Ministering to Moral Pioneers
Prenatal Testing and Christian Parenting

Bridget Burke Ravizza

Parish ministers can do more to accompany people who are considering the hefty ethical questions that come with prenatal testing in light of their Christian faith. Catholic women and their partners need support and guidance in their attempt to discern what it might mean to be good Catholics in relation to these technologies.

The prospect of parenting has always been somewhat daunting—after all, with any child comes increased responsibility and uncertainty—but today’s reproductive and genetic technologies put a whole new set of moral quandaries in the laps of parents-to-be. We often imagine that couples who are dealing with infertility (up to one in six couples) are the ones facing moral dilemmas about these technologies, and indeed they are, but fertile couples are also likely to face difficult choices about reproductive and genetic technologies. Prenatal testing—using technology to test a fetus for various conditions associated with disease and/or disability—is increasingly routine in prenatal care. Such tests can detect a number of anomalies—from a cleft palate or extra digit to more severe conditions such as Tay-Sachs or neural tube defects. Women in certain “risk” categories, such as women over 35 years of age, or women with a family history of a particular condition, are especially encouraged to utilize available tests; but prenatal testing for

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all pregnant women now is considered by many to be a standard part of good prenatal care. To complicate matters, for those using in vitro fertilization, it is possible to test embryos for certain traits prior to implantation in the woman’s body (called preimplantation genetic diagnosis, or PGD). Today, PGD is used to avoid the implantation of embryos with certain medical conditions or to select for a particular sex; in the future, parents will likely be able to select for any number of genetic traits, such as height and weight, and enhance those traits through genetic manipulation.

What women (and their partners) do with the “positive” results of fetal genetic testing obviously varies, but they frequently result in termination of the pregnancy. Studies show, for example, that approximately 90 percent of women who test positively for Down syndrome decide to abort (Kennedy Shriver, 1; Rapp, 97). Rayna Rapp, an anthropologist who has researched women’s experience with prenatal diagnosis (in particular, amniocentesis), contends in Testing Women, Testing the Fetus, that “the construction and routinization of this technology is turning the women to whom it is offered into moral pioneers: situated on a research frontier of the expanding capacity for prenatal genetic diagnosis, they are forced to judge the quality of their own fetuses, making concrete and embodied decisions about the standards for entry into the human community” (3). Rapp rightly uses pointed language here about moral pioneering and determining “standards for entry into the human community.” While testing is more and more frequently viewed as a routine part of prenatal care, many disability rights activists, bioethicists, and others warn that it is morally dangerous, leading to a kind of “quality control” that bespeaks eugenics.

The Power of Technology and the Myth of Neutrality

It is clear that Catholic women and couples need support and guidance in order to negotiate these technologies, which are often presented in the medical community as morally neutral. In the United States, reproductive and genetic technologies are largely discussed and understood within a liberal, capitalistic framework. In this framework, the autonomy of the individual—the freedom to make choices according to one’s notion of the good life—is highly prized, if not absolutized. As a result, many medical professionals and genetic counselors are committed to “value neutrality.” Their goal is to help the client understand the options, the diagnosis, and the science behind the technologies, which will promote an informed choice. They do not, as a rule, advise a client toward one option or another, nor is it their responsibility to discuss the religious or ethical dimensions of possible choices. However, in the context of prenatal testing, Rapp calls the counselor’s goal of value-neutrality “a thorny one” since the technology is “explicitly developed to identify and hence eliminate fetuses with problem-causing chromosomes (and
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Increasingly, genes)" (59). Indeed, some theologians and feminist scholars note that while the proliferation and routinization of testing often is perceived as purely beneficial because it “increases choice,” in fact the technologies can limit certain kinds of choices and force burdensome choices on pregnant women. As a result, often women feel the need to justify either: (1) a refusal to use technologies or (2) a decision to continue with a pregnancy after a positive diagnosis.

