious, feels gratitude for every child's gifts and talents, and watches for God's purposes to unfold in each child's life. God can use each of us to fulfill his purpose. The presence of an extra chromosome does not change our worth in God's eyes. In fact, his power is made perfect in our weakness, as he uses our imperfections for his glory.

## Notes

[1] Spina bifida is a defect of the spinal column resulting from the failure of the spine to close properly in the first month of pregnancy.

[2] Sometimes the screening test result is a false negative: the levels are normal although the baby has one of the defects.

[3] In this procedure, called chorionic villus sampling (CVS), samples of cells that line the placenta are removed and tested.

[4] Noreen M. Glover and Samuel J. Glover, "Ethical and Legal Issues regarding Selective Abortion of Fetuses with Down Syndrome," *Mental Retardation* 34 (August 1996): 207–14.

[5] Ibid., 209.

[6] Ibid., 208.

[7] E. Parens and A. Asch, "The Disability Rights Critique of Prenatal Testing: Reflections and Recommendations," A special supplement to the *Hastings Center Report* 29 (September–October 1999): S1–S22.

[8] Ibid., 10.

[9] Ibid., 7.

[10] *Down Syndrome News: The Newsletter of the National Down Syndrome Congress* 17, no. 7 (September 1994), 3.

[11] Parens and Asch, "The Disability Rights Critique," 9.

[12] Peter and Mary Graber, *Lessons from Emily* (Goshen, Ind.: Mennonite Mutual Aid, 1993).

## About the author

Sherry Wenger, Goshen, Indiana, is a nurse, wife to Curt, and mother of Olivia and Elise. She worked as a nurse for twenty-two years, ten in nursing education and administration. Currently at home full time, she serves as president of a Down syndrome parent support group, on the executive board of the Anabaptist Disability Network, and as a council member for the local early intervention program for children with disabilities.