



## Reproductive Genetic Testing: What America Thinks



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# Preface

We are currently in the midst of a genetic revolution in medicine. Advances in science, especially the completion of the human genome sequence, have led to greater understanding of the role of genes in health and disease. Genetic tests for diseases and disease risks are available currently and new medicines and preventive strategies are on the horizon.

Many people first encounter genetic testing when having a baby. Reproductive genetic testing — carrier testing, prenatal genetic testing, preimplantation genetic diagnosis — combines the newest advances in genetics with the most profound human activity of creating life. Reproductive genetic testing provides information: information about the risk of parents passing a genetic mutation to their children; information about the genetic characteristics of embryos produced through in vitro fertilization; information about the genome of a fetus in utero. This information can provide reassurance to prospective parents, or the basis for important decisions: to attempt a pregnancy or not; to transfer an embryo to the uterus or not; to continue a pregnancy or not. The growing availability and use of reproductive genetic testing presents a host of complicated ethical, legal and social issues.

New genetic technologies will touch the lives of millions of Americans. Yet, there is relatively little oversight of reproductive genetic testing. As the number and type of genetic tests grows and their use becomes more widespread, the time has come to seriously consider whether and how these new technologies will affect individuals and shape society, and whether changes in oversight are needed. Some believe that the decision to use reproductive genetic testing should be left up to individual parents in consultation with their doctors. Others believe that reproductive genetic tests should be either controlled stringently or banned entirely.

The growing debate about the use and oversight of reproductive genetic testing has been largely framed by two opposing views: those who see reproductive genetic testing as an opportunity to prevent suffering and who oppose limitations on research, technological advance and reproductive choice; and those who believe that reproductive genetic testing will have adverse ethical and social impacts and who support restrictions on its development and use. The views of most Americans, however, are more nuanced and elastic, reflecting the tensions among hopes, values and personal experience.

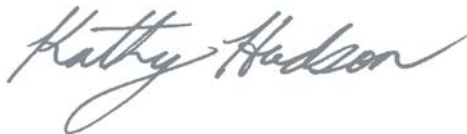
The Center has undertaken an in-depth effort to assess public attitudes toward genetic technologies — with public opinion surveys, town hall meetings, focus groups, interviews and online group discussions — as a means of making the discussion about genetics and public policy more democratic, less divisive and less the province of special interests. The goal is not to encourage policy making by public referendum, but to give everyone involved a clearer sense of the diversity of opinion surrounding these issues.

From 2002 to 2004 we used multiple methods to conduct a comprehensive assessment of Americans' opinions about reproductive genetic testing and technologies. This assessment included two surveys — one of which is the largest to date on this topic — focus groups and interviews. We organized public meetings around the country and invited those whose voices are not typically heard by policy makers; we held meetings with stakeholders to gather their input on policy options; and we held interactive forums

online that allowed individuals to register their opinions. This report, *Reproductive Genetic Testing: What America Thinks*, presents the results of our research on the public's attitudes about reproductive genetic testing and possible approaches to its oversight.

The accompanying report, *Reproductive Genetic Testing: Issues and Options for Policymakers*, aims to help focus and facilitate the discussion about reproductive genetic testing by outlining key scientific and medical facts, considering ethical and social implications, and assessing both current and potential oversight for the development and use of reproductive genetic tests. It presents a range of policy options supported by expert analysis that consider the potential effects, positive and negative, of distinctly different policy directions. Our goal at the Genetics and Public Policy Center is not to advocate for or against any technology or policy outcome but to make sure that policy decisions, including the decision to maintain the status quo, are undertaken with a clear-eyed understanding of their potential impact.

We hope that together these two reports will be useful tools for enhancing public discussion of reproductive technologies and assisting decision makers in both the private and public sectors as they consider policies to govern the development and use of reproductive genetic testing.

A handwritten signature in cursive script that reads "Kathy Hudson". The signature is written in a dark ink and is positioned above the printed name and title.

Kathy Hudson  
Director, Genetics & Public Policy Center

# Chapter 1: Introduction

## Why Conduct Public Opinion Research?

The Genetics and Public Policy Center operates under the principle that, in a democratic system of government, the voice of the public is critical in making sound public policy decisions. To better understand the views of the public about reproductive genetic testing, the Center conducted both qualitative and quantitative research between October 2002 and August 2004. Findings from this research are being used to support the Center’s goals of providing appropriate informational materials for policymakers, the public and the media; developing a comprehensive set of policy options; and engaging key stakeholders and decision makers in both the private and public sectors. This report summarizes the findings from our research into public opinions about reproductive genetic testing.