Consider, for example, a forty-year old woman who is strongly encouraged by her doctor to have an amniocentesis and, upon a diagnosis of Down syndrome, is repeatedly told to consider all of her options before “deciding” whether to continue with her pregnancy. The obvious assumption here is that abortion is an option to carefully consider and that the diagnosis of Down syndrome is a reasonable and likely justification for termination. (In fact, for those concerned with the cost effectiveness of prenatal testing, abortion is considered the preferred option.) In a case of positive diagnosis such as this, disability rights activists note that one trait—the chromosomal disorder—too often begins to stand in for the whole, or the essence of the fetus. In the words of Bruce Jennings, a senior research scholar at the Hastings Center, the technology thereby has a “powerful reality-shaping force” insofar as the diagnosed condition becomes the dominant or “only reality of the pregnancy” in the parents’ imagination. In this way, testing can have a “morally corrupting effect” by limiting the moral vision of the parents (139). Jennings stresses the importance of the development of an expansive moral imagination that can equip people to make truly informed moral choices rather than being pushed in a particular direction through the “genetic imaginary” or the limiting image of the fetus given to the parents through technology. He emphasizes the importance of parents and families surrounding themselves “with other types of discourse,” including religious discourse, which can “carry very different interpretations of . . . pregnancy and that place it in quite different narratives than those offered by medicine and genetics” (Jennings, 140). I should note here that, contrary to Roman Catholic Church teaching, Jennings supports the right of women to terminate pregnancies (as do many disability rights activists and scholars who nevertheless condemn the abortion of fetuses with disabilities). His concern is that women/couples make truly informed decisions, supported by a broad and thick moral vision.
Generally, discussion of options with medical professionals and genetic counselors is not enough to help people of faith make decisions about reproductive and genetic technologies. The fact is that these specialists are part of a medical system that is not neutral, developing and using technologies that are not neutral. The scientific discourse offered—along with the liberal, capitalistic framework that is often at play—must be supplemented, even counteracted, by another narrative: the Christian narrative. My contention is that a vibrant alternative discourse should be alive and well in our parish communities. I think we can and ought to do more to minister to people who are considering the hefty ethical questions that accompany prenatal testing in light of their Christian faith. Catholic women and their partners need support and guidance in their attempt to discern what it might mean to be “good Catholics” in relation to these technologies.

**An Alternative Discourse:**
*Expanding the Moral Imagination*

The magisterium is surely doing its part to address these issues theologically and provide direction. For example, the 2008 Instruction from the Congregation for the Doctrine of Faith, *Dignitas Personae*, directly responds to bioethical questions prompted by new technologies. It clearly builds on the CDF’s 1987 *Donum Vitae* as well as other encyclicals, speeches, and documents that concern issues of life, biology, technology, and sex. *Dignitas Personae* is straightforward and specific in its teaching regarding what uses of technology are morally appropriate based on a theological anthropology and understanding of human sexuality. On one hand, technology is considered beneficial insofar as it can safely diagnose conditions that may be treated in utero (such as the presence of a hole in the fetus’s heart) and insofar as it provides information that can help parents prepare to care for a baby with special needs. Hence, the magisterium deems acceptable prenatal diagnosis that respects the integrity of the embryo and “is directed toward its safeguarding and healing” without subjecting it to disproportionate risks (*Donum Vitae*, sec. 1, no. 2). On the other hand, preimplantation diagnosis is considered “...the expression of a eugenic mentality that ‘accepts selective abortion in order to prevent the birth of children affected by various types of anomalies.’” PGD is summarily rejected by the magisterium because it “presumes to measure the value of a human life only within the parameters of ‘normality’ and physical well-being.” (*Dignitas Personae*, 22; *Evangelium Vitae*, 63). In addition to the teaching of the magisterium, philosophers and theologians (both Catholic and Protestant) are conversing and thinking through the use of these technologies philosophically and theologically. Combined with church teaching, the work of these scholars can help people inform their consciences, enabling them to evaluate reproductive and genetic technologies, and faithfully discern if and how to utilize them.
But are ministers in parishes doing enough to expose people to this information, assist in its translation, and encourage discussion of it? In my experience, a gap exists between: (a) church documents and the work of bioethicists in the academy and (b) education and discussion at the parish level. For instance, my husband and I help prepare engaged couples for marriage through our parish. As far as I know, within the standard preparation for marriage in our diocese, there is no extended conversation about the choices couples may face around reproductive and genetic technologies nor any intentional examination of church teaching or theology that might offer guidance. It may be prudent to move beyond discussion of natural family planning to include these issues in marriage preparation programs; as noted above, they are issues that many couples will encounter. Moreover, anecdotal evidence from conversations with people who work in parishes throughout northeastern Wisconsin points to a lacuna regarding teaching and conversation on these subjects with Catholic adults. So I wonder: if couples are not formally discussing these matters when preparing for marriage and are not educated about them at the parish level, is the church doing enough to equip people to make ethical choices about reproductive and genetic technologies? I recognize, of course, that interested individuals and couples can research pertinent church teaching and theology on their own, but do they? I would venture to guess that many (most?) couples in parishes do not make a habit of reading encyclicals and the work of bioethicists on their own initiative. Even when they do, qualified assistance in thinking about such texts and applying the information to their lives would be beneficial. It would serve the church well to be more proactive, particularly when we have the opportunity to help people reframe these issues, envisioning them as communal rather than simply private and personal.

