Eugenics Triumphant in Prenatal Testing

Mary Meehan

Part II: The Resistance

The first part of this series described the deep influence eugenics—the effort to breed a better human race—had in encouraging prenatal testing and eugenic abortion. It explained the major roles of the American Eugenics Society, the American Society of Human Genetics, and the March of Dimes in spreading the deadly combination. Part II will show how the U.S. government has funded and promoted prenatal testing and counseling. It will describe how the testing-abortion combination has made pregnancy an ordeal for many women and couples. It will report resistance to the eugenics program and suggest how that resistance might become stronger.

The Heavy Hand of Government

In the 1960s, there was great interest in genetics at a major government agency, the National Institutes of Health. But Rep. John Fogarty (D-R.I.), a key congressional supporter of NIH, was bothered by some 1963 discussion about preventing births of handicapped children. “That is what Hitler was trying to do, was he not?” Fogarty asked. After the congressman’s sudden death by heart attack several years later, President Lyndon Johnson named NIH’s Fogarty International Center in his honor. The Center, ironically, sponsored a 1970 conference on prenatal testing that defied Fogarty’s warning.

Government agencies quietly had funded research on prenatal testing in the 1960s; but the 1970 conference signaled a major push for it. Eugenicists and some of their fellow travelers from both the U.S. and England were there. One eugenicist chaired the conference, and others gave major talks.

Amniocentesis was the main method then used for prenatal testing. It’s an invasive procedure in which a doctor pushes a needle through a woman’s abdomen and into her uterus to withdraw amniotic fluid for analysis. The test itself causes anxiety. When followed by eugenic abortion, it has devastating effects on many couples—especially on the women. Yet of the 58 participants in the 1970 NIH conference, only three were women. Participants barely mentioned the psychological effects of eugenic abortion. Discussion of ethics was limited and heavily weighted toward the eugenics side. The fix was in.

Abortion was still illegal in most states, for most reasons, when the
conference took place. But eight years before, the American Law Institute had proposed that states allow abortion when there is substantial risk of grave fetal defects. Eleven states allowed this by the time of the NIH conference. Denmark’s similar provision for eugenic abortion, dating back several decades, had enabled research on prenatal testing in the 1950s and 60s. In the U.S., changes in state laws now offered more research subjects.

Kurt Hirschhorn, a leading geneticist, told the NIH conference about his laboratory’s work on prenatal testing in pregnancies “that were going to be terminated for other reasons.” Ironically, in his youth the Austrian-born Hirschhorn had fled the Nazis, who also did experiments on humans destined to be “terminated for other reasons.” After Hirschhorn finished medical school and some postgraduate work in the U.S., the American Eugenics Society recommended him for a medical-genetics fellowship. That enabled him to study genetics in Sweden and to write an article about Western European genetics for a 1958 issue of *Eugenics Quarterly.*

In a 1993 interview, though, he said he was not a member of the eugenics group. To the suggestion that experience as a refugee from the Nazis should have made him “very anti-eugenics,” Hirschhorn responded, “Oh, I’m not for eugenics at all” and denied that prenatal testing is one form of it. He said that “you’ve got to differentiate between genetic manipulation of populations as opposed to helping a particular family with a particular problem.” Many others make this argument, but it does not stand up historically. As early as 1940, eugenics leader Maurice Bigelow called for primary emphasis on “family eugenics.” And in 1972 Hirschhorn himself referred to abortion for disability, at the family level, as “negative eugenics.”

Other refugees from the Nazis who played a role in American eugenics included geneticists Franz Kallmann, Arno Motulsky, and Curt Stern and medical statistician Christopher Tietze. While they rejected the ethnic and racial bigotry of eugenics, they accepted its bias against people with disabilities. This contradictory attitude is still widespread today.

Of the icy hearts at the 1970 NIH conference, some seemed frozen right through. Amniocentesis at times causes miscarriage of a child who is not disabled. But one participant remarked, “I don’t think we should be overwhelmingly concerned about aborting a normal fetus. For social reasons this is going to be done more and more commonly.” Another participant suggested aborting not only affected children but also carriers of some harmful genes. Still another said this could be done “for generation after generation.”

Leon Kass, an M.D. with a special interest in ethics, was alone when he asked, “Are there suboptimal babies? Will they get suboptimal rights? . . .
Doesn’t society rest on the presupposition of equal respect for all human life?” But a high-ranking NIH official, Robert Berliner, remarked that NIH had avoided “overly rigid positions” on medical ethics. “We believe,” he added, that ethics policy must be “developed by the very people charged with carrying it out—clinicians, investigators, and their colleagues—and not by administrators in Washington.”