## Who Was Consulted?

The Center has engaged in a series of research projects designed to elicit public opinion about the use and regulation of reproductive genetic testing. It began with a telephone survey of 1,211 members of the general public in 2002.<sup>2</sup>

To get a nuanced picture of the public’s level of knowledge and opinions about reproductive genetic testing, 21 focus groups were conducted in five cities with members of the general public — most of whom had little experience with reproductive genetic testing. To ensure that a broad range of perspectives were solicited, participants were grouped by gender, age, race/ethnicity, parental status and education (see Appendix). In order to obtain the full range of views and perspectives related to the technologies, telephone interviews were conducted with 62 people who

had experience with reproductive genetic testing, including adults with a genetic disease, parents of children with a genetic disease, individuals with personal experience using preimplantation genetic diagnosis and health-care providers (Table 1.1).

In 2004, the Center conducted a nationally representative survey of 4,834 people via the Internet in order to test hypotheses and explore issues that emerged from the focus groups in a representative sample of the general public. This is the largest survey of American opinions on this topic to date.

One of the criticisms of both quantitative and qualitative opinion research, especially in the area of science policy, is that individuals are asked to comment on issues involving complex technologies about which they may have had little opportunity to consider in depth.

**Table 1.1: Summary of Public Opinion Research Studies**

| Study Methodology             | Data Collection Period | Number of Participants                      | Description of Population(s)                     |
|-------------------------------|------------------------|---|--|
| Telephone survey              | October 2002           | 1,211                                       | Nationally representative sample                 |
| Internet survey               | April 2004             | 4,834                                       | Nationally representative sample                 |
| Focus groups                  | April 2003             | 21 focus groups with 181 total participants | Members of the general public in 5 U.S. cities   |
| In-depth telephone interviews | July 2003—March 2004   | 62 total                                    | Parents of children with genetic disease (5)     |
|                               |                        |   | Adults with genetic disease (5)                  |
|                               |                        |   | Individuals who have experience with PGD (13)    |
|                               |                        |   | Primary care providers (20)                      |
|                               |                        |   | PGD health-care providers (19)                   |
| In-person town halls          | June 2004-August 2004  | 536   | Members of the general public in six U.S. cities |
| Online town halls             | July 2004-August 2004  | 133   | Members of the general public                    |

## What Is Reproductive Genetic Testing?

**Genetic testing** is the laboratory analysis of DNA, RNA or chromosomes. Testing can also involve analysis of proteins or metabolites that are the products of genes. Genetic testing is done to predict risk of disease, screen newborns for disease, identify carriers of genetic disease, establish prenatal or clinical diagnoses or prognoses and direct clinical care. Testing can be done using many different biological samples, including blood, amniotic fluid (from which fetal cells are obtained) or individual embryonic cells.

**Reproductive genetic testing** refers to those genetic tests and procedures that are used to provide prospective parents with information about their chances of having a child with a specific genetic disorder or characteristic in a current or future pregnancy. It includes: (1) carrier testing, which is done to determine whether an individual carries one copy of an altered gene for a particular recessive condition; (2) prenatal genetic testing, in which fetal cells obtained through procedures such as amniocentesis and chorionic villus sampling (CVS) are genetically tested; and (3) preimplantation genetic diagnosis (PGD), in which embryos produced through in vitro fertilization are genetically tested to select which embryos to transfer to a woman's uterus.

**Carrier testing** is genetic testing to determine whether an individual carries one copy of an altered gene for a particular recessive condition. Carrier testing is done because of a family history of a genetic disorder or because of racial or ethnic background. Examples of autosomal recessive disorders that are more frequent in certain populations for which carrier testing can be done include cystic fibrosis in Whites, sickle cell disease in Blacks, thalassemia in Asians and individuals of Mediterranean descent, and Tay Sachs disease, Canavan disease and familial dysautonomia in Ashkenazi Jews. In autosomal recessive disorders, a person must have two copies of the mutation to be affected. Individuals who carry one copy of the alteration are carriers and typically show no signs of the disease. When both parents are carriers, there is a one in four, or 25 percent, risk for each child to inherit the mutation from both parents and be affected.

**Preimplantation genetic diagnosis (PGD)** is genetic testing that is done on embryos produced through in vitro fertilization. Most commonly, one or two cells are removed from the embryo and tested for the presence of a particular trait or condition. The test results are used to inform the selection of embryos for transfer to a woman's uterus. For example, parents may want to select only embryos that do not have a particular genetic mutation or that have a particular genetic characteristic, such as sex. Preimplantation genetic diagnosis has been used for patients carrying chromosomal rearrangements and those at risk of transmitting a single gene disorder to their offspring. It has also been used to detect chromosomal abnormalities in embryos from women of advanced maternal age undergoing fertility treatment.