I am a theologian by training, not a minister, but I would like to suggest a few ways that we might better equip people to make good choices about reproductive and genetic technologies—particularly genetic testing—in our churches. The following goals overlap, but are distinguished here for clarity.

**Goal One: Create a Safe Space for Conversation**

A couple of realities make this goal particularly challenging. First of all, civil conversation is not modeled well in the wider culture. Instead, when sensitive issues are “discussed” on news and talk shows we often see demonization of others, the repetition of sound bites, and people screaming over one another. In our church communities, we clearly need to foster a different, respectful level of discussion about sensitive topics. In the spirit of charity, we should be able to listen and to speak to one another in a common effort to inform our consciences and follow Jesus Christ. Second, I sense some hesitance to encourage and participate in conversation in our churches about ethical issues that can be controversial and divisive. I dare say...
that a punitive environment—in which ministers and others lose their jobs in Catholic churches and schools, and in which people are denied the sacraments for acting against, or expressing positions contrary to, the magisterium’s teaching—creates fear in the hearts of people and contributes to this hesitance. While I understand the need for church leadership to establish certain boundaries and ensure that its teaching is properly understood, it must also take very seriously the pastoral effects of such decisions. When people fear being reprimanded, critical questioning and open conversation are stymied. Unfortunately, as a result, decisions continue to be privatized and individualized rather than discussed and discerned communally. Moreover, it seems that too often education and conversation are falsely equated with relativism or “leading people astray.” In other words, some people assume that if issues (e.g., reproductive and genetic technologies, abortion) are openly discussed in our parishes, it will confuse people and imply an “anything goes” mentality. On the contrary, I think if we take these issues seriously, we ought to be talking about them and examining them critically with the help of church teaching and theology. Are not our churches the very places that this should be happening?

All in all, ministers need to be courageous in order to foster discussion and promote education about Christian parenting and technologies. Further, they must be given the tools necessary to do so (more on this below). To be sure, the decisions that couples must make around reproductive and genetic technologies are charged and not easily talked about; they deal directly with heart-of-life matters such as sex, birth, family, and death. These are messy and complicated matters, and—again—our tendency is to treat them as purely personal and private. But this does our parishioners a disservice by pushing the decision-making into their living rooms and out of their churches. Church leaders must be supportive of the efforts of ministers to create safe spaces for conversation, trusting that critical examination of issues will—through faith and reason—lead people to what is right and good. We must create an environment in which people can safely and truthfully consider what it means to use (or not use) technologies as a member of a Christian community.