How the Government Manipulates Its Citizens

As NIH revved up funding of prenatal-testing research, a committee linked to the National Academy of Sciences studied how to institutionalize genetic screening in medical practice. (Although technically private, the Academy is the federal government’s official adviser on science and technology.) The committee produced a book on genetic screening that included the question, “Can Behavior Be Modified without a Direct Attack on Motives and Beliefs?” Yes, the committee said, it’s possible to persuade people to act “rather independently of their belief systems.” The key lies in “structurizing of the environment” by law and/or having something accepted as part of regular medical practice. The committee found it “interesting and encouraging” that change in behavior often leads to change in beliefs. It piously added that trying to change behavior without changing its psychological basis “may not always be ethical” and then suggested working on both components. To draw more people to genetic screening, it said, “A spokesman should be chosen who is likely to be believed by the intended audience.” That person “should be seen as knowledgeable, unbiased, likable, noncontroversial, similar to the audience in some respects, and having the best interest of the audience at heart.” The committee added: “For one group, a black physician might be an ideal spokesman; for another, a schoolteacher; for another, a mother of a child with Down’s syndrome; and so on.”

Down the road, this approach would help produce great victories for eugenics.

Meanwhile, supporters of prenatal testing “structured the environment” by making the testing a part of routine obstetrical practice. After Roe v. Wade, state courts helped achieve this by making large financial awards in “wrongful birth” cases. They made the awards to parents who had not been offered prenatal tests that—if used in combination with abortion—could have prevented the births of their handicapped children. Such awards put heavy financial pressure on obstetricians. To that stick for doctors, insurance companies added a carrot for parents by covering costs of the testing and abortions.

Margery Shaw, a geneticist who held both medical and legal degrees, was a strong supporter of wrongful-birth cases. In 1977 she wrote that “we are
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witnessing a neo-eugenics movement.” She had good reason to know this, since she was on the 1974 membership list of the Society for the Study of Social Biology. That’s the old American Eugenics Society, sailing under its newer and more respectable flag. (The old pirate crew had hauled down its skull-and-crossbones banner and hoisted, instead, a bland and boring one.) Shaw suggested it was “only a matter of time” until doctors would be required to offer amniocentesis to pregnant women.

State-court awards for “wrongful birth” had accomplished that in large measure when Shaw addressed the issue again in 1984. In her earlier article, she had referred to “defective children” and “mental defectives,” but this time she argued for eugenic abortion as a benefit for such children. From the child’s viewpoint, she wrote, “a rational argument can be made that non-existence is preferable to existence filled with incapacities and suffering.” Society, she said, “should decide to wipe out muscular dystrophy, Tay-Sachs disease, cystic fibrosis, and sickle cell anemia.” But that meant wiping out unborn children who had those diseases.

Meanwhile, government support for prenatal testing had grown steadily after Sen. Edward Kennedy (D-Mass.) led a successful effort to pass the 1976 Genetic Diseases Act. Kennedy aide W. Carey Parker, a geneticist and an attorney, had shown the eugenics orientation so widespread in genetics in a 1970 article for Birth Defects. Writing when abortion was still illegal in most states, and when prenatal testing was not fully developed, Parker said that “the possible birth of a defective child” was something that could “produce drastic and irreversible effects” on a family. Then he predicted: “Once the certainty of a seriously defective fetus can be determined, once the information provided by genetics is more complete, there will inevitably be pressure on the states to ease their abortion laws to accommodate such cases.”

After Roe v. Wade cleared the way, Senator Kennedy and others put the 1976 genetics law through Congress as part of a larger health bill. It involved the federal government deeply in promotion of genetic testing. The 1975 Senate hearing on the bill included testimony from three geneticists who were, or later would be, associated with the renamed American Eugenics Society: Margery Shaw, Arno Motulsky, and Michael Kaback. Either during the hearing or in formal statements submitted for it, Motulsky, Kaback, and others specifically referred to prenatal testing. But floor debates were vague, and the final bill provided support for “genetic testing and counseling”—not excluding prenatal testing yet not mentioning it specifically, either. Many members of Congress probably didn’t realize that prenatal testing would be covered and that it was closely linked to abortion. Advocates of the bill kept
the debates vague because abortion was then, as now, an extremely divisive issue in Congress. (Most Senate members supported it then, while most House members opposed it.) As Beverly Rollnick wrote in her doctoral dissertation on the bill, two key staff members “avoided any overt or covert reference to any social or eugenic issues during the legislative process,” since they “did not want to alarm the anti-abortion lobby.” One of them “deliberately kept the screening language in the House bill as general as possible to provide flexibility.” The stealth strategy worked. Looking to the future, Rollnick remarked: “The brave new world may arrive unheralded, taken for granted as part of routine medical care.”