**Prenatal genetic testing (or prenatal genetic diagnosis)** is genetic testing of fetal cells obtained through procedures such as amniocentesis and chorionic villus sampling (CVS). Test results may be used to help parents prepare for the birth of an affected child or make a decision about terminating the pregnancy.

**Prenatal screening** involves those tests and procedures used to assess fetal risk for an abnormality, including genetic disorders. It does not provide a definitive diagnosis of a genetic abnormality.

**In Vitro Fertilization (IVF)** is a process in which eggs are retrieved from a woman's ovaries and fertilized with sperm in the laboratory, and the resulting embryos are grown in culture and then transferred into a woman's uterus. Embryos that are not transferred may be discarded, frozen and stored for future use, donated to other couples or used for research.



Thus, the Center undertook a project to assess whether people would have more informed, reflective opinions if they had a chance to learn more about the technology and issues, hear contrasting viewpoints from “the experts” and engage in discussion with their fellow citizens about the issues.

To capture opinion data based on informed decisions, an extensive public engagement activity took place during the summer of 2004 called *The Genetic Town Hall: Making Every Voice Count*. The engagements took place in six U.S. cities using a town hall format and with 15 discussion groups online using state-of-the-art Internet meeting capability. A separate report, *The Genetic Town Hall: Making Every Voice Count*, which summarizes the findings from this project, will be available through the Center.

A description of the methodologies for each study is provided in the Appendix.

**NOTES:**

<sup>1</sup> Public Awareness and Attitudes about Reproductive Genetic Technology, available at [www.DNAPolicy.org](http://www.DNAPolicy.org)



# Chapter 2: Public Awareness and Knowledge

Prior to asking any questions about people's opinions concerning reproductive genetic testing, it was important to get a sense of how aware Americans were about these technologies, and how much they really understood about genetics and the current capabilities of genetic testing.

Focus group participants were presented with a series of hypothetical scenarios involving the use of different reproductive genetic testing. They were then asked whether they had ever heard of a particular technology before and, if so, whether they could describe it. Similarly, survey participants were provided with a definition of the technology and asked a series of awareness and knowledge questions. Many of these same questions were put to town hall participants prior to the discussions.

## Awareness

The majority of the focus group participants had heard of prenatal genetic testing, primarily amniocentesis for Down syndrome. Most had not heard of carrier testing, with the exception of participants in the Jewish women's focus group, most of whom were highly educated and had children. Several of these women reported that they had had carrier testing for Tay Sachs disease, which is more prevalent among Ashkenazi Jews. Preimplantation genetic diagnosis (PGD) was unfamiliar to almost all focus group participants; however, a number of participants spontaneously predicted or envisioned a technology like PGD.

Most of the interview participants who had used or considered PGD reported that they first became aware of the technology only after the birth of an affected child. Information typically came from a genetic counselor rather than a primary care provider, the media or a genetic disease support group. Participants reported that they had difficulty locating both unbiased information about PGD and PGD providers.

Based on survey data, a majority of the American public was aware of technologies that have been in clinical use for a longer period of time, such as in vitro fertilization (IVF) and prenatal genetic testing, and with reproductive genetic technologies, like cloning, that have received extensive media attention, while only 40 percent said they had heard of PGD — a much newer technology (Figure 2.1).

Awareness of reproductive genetic technologies varies not only by type of technology but also by socio-demographic characteristics

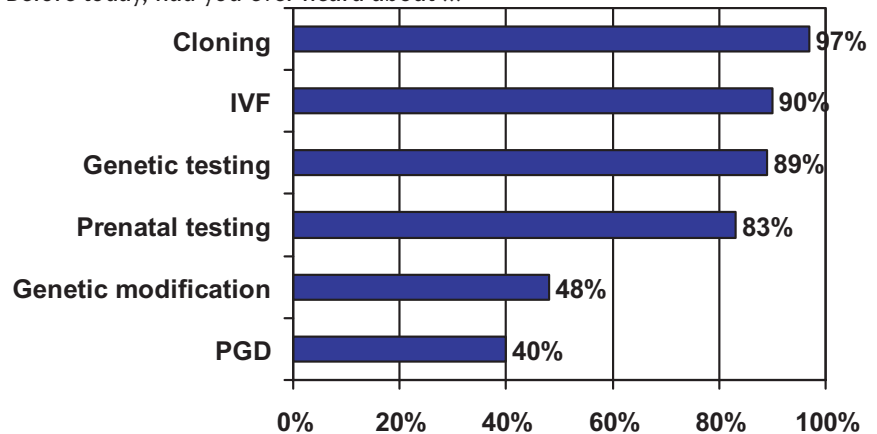
(Table 2.1). After adjusting the results to account for differences in the demographic characteristics of respondents, the two most significant characteristics associated with awareness of reproductive genetic testing technologies were being female and having a higher education. Lower income was associated with reduced likelihood of awareness of IVF and prenatal genetic testing. Those who reported their political affiliation as "other" were less aware of all of the technologies compared to people who self-identified as Republican or Democrat. There were no statistically significant differences in awareness between Republicans and Democrats.