**Goal Two:**
**Expand the Moral Imagination by Telling the Story**

Simply put, a good place to begin ministry to “moral pioneers” is by telling the Christian story and helping them understand and embrace it. If the trend in the wider culture is to place decisions about reproductive and genetic technologies in a consumer-driven, liberal framework, then a Christian framework is necessary in order to expand the moral imagination. Autonomy and the fulfillment of individual needs, for example, are values that must be supplemented—and sometimes
challenged—by Christian values, such as: hospitality, respect for the human person as made in God’s image, a preferential option for the poor, and the common good. These values, rooted in the Christian story, can serve as a compass for moral decision-making.

Ministers can encourage people to move beyond the notion that the evaluation of reproductive and genetic technologies is fundamentally about the freedom to make choices according to personal preference. In *Prenatal Testing and Disability Rights*, Mary Ann Baily, a woman who grew up Catholic, explains why she had amniocentesis. She frames her decision-making in the language of choice. She writes: “... all other things equal, disability (specifically, a disability for which I would consider an abortion) would make life more difficult for my child, my family, and me. This is not the same thing as saying it would be an overwhelming burden or would make a fulfilling life impossible. It does not mean that my child, my family, and I could not handle the difficulties. It means only that if I have a choice, I would prefer to avoid them, for all our sakes. And I believe that I do have a choice” (67). She argues that: “even with substantial social support, life will still be more difficult for people with genetic disabilities and for their families than it would be in the absence of the disability. People who believe they have a choice may still reasonably prefer to avoid the difficulties,” adding, “most people are ‘risk-averse’ ” (70).

Surely, Baily’s autonomy is a good to be protected; her firm claim to shape reproductive decisions that will dramatically affect her life and her family’s seems appropriate (unfortunately, many women in the world have little or no say in such matters). And yet the way she frames the decision seems overly narrow. What Baily emphasizes repeatedly is her ability to choose, and—more specifically—her right to choose what will make her life (and the life of her family) most comfortable and secure. From a Christian perspective, there are other goods to be considered. The Christian narrative asks something more of us. It calls us, in contrast, to be uncomfortable, to forego security for Gospel values, to embrace risk. Theologian Sallie McFague helpfully describes the converted Christian life as “life on the edge of the raft,” an image that conjures up vulnerability, even danger, rather than comfort and safety. A number of theologians today, such as Stanley Hauerwas and Thomas Reynolds, offer us extended reflections on the Christian narrative and how it relates to disability, developing the notion of vulnerability as essential to the Christian life. They argue that Christians are called
to follow the way of the nonviolent Jesus, a way marked by gentleness, vulnerability, radical hospitality, and communion in diversity. Such a way of life is inherently risky because it stands in contrast to a value system that prizes control, self-sufficiency, independence, autonomy, and productivity, a system that rejects those who do not meet certain standards of what it means to be human. Christianity is a way of living in community that embraces the way of the cross, entailing a willingness to suffer with and on behalf of the other rather than seeking to escape all suffering. If Baily is correct that most people in our society are risk-averse, then we must work to emphasize this alternative discourse—one that honors risk and vulnerability in the name of love—in our church communities. Ministry begins, then, not with a list of dos and don’ts, but with the repetition of the Christian story and the basic question: how do we conform to Christ?