The 1976 genetics law authorized aid to states for genetic-testing services. By now, many states have encouraged prenatal testing for decades. Combined with pressures from state courts and the private medical establishment, this has institutionalized eugenics in a profound way. When testing indicates Down syndrome or anencephaly, abortion rates soar to 80-90 percent or even higher.

California has a notably vigorous screening program. Years ago, a doctor who led it presented eugenic abortion as a way to reduce the cost of medical care. According to a 1986 report, the doctor “estimates that if 90 percent of women found to be carrying severely malformed babies choose abortions, $13.3 million will be saved statewide in lifetime medical costs for every 100,000 women screened.” California also has a Birth Defects Monitoring Program. A 1995 study, based largely on data from that program, estimated the extra lifetime cost of someone with Down syndrome at $451,000. Why, one might ask, doesn’t anyone calculate the extra lifetime cost of eugenicists? Or of their many supporters in the American establishment? We could count their high salaries, the palatial homes and upscale cars that some have, luxury vacations abroad, and so on. And let’s not forget their medical costs: Some may need expensive medical care, possibly on several different occasions. Perhaps each of them costs far more than someone with Down Syndrome. Or perhaps we shouldn’t reduce human life to cost estimates. In the “Peanuts” comic strip, Charlie Brown’s little sister once exclaimed that Snoopy “is more trouble than he’s worth!” And Charlie Brown replied, “Most of us are.”

The Ordeal that Couples Face

The early use of prenatal testing, to treat Rh blood incompatibility, was truly therapeutic. Some use still is therapeutic in intent and result; and if all of it were, there would be universal praise for it. But the testing would be far more limited than it is today. It would not involve screening nearly all pregnant
women, and it would not be the search-and-destroy mission that it has become. Since the early days of eugenic testing, many couples have gone through ordeals of anxiety and dread. Enticed or pressured to have the testing as part of routine care, many suddenly find themselves torn between eugenics and their own ethical convictions. Those who are told their babies have serious handicaps, and who decide to abort them, suffer grief and often much guilt as well. Advocates of prenatal testing have known this for decades. Yet they have not questioned the whole eugenics enterprise, nor felt guilty about the misery they have caused. Instead, they have developed more screening, such as the alpha feto-protein (AFP) test and chorionic villus sampling (CVS). Now many women undergo a whole battery of tests, sometimes over a long stretch of pregnancy. Many, finding that their children have disabilities, undergo abortion when they can feel their babies’ movements—a timing that intensifies suffering.

Some women and couples acknowledge the suffering, but say they are glad they have the choice. It enables them, they say, to have healthy children later. Some even abort for relatively minor problems such as cleft lip. Whether for major or minor concerns, they accept the eugenics rationale. Genetics counselors and their colleagues in medicine encourage such acceptance by treating post-abortive couples as bereaved parents who are grieving a natural death. They offer parents a chance to hold the baby after abortion (if intact) and to have photographs taken for keepsakes. They may arrange baptisms and suggest funeral services. It is as though no one—not the parents, nor the abortionist, nor those who brought them together—ever made a conscious decision to kill the child.

It’s doubtful, though, that grief counseling and the pretense of natural death can alleviate all the suffering. And they do nothing to relieve the stress of the testing itself. Abby Lippman, a noted feminist professor at Canada’s McGill University, once wrote that “deciding for or against testing makes many women feel they will be making a terrible mistake regardless of the path chosen.” Advocates claim that tests usually relieve parental anxiety by ruling out Down syndrome or another disability. But Lippman suggested this is a matter of “tranquilizing women who have first been made fearful.” Two other scholars said their research suggested that “over the entire pregnancy, amniocentesis may heighten rather than reduce anxiety” and that for some it “unleashed terrors that previously had been absent or suppressed.”

Some couples go through a roller coaster of emotion with unclear results, retesting, and another agonized wait for information. Many face an obstacle course in which they clear one disease hurdle only to be confronted with
others. Sometimes, too, the experts are wrong. Researcher Robin Gregg described one mother who went through a battery of tests, none of which indicated any problem with her unborn child. Yet the little boy had such severe problems that he died when only 16 days old. His mother “felt betrayed.” There are mistakes in the other direction, too, sometimes revealed when parents decline abortion despite dire predictions based on testing. After ultrasound, one woman was told her child might have Down syndrome and that his “stomach was outside of his body.” A short time later the experts “added the possibility of toxoplasmosis, and water on the brain.” Still later, there was a diagnosis of dwarfism. All of the warnings and predictions were wrong; and 18 months after birth, the little boy was doing very well.