## Knowledge

Focus group participants generally understood that genetic testing can be used to make reproductive decisions; however, there were some notable misperceptions about carrier testing and, to a lesser extent, about prenatal

**Figure 2.1 Awareness of Genetic Technologies**

"Before today, had you ever heard about ..."



Source: 2004 Survey

**Table 2.1: Proportion of Respondents Who Stated They Had Heard about the Following Technologies Prior to the Interview**

| Demographic Characteristics |                       | IVF  | Genetic Testing | Prenatal Genetic Testing | PGD  | Genetic Modification | Cloning |
|-----------------------------|-----------------------|------|-----------------|--------------------------|------|----------------------|---------|
| Total                       |                       | 90.4 | 88.5            | 83.4                     | 40.2 | 48.1                 | 96.6    |
| Sex                         | Men                   | 88.4 | 86.0            | 78.0                     | 36.3 | 51.6                 | 96.3    |
|                             | Women                 | 92.3 | 90.9            | 88.3                     | 43.9 | 44.9                 | 96.9    |
| Age                         | 18-29                 | 89.4 | 89.6            | 81.4                     | 41.5 | 56.4                 | 96.8    |
|                             | 30-49                 | 90.1 | 88.7            | 84.0                     | 39.4 | 48.3                 | 96.6    |
|                             | 50+                   | 91.2 | 87.8            | 83.8                     | 40.4 | 43.1                 | 96.6    |
| Race/<br>Ethnicity          | White                 | 92.8 | 91.0            | 85.1                     | 41.4 | 50.4                 | 97.7    |
|                             | Black                 | 83.7 | 85.0            | 76.9                     | 34.7 | 34.8                 | 96.1    |
|                             | Hispanic              | 86.2 | 81.6            | 81.8                     | 38.7 | 46.0                 | 93.5    |
| Religion                    | Protestant*           | 91.3 | 90.3            | 83.3                     | 41.0 | 42.6                 | 98.3    |
|                             | Fund/Evang**          | 92.0 | 90.1            | 84.9                     | 39.4 | 47.8                 | 98.0    |
|                             | Catholic              | 92.7 | 88.9            | 84.8                     | 39.5 | 50.8                 | 96.8    |
|                             | Other Christian***    | 88.6 | 87.9            | 86.0                     | 42.7 | 45.1                 | 96.0    |
|                             | Other (Non Christian) | 88.3 | 82.3            | 76.5                     | 30.7 | 55.6                 | 93.3    |
|                             | No Religion           | 87.0 | 87.0            | 81.2                     | 43.0 | 56.1                 | 93.9    |
| Income                      | Under 25k             | 87.0 | 83.2            | 80.1                     | 40.5 | 42.7                 | 93.9    |
|                             | 25k-49k               | 90.0 | 89.4            | 82.3                     | 38.4 | 46.3                 | 97.4    |
|                             | 50k-74.9k             | 92.7 | 92.0            | 84.4                     | 39.8 | 52.4                 | 98.7    |
|                             | 75+k                  | 95.8 | 94.2            | 91.4                     | 44.2 | 58.9                 | 98.4    |
| Education                   | No College            | 85.6 | 82.5            | 77.4                     | 34.2 | 35.5                 | 94.6    |
|                             | Some College          | 92.0 | 92.0            | 84.8                     | 43.6 | 53.2                 | 98.0    |
|                             | College               | 97.7 | 96.5            | 93.8                     | 45.0 | 65.3                 | 99.2    |
|                             | Post Grad             | 97.8 | 96.2            | 92.2                     | 53.1 | 68.8                 | 98.4    |
| Political<br>Affiliation    | Republicans           | 92.5 | 91.2            | 86.8                     | 38.9 | 48.9                 | 98.4    |
|                             | Other                 | 83.9 | 80.6            | 75.9                     | 36.1 | 39.3                 | 92.7    |
|                             | Democrats             | 89.8 | 86.6            | 81.4                     | 38.2 | 45.3                 | 96.6    |