**Goal Three: Commit to Persons with Disabilities and Educate the Community**

Persons with disabilities and their families are often marginalized, even ignored; and our churches are not exempt from this kind of treatment. Christians must commit to overcoming such marginalization, breaking down walls of fear and exclusion. (See Jean Vanier’s essays in *Living Gently in a Violent World* for excellent reflections on the Christian call to overcome anxiety and exclusion as it relates to disability.) Living in solidarity with persons with disabilities can take many forms, such as: ensuring inclusive worship (meaning more than physical accessibility); advocating for quality education for children with special needs; and offering resources to persons with disabilities and their families. Theologians Joel Shuman and Stanley Hauerwas powerfully claim that the whole Christian community is obligated to care for persons with disabilities, not just the parents and families of those persons. Hence, if we do not create a welcoming community in which we adequately care for persons with disabilities, leading some parents to “feel they have no choice but to abort a disabled child,” we all bear the burden of responsibility (Hauerwas and Shuman 2000, 135). The refusal to see every person as made in God’s image and as a valuable part of the body of Christ is a failure of the community. Recognizing this lack of moral imagination and subsequent lack of care for one another reminds us that abortion is not simply a matter of individual morality.

Due to marginalization in church and society, many of us have little or no interaction with persons with disabilities. Therefore, as disability activists note, it is not uncommon for those who discover a positive diagnosis to rely on an understanding of disability based on stereotypes and misinformation. The immediate assumption upon a positive diagnosis is often that it means tragedy for a family,
and that disability will negatively affect its overall quality of life. Hence it is vital for persons be exposed to current and accurate information about the realities of living with disabilities. In fact, the bulk of recent literature suggests that the quality of life of families of children with severe disabilities resembles that of families generally (Ferguson, Gartner, and Lipsky). Research shows that families adapt to different challenges, whether or not the families include children with disabilities. Some married couples and families do not adapt successfully, but many do, and thus report a good quality of life; social support from within the community and within the family has a “powerful mediating role” to play (Risdal and Singer, 96). Indeed, persons with disabilities and their families often tell joyful, positive stories about their lives, stories that are far from tragic. But do we hear them? Do we know about the experiences, positive as well as negative, of persons with disabilities and their families? Many of us do not, including the medical professionals and genetic counselors who discuss the results of prenatal tests with their clients. (Ferguson, Gartner, and Lipsky, 73). Hans S. Reinders, a theologian interested in ethics and intellectual disability, suggests that hearing accounts of persons with disabilities (and their families) and living in solidarity with them, will—ideally—result in a different kind of moral discernment as we consider reproductive and genetic technologies. Those who are temporarily able-bodied will be more capable of imagining that people with disabilities “lead lives as rich and complex as their own” and will act accordingly (Asch and Parens, 8).

So what are the implications of this for ministers? First of all, ministers should take the time to make themselves aware. It is vital to be cognizant of those within our church and local communities who are living with disabilities. Talk to them. Discover what their needs are and how the church community might help meet those needs. Make a commitment to fully include them in liturgy and other church activities. Full inclusion may be challenging depending on the situation, but this seems an important goal. Details must be worked out at the parish level with open and honest conversation about specific challenges, such as: safety concerns, disruption, and possible discomfort of either the temporarily able-bodied or persons with disabilities. These are teachable moments for all involved. In such efforts toward inclusion, education of the members of the community will likely happen organically. But more formal education is also important.
Two levels of education apparently are needed: *broad education at the communal level*, and *specific education/guidance* for those who are actually considering or using reproductive and genetic technologies, and who may in fact have gotten a positive diagnosis. Broad education of the community—about disability and about the ethical implications of reproductive and genetic technologies—is key in order to expand the moral imagination. One benefit of proactive education at the communal level is that, when people do get a positive diagnosis, they are likely to feel vulnerable and scared, and may be under time constraints to “consider options.” This is not the ideal time to begin education and formation of conscience. Moreover, a focus on education of the whole community broadens responsibility and rightly sees these issues as communal ones. Ministers can do broad education through programming, such as: book discussions, films, and panels of persons with disabilities and families—drawn from the parish or the wider community—who are willing to share their experiences.

Depending on the type of program and the background and training of the minister, experts (i.e., bioethicists, theologians, counselors, disability activists) may be needed to help design and/or lead these programs. More generally, ministers might need additional formation in order to properly educate the community, which will require funding and accommodation. Perhaps funding could come through the USCCB (Pro-Life Activities) or other diocesan or Pro-Life sources. Proper education and training will be particularly important for those who handle both the broad education of the community and the specific education/guidance for couples discerning technologies.