Writing in the New York Times, Natalie Angier described her ordeal when she was told that her unborn daughter had a “clubfoot.” She and her husband didn’t know the particulars of that disability. “The term was so thuddingly ugly and Dickensian,” Angier wrote, “that we could not help imagining the condition must be ugly and severe.” But while it often requires minor surgery to lengthen the Achilles tendon, it can be corrected mainly by casting and splinting. Angier spoke to women whose children had the condition and was encouraged by what she heard. In the end, though, her daughter was born “with a lusty set of lungs, a full head of black hair—and no clubfoot at all.” Why the misdiagnosis? Angier said her own feet are “unusually supple” and that her daughter may have inherited that trait. She added: “Perhaps my daughter was dreaming that she was a ballerina, flexing her foot into en pointe position, and preparing to dance the dance.” Angier realized she was fortunate, yet her experience made her wonder: “How perfect must a person be to deserve health insurance, a job, a parent’s love, or life itself?”

Sometimes the experts say a child will be “born dying” because of anencephaly or another lethal condition, and they suggest abortion for that reason. In the old days, a couple didn’t know their child would die soon after birth, so they didn’t face months of dread. Nor did they face the guilt many now have after eugenic abortion. One woman chose abortion to prevent suffering for her child, who had a lethal kidney condition. Later, though, she said, “There are times that I really curse modern technology. No one should have to make these kinds of decisions.” Another woman received a bad diagnosis, but did not have an abortion; her child was stillborn several months later. “The only time our son lived was inside me,” she said, “and we lost all joy in that for the last four months. If we were to have a disabled child we have the rest of our lives to get used to it—why start before you can even hold them?”

One woman said a baby with Down syndrome “can live to a mature age,
and have a rather good life, so there's a tremendous amount of guilt involved—that you're getting rid of it because it is not a perfect human being.” Another, after an abortion for Down syndrome, reported that the “first few months were really horrible.” Guilty and depressed, she didn’t “want to talk to anybody, didn’t want to move, really didn’t want to do anything.” And a man whose daughter was aborted for “a brain anomaly which included seizures and clenched fists” later said, “I let the doctors kill my daughter via a huge needle, a shot to the heart through my wife’s belly as she lay sedated. . . . The grief is unbearable sometimes. Does the fact that I murdered my daughter show on my face?”

There has not been much research about the effects of eugenic abortion on other children in the family. In the early days of prenatal testing, though, psychiatrist Richard Restak reported a story that should have been a warning to many: “In Washington, D.C., the mother of a mentally retarded son visited a genetic counseling unit for amniocentesis when she became pregnant again, for she and her husband were anxious to prevent the birth of another genetically abnormal child. Upon returning home she found her retarded son hiding in a closet. Over the next few days he had trouble sleeping because of nightmares that someone was trying to hurt him.”

How do adults with disabilities feel when they learn that their parents might have aborted them? Ashley Wolfe, a young woman with Down syndrome, had done some college work, acting, and public speaking when she had a conversation with her parents about this. Her mother said she didn’t know “what I would have done” had she known in advance about the Down syndrome; she added that “I would never judge anyone who makes that choice, either way.” And her father remarked, “There’s every possibility that we would have elected to have an abortion.” Ashley gamely replied that, with abortion, “You’re ending a life. That is the fear, the insecurity of a person taking over. There are obstacles in life and you get through it.” I would guess that, despite her brave response, her parents’ comments hurt her deeply.

Three Sources of Resistance

When the Declaration of Independence speaks of our right to life, it does not exclude unborn children, people with disabilities, or any other group. The right-to-life movement, in harmony with the Declaration, believes that government has an obligation to uphold the right to life on an equal basis.

Most movement activists believe this right is a gift from God. Here, too, they are in harmony with the Declaration, which says that humans are “endowed by their Creator” with the unalienable right to life. Yet atheists
such as Nat Hentoff believe in the right to life and apply it to abortion. Queried about this once by a priest, Hentoff recalled, “I told him that it’s a lot easier for an atheist—at least, this atheist—to be against abortion because all I have is life, this life. All I can believe in is life.” Dr. Bernard Nathanson, an atheist when he turned against abortion, based his position on the ancient Golden Rule, “Do unto others as you would have them do unto you.” Nathanson said this is not a sectarian doctrine, but “simply a statement of innate human wisdom.” He added: “Unless this principle is cherished by a society and widely honored by its individual members, the end result is anarchy and the violent dissolution of the society. This is why life is always an overriding value in the great ethical systems of world history.”