Source: 2004 Survey

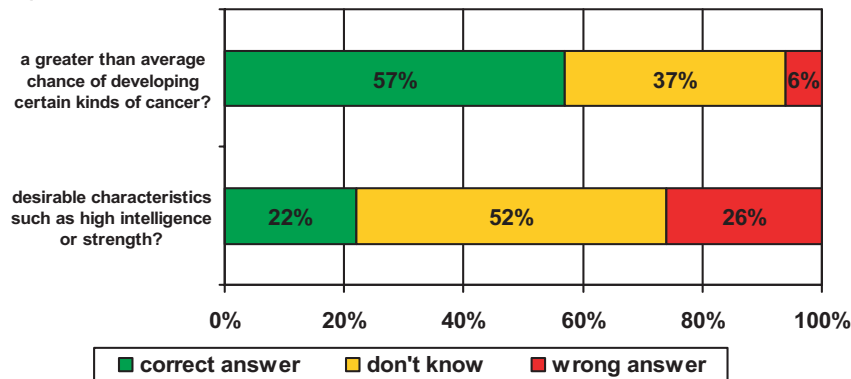
\* Protestant includes respondents who self-identified as Protestant, excluding those who additionally self-identified as Fundamentalist or Evangelical.

\*\* Fundamentalist/Evangelical includes all Protestant or Other Christian respondents who additionally self-identified as either Fundamentalist or Evangelical.

\*\*\* Other Christian includes all who self-identified as Other Christian, excluding those that additionally self-identified as Fundamentalist or Evangelical.

**Figure 2.2 Knowledge of Genetic Technologies**

“As far as you know is it scientifically possible to use genetic testing to find out if a person has ...”



Source 2004 Survey

testing. A common misperception that arose in one-third of the 21 focus groups was the belief that carrier testing is unnecessary unless there is some family history of genetic disease. Other misperceptions about carrier testing included the belief that carrier testing is a routine part of prenatal care and, therefore, patients do not have a choice; the belief that carrier testing is the same as Rhesus (Rh) factor testing; the belief that carrier testing is diagnosing a condition in the fetus rather than providing information about the individual tested and the risk for a current or future pregnancy; and belief that carrier testing is a routine part of premarital blood testing. Misperceptions about prenatal testing included the belief that amniocentesis can provide information about all diseases and confusion about whether amniocentesis is a fetal biopsy or test of fetal blood, even among those who had experienced amniocentesis.

Survey respondents were asked whether genetic testing can be used to

find out if a person has an increased risk of developing certain kinds of cancer or to find out if a person has desirable characteristics such as high intelligence or strength. Fifty-seven percent of the respondents correctly answered that genetic testing can detect an increased risk of contracting certain kinds of cancer, though a substantial minority (37 percent) did not know the answer. More Americans (26 percent) answered incorrectly that genetic testing can detect traits such as intelligence than answered correctly that it cannot (22 percent) and a majority of those questioned stated they did not know (Figure 2.2).

Higher education is clearly associated with a greater understanding of the capabilities of genetic testing (Table 2.2). Sixty-eight percent of those with post-graduate education answered the cancer question correctly, while only 50 percent of those with no college education answered correctly. Even after adjusting for demographic

characteristics such as income and race, differences by education remain robust.

Fifty-eight percent of Whites correctly answered the question on cancer detection, compared to 51 percent for Blacks and 55 percent for Hispanics. After adjusting for demographic characteristics in logistic regression models, Blacks were still less likely than Whites to answer correctly, although the differences for Hispanics fell away. Fewer women answered knowledge questions correctly than men; these sex differences were still observed even after adjusting for demographic characteristics. Differences among age groups were more pronounced in the knowledge question about desirable characteristics: older adults were less likely than younger age groups to answer correctly, even after controlling for other characteristics. The differences in knowledge among the religious groupings were relatively small, although as Table 2.2 illustrates, the greatest number of correct answers were observed among respondents who either self-identified as Other (Non Christian) or had no religious affiliation.

**Table 2.2: Percentage of Correct Responses to Genetic Testing Questions**

| Demographic Characteristics |                       | It is possible to test for certain kinds of cancer | It is not possible to test for intelligence or strength |
|-----------------------------|-----------------------|--|---|
| Total                       |                       | 56.9   | 22.1  |
| Sex                         | Men                   | 59.1   | 24.4  |
|                             | Women                 | 54.9   | 20.0  |
| Age                         | 18-29                 | 56.5   | 28.3  |
|                             | 30-49                 | 57.8   | 26.7  |
|                             | 50+                   | 56.2   | 13.7  |
| Race/<br>Ethnicity          | White                 | 57.9   | 22.3  |
|                             | Black                 | 51.4   | 16.0  |
|                             | Hispanic              | 55.4   | 23.1  |
| Religion                    | Protestant*           | 57.2   | 18.7  |
|                             | Fund/Evang**          | 55.2   | 19.0  |
|                             | Catholic              | 58.1   | 22.8  |
|                             | Other Christian***    | 53.9   | 20.5  |
|                             | Other (Non Christian) | 58.9   | 33.0  |
|                             | No Religion           | 60.6   | 29.7  |
| Income                      | Under 25k             | 52.5   | 18.1  |
|                             | 25k-49k               | 57.2   | 22.3  |
|                             | 50k-74.9k             | 58.5   | 23.5  |
|                             | 75+k                  | 63.7   | 29.0  |
| Education                   | No College            | 49.5   | 16.9  |
|                             | Some College          | 62.2   | 23.1  |
|                             | College               | 63.3   | 28.5  |
|                             | Post Grad             | 68.4   | 35.7  |
| Political<br>Affiliation    | Republicans           | 57.4   | 23.3  |
|                             | Other                 | 47.3   | 19.7  |
|                             | Democrats             | 56.0   | 19.5  |