It would be especially helpful to have a designated resource person with expertise in the parish (or in a group of parishes), whether ordained or lay. This person could coordinate efforts to meet the needs of persons with disabilities within the community and to educate, broadly and specifically. The presence of this resource person(s) would be advertised in the church community(ies) so that he or she could be sought out by couples who are facing decisions about reproductive and genetic technologies. Strict confidentiality would be essential, considering the vulnerability of couples around these issues. Depending on his or her expertise, the resource person may:

- help couples think through the religious and ethical implications of the use of various reproductive and genetic technologies
- direct folks to pertinent resources (church documents, theological and philosophical works that address these matters) and be available to answer questions or discuss them
- respond when couples receive a positive diagnosis (at the impetus of the couple)—this could involve: assisting in the discernment process (making references for counseling if necessary); educating about the realities of living with disability; and directing the couple to community disability resources.
Some Concluding Thoughts

The rapid routinization of prenatal testing should give us pause. We must take seriously the high numbers of women who choose to abort when facing a positive diagnosis of conditions like Down syndrome. Moreover, we must acknowledge that, in general, Catholic women do not use abortion services less than non-Catholic women. National and regional surveys suggest that Catholic women obtain about 32 percent of abortions in the United States, which is a figure higher than their representation in the general population (Rapp, 252). As explained above, a moral vacuum has been created by the “value-neutral” approach of many in the medical community regarding decisions about reproductive and genetic technologies. Particularly in our culture—which is highly influenced by consumer-driven, liberal values—Catholic couples need more assistance in order to inform their consciences and discern their interaction with these technologies. We must do a better job in our parishes by: living in solidarity with persons with disabilities; educating about issues surrounding reproductive and genetic technologies; and creating safe spaces for conversation in our churches. And we must commit to properly educating the ministers and resource persons who can lead the way. Rapp’s research on prenatal testing shows that “strong religious affiliations” and “strong kinship or other communitarian social support” are among the reasons that women are “most likely to decide against the biomedical information amniocentesis brings as a basis for accepting or rejecting a particular pregnancy” (190). (One can safely assume this is true for other kinds of prenatal tests as well, not only amniocentesis.) We have an opportunity to more intently build up our church communities as it relates to parenting, technologies and disability. We should answer the call.

References


Moral competence is: The ability to resolve problems and conflicts on the basis of one's moral principles through deliberation and discussion, instead of through violence and deceit, or through submitting to others. Operational definition (MCT): The MCT measures participants' ability to rate arguments by their moral quality rather than by other criteria like opinion-agreement. World Health Organization. WHO Library Cataloguing-in-Publication Data. Neonatal and perinatal mortality: country, regional and global estimates. 1.Infant mortality - trends. 2.Fetal mortality - trends. 3.Data collection - methods. I.World Health Organization. ISBN 92 4 156320 6 ISBN 978 92 4 156320 8. (NLM classification: WS 16). © World Health Organization 2006 All rights reserved. Publications of the World Health Organization can be obtained from WHO Press, World Health Organization, 20 Avenue Appia, 1211 Geneva 27, Switzerland (tel: +41 22 791 3264; fax: +41 22 791 4857; email: bookorders Keywords: noninvasive prenatal testing (NIPT), implementation, global, ethics, genetic testing, chromosome aneuploidies. Introduction. In many countries, the use of maternal serum marker screening and ultrasound imaging (ultrasonography) to detect chromosome aneuploidies and other birth defects are a routine part of prenatal care in the first and/or second trimesters. However, both of these approaches suffer from high false positive rates, ranging from 2%–7%. If these tests indicate that a fetus is at increased risk of aneuploidy, invasive methods like chorionic villus sampling (CVS) or amn