Right-to-lifers are alarmed when government, instead of defending life, authorizes the killing of one or more classes of people. Thus in 1959, when the American Law Institute debated a recommendation to permit eugenic and some other abortions, attorney Eugene Quay told his colleagues: “The state cannot give the authority to perform an abortion because it does not have the authority itself. Those lives are human lives, and are not the property of the state.”

Novelist Pearl Buck explained why she would not have wanted an abortion had she known in advance that one of her daughters would be profoundly retarded. “I fear the power of choice over life or death at human hands,” she wrote. “I see no human being whom I could ever trust with such power—not myself, not any other. Human wisdom, human integrity are not great enough.” British writer and parliament member Norman St. John-Stevas, countering the idea that a handicapped baby may be better off dead, declared: “No human being has the right to make any such judgment about another human being. Even if one had the right, there would be no guarantee of making a correct decision.” And feminist pro-lifer Cecilia Voss Koch noted that “every time we cheapen someone else’s life, we cheapen our own and place it in jeopardy. Not one of us knows when she will be helpless—completely dependent on the whim of some powerful arbiter.”

There are also feminists who support legal abortion, yet discourage eugenic use of it. Sociologist Barbara Katz Rothman, epidemiology professor Abby Lippman, and biologist Ruth Hubbard are in this group. Rothman’s 1986 book, The Tentative Pregnancy, quoted many women about the sheer misery they experienced in testing and eugenic abortion. She questioned how much choice women have when they face social and medical pressures to abort for handicap. With fine irony, she said that “for those who want what the society wants them to want, the experience of choice is very real.”

Abby Lippman once said she was not trying “to limit women’s options.”
But she declared that prenatal testing "allows geneticists and their obstetrician colleagues to impose a 'choice' for abortion covertly, if not overtly, when they decide which fetuses are healthy, what defines healthy, and who should be born." Lippman proposed public funding "for home visitors, respite care, and domestic alterations" to help with major childhood health problems—whether congenital or occurring later. This, she suggested, would provide the type of reassurance women really need.39

Ruth Hubbard, biology professor emerita at Harvard, is a veteran critic of over-emphasis on genetics in health care. In Exploding the Gene Myth, she decried prejudice against people with genetic disease. She noted that songwriter Woody Guthrie, "who died of Huntington disease, lived a productive life and left a legacy of over a thousand wonderful songs." Woody’s son Arlo, she added, did not want to be tested for the late-onset disease: "As all of us die sooner or later, he feels that the point is to contribute to society while we live, rather than worry about when death will come, or from what cause." She also remarked that "all of us can expect to experience disabilities—if not now, then some time before we die, if not our own, then those of someone close to us. If only for our own good, we must dispel the dread of disability that motivates such pervasive prejudices, and so limits the lives of many people."40

Despite these excellent comments, Hubbard still “unequivocally” supported a right to abortion for any reason. In an earlier article, she had said women need this right “precisely because it is a decision about our bodies and about the way we will spend our lives.” Then she added: “But it should not become a decision about someone else’s life. Arguments regarding the ‘quality of life’ of the future child are off the mark.”41

Hubbard was born in Austria. When she was in her teens, she and her family fled the Nazis and found refuge in the United States.42 While she is keenly aware of Nazi eugenics, perhaps she has not reflected enough on the fact that the Nazis used abortion as one tool of eugenics—and reserved it for their enemies. They were pro-abortion when it prevented the births of Jews, Slavs, and people with genetic disease. They banned abortion for Germans, not because they respected human life, but because they wanted to expand the German population for eugenic and political reasons.43

The disability-rights movement should be a major source of resistance to abortion for disability. And, indeed, some disability-rights activists are also strong pro-lifers: Lillibeth Navarro and Mary Jane Owen, for example. Others, though, are feminists who support legal abortion but are conflicted over its eugenic use. When bioethics groups discuss prenatal testing, they often feature such feminists as speakers or writers. Adrienne Asch, who is blind, is one of
their favorite presenters. While she makes good criticisms of prenatal testing, her bottom line is that parents should be free to choose abortion for any reason.