Source: 2004 Survey

\* Protestant includes respondents who self-identified as Protestant, excluding those who additionally self-identified as Fundamentalist or Evangelical.

\*\* Fundamentalist/Evangelical includes all Protestant or Other Christian respondents who additionally self-identified as either Fundamentalist or Evangelical.

\*\*\* Other Christian includes all who self-identified as Other Christian, excluding those that additionally self-identified as Fundamentalist or Evangelical.

# Chapter 3: Perceptions About Appropriate Uses

Reproductive genetic testing was developed to provide prospective parents with information about their risk of having a child with a severe, life-threatening genetic disease, but it is also possible to use it to identify other genetic characteristics of fetuses or embryos such as sex and tissue type.<sup>1</sup> Researchers are learning more about genes responsible for a host of inherited characteristics — from disease risk to physical appearance — giving rise to new genetic tests that could be used to test embryos and fetuses. In the future, it may be possible to test for genes that influence behavior or appearance.

Preimplantation genetic diagnosis (PGD) can be used to identify and select embryos based on the absence of deleterious characteristics or the presence of desirable genetic characteristics. Prenatal genetic testing can identify genetic characteristics of a fetus in utero. Test results can be used to provide reassurance, aid in preparing for the birth of an affected child or be the basis of the decision to continue or terminate the pregnancy. For many Americans, the type of test and the motivations behind parents' use of reproductive genetic testing are important considerations in assessing whether or not testing is appropriate.

To understand more about Americans' opinions about the appropriate uses of reproductive genetic testing and what shapes them, survey, focus group, interview and town hall participants were asked their views about using reproductive genetic testing for different purposes.

Survey respondents were asked a set of questions about the appropriateness of using prenatal testing to find out whether a fetus would:

- develop a fatal childhood disease;
- have a tendency to develop a disease like adult-onset cancer;
- be a certain sex;
- be a good match to donate his or her blood or tissue to a brother or sister who is sick and needs a transplant; and
- have desirable characteristics like high intelligence or strength (hypothetically).

Respondents were then asked whether it was appropriate to use PGD to select which embryo(s) to transfer to a woman's uterus.

Similarly, focus group and town hall participants were asked

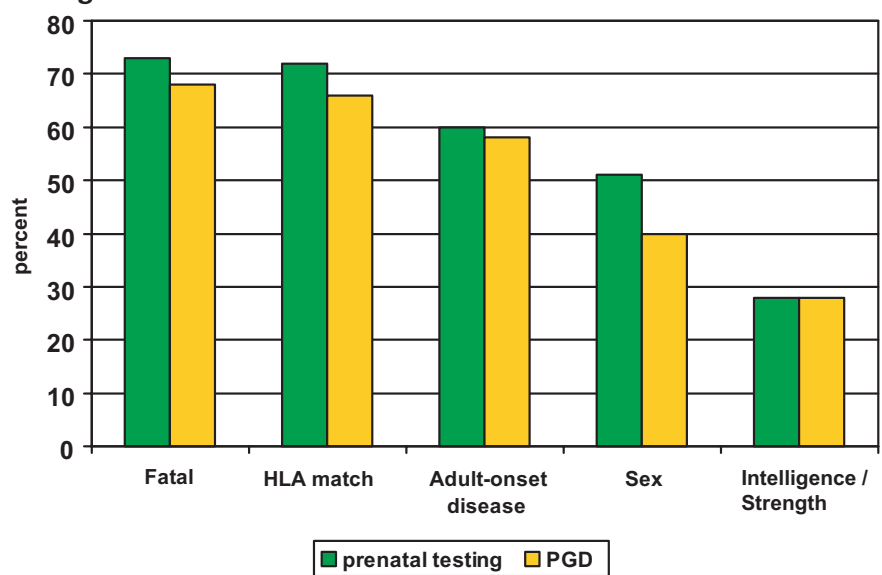
to discuss whether they thought prenatal genetic testing or PGD was appropriate for a range of circumstances.