Alison Davis, a feminist and disability-rights activist in England, used to support legal abortion, but began to change her mind after reading about the infanticide of a baby girl who had spina bifida. A doctor had sedated the little girl, Davis said, so that “she was too sleepy to cry for food, and thus starved to death.” Davis uses a wheelchair because she, too, has spina bifida. The baby, if allowed to live, would “have been exactly as disabled as I am myself.” Davis didn’t change her views overnight, though. She reached an intermediate position: that women have a right to abortion, but not to “a selective, discriminatory” one. Finally, though, she realized this meant that disabled people “should have more rights than anyone else,” since only unborn children who were handicapped would have protection from abortion. She understood that “if I wanted equal rights for me and those like me, I could not in turn deny them to the unborn.” Feminists who support abortion should ponder Davis’s conclusion. Meanwhile, though, we should cheer them every time they land a solid blow against the manipulation and misery of prenatal testing.

Making Resistance More Effective

Congress passed a law in 2008 to improve information and support for parents who find, before or after birth, that their children have handicaps. The law authorizes a telephone hotline for parents; expansion of a government information center on childhood disabilities; expansion of peer-support programs for parents; a registry of families who are willing to adopt children with handicaps; and “awareness and education programs” for health-care professionals. Sen. Sam Brownback (R-Kan.) was the chief sponsor and promoter of the law, and the late Senator Kennedy cosponsored it. If well-funded and well-administered, it may prove to be a major step forward.

Yet the new law does not directly challenge eugenic testing and abortion for disability. Congress has not come close to slaying the monster it helped create. We need a complete exposé of government promotion of eugenics—and a campaign to roll back eugenic laws and court decisions. That is a tall order, yet it can begin with a simple step: confronting the false history that leads many to believe that the eugenics movement died with the Nazi regime in Germany, or that U.S. eugenicists developed a “reform eugenics” after World War II—a kinder, gentler eugenics that really harms no one. Eugenics in the U.S. and Europe merely paused for a short time after the war, then roared back with a huge and successful campaign for population control.
That was—and still is—aimed primarily at poor people and minorities, at home and abroad. Eugenicists drove prenatal testing and “selective” abortion on a parallel track of their railroad in order to prevent the births of people with disabilities. There is abundant evidence on these points. But there is also a great need to get that evidence into the mainstream media.

A second step is to challenge politicians who support eugenics. We must make them come out from behind their euphemisms and defend what they support—or give it up. It’s a fair guess that many politicians will not want to defend the current system of prenatal testing once they understand its strong links with organized eugenics. But much educational work with politicians is needed. Its practical focus should be a demand to end government subsidy of the testing/counseling/manipulation/pressure regime. Instead, we should use the money to deal with environmental causes of disability, including nutrition problems. Folic-acid supplements, for example, are making a dramatic improvement in prevention of spina bifida and anencephaly.

We must show how the current, eugenic regime undermines government laws and programs that disability-rights activists have won over the past 35 years. And those laws and programs should be studied to see how effective they are and where change is needed. Employment, for instance, is still a major problem for people with disabilities. Many have benefited greatly from early intervention and special education, yet still can’t find the jobs they need when they finish school.

A third step is to challenge health-care professionals to face their own contradictions—that is, to make a decision between the “First, do no harm” principle of medicine and the “throw the disabled to the wolves” mentality of eugenics. The two approaches cannot be reconciled. With the prenatal-testing/abortion combination, eugenicists and their co-workers have institutionalized homicide as medical practice. Now they are trying to do the same thing with euthanasia. These issues are deeply involved in current battles over health care in the U.S., so it’s important to put eugenics front and center in the debate. We must force eugenicists to come out from behind their camouflage and defend—if they can—what they actually are doing.

There is also a need for ever-stronger resistance to eugenics from people who have disabilities and from their relatives and friends. There are some fine examples to follow. Barbara Sieger, a Feminist for Life activist in Wisconsin, referred to her spina bifida when she testified before state legislators years ago. She emphasized the joy of life and the way people with disabilities share it: “Please take a good look at me, not at the cosmetic of the non-handicapped, but at the beauty of God’s creative love, a human being with emotions and feelings. Children, not blinded by society’s
prejudices, love me. Friends share experiences of their daily lives, including joys, sorrows and pains, and we celebrate the joy of life's experiences together. I feel the warmth of a gentle sun, and a rose brushed up against my cheek is as velvet to the touch to me as it is to you."

Leonard Sawisch, a dwarf who has a Ph.D. in psychology, explains his perspective on disability with anecdotes and wit. In one talk, he recalled that when he was a new father and referred to his children, "Invariably, someone would sheepishly ask, 'Are your kids small, too?' and I would respond, 'So far!'" But he also highlighted the contradiction of mainstreaming people with disabilities and, at the same time, trying to prevent the births of more such people. He added that some suggest "that if we are born, we should not be allowed to live. Which way is it to be? On the one hand, I should participate fully in society; on the other hand, I should not be here."

Anya Souza and Kathy Gilbert, two women with Down syndrome, were leaders of a protest against a Down syndrome screening conference in London several years ago. The protest received enough attention that Souza was allowed to address the conference. "I can't get rid of my Down syndrome," she told participants. "But you can't get rid of my happiness... It's doctors like you who want to test pregnant women and stop people like me [from] being born. You can't abort me now, can you? You can't kill me. Sorry!" If any of the docs had dozed off during previous talks, they undoubtedly woke up for this one—and remembered it.

When Mimi and Tito Citarella were told—mistakenly, as it turned out—that their unborn child had severe brain damage, they made it clear that they would not abort her. Yet health professionals repeatedly pressured them to do just that, until Mimi finally blurted out: "What's going on here? Are you people Nazis or something?" If enough parents ask that question, the eugenics enforcers may back off.

Medical professionals are not the only offenders, though. Bare acquaintances, and sometimes strangers, ask pregnant women if they plan to have prenatal testing. Friends and family members advise or even pressure them to have it. Some parents hear appalling and deeply hurtful comments both before and after the birth of their handicapped children. Former Washington Post reporter Patricia Bauer wrote about a time when her daughter Margaret, who has Down syndrome, was a little girl and was playing in a park. "New in town," Bauer recalled, "I had come to the park in hopes of finding some friends for myself and my little ones." What she found instead was a rude, cold, young woman who was at the park with her own children. The young woman looked briefly at Margaret, then said to the person beside her, but loudly enough that Bauer could hear: "Isn't it a shame that everyone doesn't get amnio?"
A website called “Carrying to Term Pages” offers good advice on responding to such cruelty. The advice comes from “Jane,” who received pressure for abortion when her daughter was diagnosed prenatally with a fatal condition. She suggests stressing the child’s name: “The woman who sniped at me, ‘When will it all be over with?’ couldn’t keep up that nasty tone when I replied, ‘Emily’s due date is July 3rd.’” If someone asked, ‘Why aren’t you terminating it?’ she was ready with, ‘You mean why aren’t I terminating Emily?’ And when a nurse asked her “why I was waiting so long to deliver”: “I said in a very even tone of voice that I probably had 60 more years to live; Emily had four months. Four months wasn’t a very long time, considering. She softened up after that.” According to Jane, responding with dead silence and a furious stare “works on the worst offenders.”

The Can-Do Approach

There are many other websites—and also books and support groups—for parents who have children with disabilities. Some specialize in psychological support, but many offer practical advice as well. Shifting from eugenics to these resources is like walking out of a dark, dank cave into a sunny day. While they acknowledge the stress of dealing with major handicaps, the resources emphasize aid that’s available. They highlight the great advances of recent decades in surgery, technical aids, education, and disability rights. They explain ways of helping children become as independent and self-reliant as they possibly can be. They show that children with disabilities—like all children—are dear and funny, unpredictable and deeply human. Thus, in Chicken Soup for the Soul: Children with Special Needs, one mother describes a visit to a doctor’s office with her autistic son when he was six years old. After a nurse gave him a flu shot that he hadn’t been warned about, “Nicholas was furious! All the way from the doctor’s room and through the crowded waiting room, he was shouting: “That woman right there hurted me! She took a sword and stab me! Right here in my arm! You are in big trouble, lady! Say you are sorry! . . . You are in time-out until you say you are sorry!”

The “Prenatal Partners for Life” website offers stories of parents who resisted pressures to abort for disability and are glad they did. It also has good advice for doctors, family, and friends on how to talk with parents about a prenatal diagnosis. A book called My Child, My Gift provides good advice and many stories. One mother recalls that “we just fastened our seatbelts and knew that, come what may, love would find a way. That’s what love is.” An Australian book, Defiant Birth, is a great resource and resolutely anti-eugenics. There are at least two online directories of pro-life obstetricians. And support groups put new parents in touch with veterans.
who can offer both practical advice and moral support. For parents whose children are likely to die soon after birth, the "Perinatal Hospice" website has a directory of such hospice programs around the country.

The Babies with Down Syndrome handbook includes helpful advice on government benefits, parents' estate planning, and special-needs trusts—information that may be useful in dealing with any major childhood disability. Some government websites also have useful information and show that there is far more public support available than many people realize. There are also foundations and funds—the First Hand Foundation and the Disabled Children's Relief Fund, for example—that may help when other resources are exhausted.