## Use to Avoid Disease Not to Select for Desirable Traits

*"I say yes if it all leads to eradicating horrifying diseases, and not wanting to pick their perfect little baby—whether it be a boy or a girl, blonde and blue-eyed."*  
*participant from female focus group, California*

Americans' support for the use of reproductive genetic testing depends heavily on the circumstances for which it is being used. In the 2004 survey, about two-thirds of the general public approved of the use of prenatal genetic testing and PGD for a fatal childhood disease and for tissue matching (Figure

**Figure 3.1: Approval for Different Uses of Reproductive Genetic Testing**



Source: 2004 Survey

3.1). A majority of both survey and town hall participants approved of using reproductive genetic testing technologies to identify alterations associated with a tendency to develop an adult-onset disease like cancer. There was less support for testing to identify, if it were possible, characteristics like intelligence or strength. Therefore a majority of Americans think that testing for health-related purposes is an appropriate use of reproductive genetic testing, but only a minority support its use for trait selection.

While there is much less support for reproductive genetic testing for non-health-related purposes, these levels were not as low as one might expect. Indeed, greater than one in four Americans said they approved or strongly approved of using hypothetical genetic tests for intelligence or strength. Since the survey question asked whether it is appropriate to use prenatal genetic testing to identify sex rather than to make a decision about abortion based on this information, perhaps it is not surprising that about half of those surveyed supported this use. In fact, during routine prenatal ultrasound, the sex of a fetus is often identified and this information shared with the parents. Close to 40 percent of Americans think that using PGD solely to select for sex is an appropriate use of the technology.

A significant minority — almost one-third — of Americans disapproved of testing for fatal childhood disease or a tissue match for a sick sibling.

### Prevent the Suffering of a Child

*“I have the [sickle cell] trait, and a couple of my cousins have it... I have seen a lot of pain and suffering from sickle cell...and it wasn't pretty.”*

*participant from Black female focus group, Michigan*

Focus group and town hall discussions shed light on why there is strong support for using reproductive genetic testing to identify severe, childhood genetic disease. Participants who believe that this use is morally appropriate typically stated that preventing the suffering of a child is a laudable goal. They described genetic disease as a substantial burden for children, families and communities.

*“[Sickle cell] is killing us wholesale through our community. So, if you actually have an opportunity where we can utilize a little bit of modern technology and science to where, let's get rid of this cancer in our community, why not?”*

*participant from Black male focus group, Tennessee*

*“Cystic fibrosis is nasty and it is horrible and it is debilitating and painful and causes suffering.”*

*participant from female White focus group, California*

Some of the parents of affected children said that others could not possibly understand how difficult it is to care for and watch helplessly while a child suffers. The emotional and financial burden of raising a disabled or sick child, the burden on siblings, the effect on the stability of

the parents' marriage, potential parental guilt at having given a child a genetic disease and concerns about loss of family health insurance were all cited as reasons reproductive genetic testing is a valid option. In fact, some parents of affected children and some adults with genetic diseases said they were determined not to bring another person into the world with the same condition.

*“There's water gushing in your boat, you're sinking, you have a bucket. And you just keep taking the bucket and you throw water on it to keep from sinking, and there's no break. It's seven days a week, 24 hours a day. You don't get a vacation. That's it. You are stuck on this boat in the middle of the ocean with a hole in it with a bucket. And that's what life is like raising a boy with CF.”*

*father of child with cystic fibrosis (interview)*

Not all shared this view. Others had a very different perspective on the challenges they or their family faced. Among this group, there was little interest in technologies that could prevent the birth of an affected child.

When asked to identify the most important benefit to parents of being able to select characteristics of their children, town hall participants across the country placed the ability to avoid having a child with genetic disease, to have healthier children or to prevent the suffering of a child at or near the top of their list. Some also stressed the need to reduce the suffering of the entire family.



Some interview participants, particularly health-care providers, said reproductive genetic testing also has the potential to benefit society by reducing the burden of disease and the costs of treatment for future generations. One provider noted that carrier and prenatal genetic testing have already reduced the number of babies born with Tay Sachs disease, and that PGD has the potential to do the same for other genetic diseases.

*“I am hoping that, like vaccination, PGD will eliminate some of these ravaging diseases from occurrence.”*  
PGD provider (interview)

During many of the focus group and town hall discussions, it became clear that some participants believe there may be a moral obligation to use reproductive genetic testing if the purpose is to prevent the suffering of a child.