Patricia Bauer's website is a great source on news stories about disability issues. And the "Disability Resources" site lists a vast number of practical resources. Also quite helpful is Reflections from a Different Journey, in which adults with disabilities write about their experience and what parents should know. A New Zealand contributor, Ross Flood, has cerebral palsy. When he was a baby, a doctor said that he would always be a "vegetable." Flood and his family proved the doctor wrong; the little boy grew up to obtain a university degree, drive a car, and become a professional writer. His chapter is called "Ain't Done Too Bad for a Cauliflower."

Some recent books explain disability to children so they won't be frightened by it and won't avoid children who have handicaps. My Friend Has Down Syndrome, for example, tells the story of two little girls who meet at summer camp. Like all good children's books, it is beautifully illustrated. Perhaps, though, medical professionals and politicians need it more than the kids do.

NOTES


3. Conference participants with formal eugenics links, then or later, included Robert S. Morison (chair) and speakers C.O. Carter, Michael M. Kaback, and Herbert A. Lubs. See 1974 membership list of Society for the Study of Social Biology or SSB (newer name of the old American Eugenics Society), folder on "Social Biol.: M.L.,” American Eugenics Society Records, American Philosophical Society Library, Philadelphia, Pa., for Morison and Lubs; Eugenics Society, "List of Fellows and Members as at August 1957" [membership list of English eugenics group], bound with Eugenics Review 49, no. 3 (Oct. 1957), National Library of Medicine, Bethesda, Md., for Carter; and U.S. Senate hearing (n. 14 below), 200-01, for Kaback.

4. Harris (n. 2), vii-ix & 213; Fritz Fuchs, "Genetic Information from Amniotic Fluid Constituents," Clinical Obstetrics and Gynecology 9, no. 2 (June 1966), 565-73; Ruth Schwartz Cowan, Heredity and Hope (Cambridge: Harvard, 2008), 90-95; and Harris (n. 2), 24, 34, 139, & 180-81. (Part I of this series covered the American Law Institute proposal.)
7. See 1956 American Eugenics Society membership list, Eugenics Quarterly 3, no. 4 (Dec. 1956), 243-52, for Kallmann and Stem; 1974 SSSB membership list (n. 3) for Motulsky, Stern, and Tietze; and 1957 [English] Eugenics Society membership list (n. 3) for Kallmann and Tietze.
8. Harris (n. 2), 85, 119, & 125.
9. Ibid., 203 & 196.
10. National Research Council, Committee for the Study of Inborn Errors of Metabolism, Genetic Screening: Programs, Principles, and Research (Washington: National Academy of Sciences, 1975), 173-74 (emphasis in original) & 244-45. The National Research Council is the operating agency of the National Academy of Sciences. For eugenics influence on the National Academy, see Mary Meehan, “What’s Wrong with the Science Establishment?” Human Life Review 26, no. 4 (Fall 2000), 63-85, 74-79.
14. 1974 SSSB membership list (n. 3); Social Biology, 1988-93 (listing Motulsky as an SSSB board member); and U.S. Senate, Committee on Labor and Public Welfare, Subcommittee on Health, 94th Cong., 1st sess. (15 July 1975), Hearing on Amendments to Revise Programs for Sickle Cell Anemia and Other Genetic Disorders, 1975, 60, 110-11, 136, 171, 183, 184, & 188-201.
22. Abby Lippman in Rothenberg and Thomson (n. 11), 11 & 18.


28. “Eleanor” and “Sondra,” quoted in Rothman (n. 27), 184 & 185.


30. Restak (n. 20), 87.


38. Rothman (n. 27), 14.


40. Ruth Hubbard and Elijah Wald, Exploding the Gene Myth (Boston: Beacon Press, 1993), 32 & 31. While Hubbard credits Wald as co-author, the book is written in (her) first person (ibid., xiv).


50. Barbara Sieger in Sweet (n. 37), 144.


53. Quoted in “Fighting for Claire,” Called to Greatness newsletter (Yonkers, N.Y.: Sisters of Life), no. 25 (Spring 2007), [4-6].


56. Rosita Ferro in Jack Canfield and others, comp., Chicken Soup for the Soul: Children with
57. See www.prenatalpartnersforlife.org; Nugent (n. 25), 70; and Reist (n. 27).
58. Pro-Life Maternal-Fetal Medicine, www.prolifemfm.org; and the American Association of Pro-Life Obstetricians & Gynecologists, www.aaplog.org/physiciansearch.aspx. To find lay support groups on the Internet, search under name of the disability and “support groups.”
59. See www.perinatalhospice.org.