*“You have a responsibility to bring a child into the world with a certain quality of life.”*  
female participant from mixed sex/race focus group, Massachusetts

The theme that there may be a moral obligation to use reproductive genetic technology to prevent suffering was explored in the survey. After answering over 80 questions about reproductive genetic technologies, survey participants were asked whether they strongly agreed, agreed, disagreed or strongly disagreed with the following statement: “Parents ought to do everything technologically possible to prevent their child from suffering including using reproductive genetic

technologies.” Responses were evenly split (Table 3.1).

Pronounced differences in opinion over whether or not parents have an obligation to use reproductive genetic technologies to prevent suffering in their children were observed between religion groups (Table 3.2). Notably, far fewer Fundamentalist and Evangelical Christians agreed with this statement compared to other Protestants. For other socio-demographic characteristics, more women, more Democrats and a greater number of Blacks and Hispanics agreed that parents had such an obligation.

There is strong support for using these technologies when there is a health benefit, even when that benefit is for another person. One of the uses of reproductive genetic testing is to determine whether an embryo or a fetus is a good tissue match and could potentially provide life-saving cells to a critically ill sibling. In the 2004 survey, 72 percent of respondents either approved or strongly approved of the use of prenatal genetic testing “to find out whether a baby will be a good match to donate his or her blood or tissue to a brother or sister who is sick and needs a transplant.” Sixty-six percent supported the use of PGD for this purpose (Figure 3.1). Data from the town halls are similar. This use was discussed during many of the interviews and one of the focus groups. These qualitative data also demonstrate strong support for using PGD to select an embryo that will result in a baby whose cells, usually umbilical cord stem cells,

can help save a sick or dying older sibling.

*“I don’t think anyone wants to see their child die... you’d do anything to save the child’s life.”*

*male participant from mixed sex focus group, Massachusetts*

*“I think that there’s a lot worse things than having a child to save another child.”*

*mother of child with genetic disease (interview)*

### **Preparing For a Special Needs Child**

*“The information is... just a powerful thing to have.”*  
participant from young male focus group, Tennessee

Prenatal genetic testing is available to pregnant women to identify fetuses affected by some genetic diseases. This information can be used to make a decision about whether or not to continue the pregnancy. Some women who would never consider abortion or who are concerned about the risk of miscarriage may refuse testing. Others, even though they would not consider abortion, nevertheless may choose to test simply to have more information about the pregnancy. Most focus group participants thought that prenatal genetic testing should be available and offered to pregnant women and that it is then up to women, and their partners, to decide whether to have genetic testing and what to do with the information it provides.

**Table 3.1: Parents Ought to do Everything Technologically Possible to Prevent Their Child from Suffering Including Using Reproductive Genetic Technologies.**

| Demographic characteristics |                       | % who strongly agreed or agreed |
|-----------------------------|-----------------------|---------------------------------|
| Total                       |                       | 51.5                            |
| Sex                         | Men                   | 55.0                            |
|                             | Women                 | 48.1                            |
| Age                         | 18-29                 | 44.1                            |
|                             | 30-49                 | 52.2                            |
|                             | 50+                   | 55.1                            |
| Race/Ethnicity              | White                 | 49.6                            |
|                             | Black                 | 55.8                            |
|                             | Hispanic              | 56.5                            |
| Religion                    | Protestant*           | 60.6                            |
|                             | Fund/Evang**          | 35.0                            |
|                             | Catholic              | 49.4                            |
|                             | Other Christian***    | 46.6                            |
|                             | Other (Non Christian) | 56.6                            |
|                             | No religion           | 58.5                            |
| Income                      | Under 25k             | 54.7                            |
|                             | 25K-49k               | 49.6                            |
|                             | 50K-74.9k             | 48.3                            |
|                             | 75+k                  | 52.6                            |
| Education                   | No college            | 53.2                            |
|                             | Some college          | 51.8                            |
|                             | College               | 46.1                            |
|                             | Post grad             | 51.1                            |
| Political Affiliation       | Republicans           | 45.9                            |
|                             | Other                 | 53.1                            |
|                             | Democrats             | 57.6                            |

Source 2004 Survey

\* Protestant includes respondents who self-identified as Protestant, excluding those who additionally self-identified as Fundamentalist or Evangelical.

\*\* Fundamentalist/Evangelical includes all Protestant or Other Christian respondents who additionally self-identified as either Fundamentalist or Evangelical.

\*\*\* Other Christian includes all who self-identified as Other Christian, excluding those that additionally self-identified as Fundamentalist or Evangelical.

While many participants in the focus groups said that prenatal testing creates anxiety, others said that having additional information about the fetus is a benefit of prenatal genetic testing. Negative test results can provide “peace of mind” by letting the couple know for sure that the child will not have a particular genetic disease.

*“[We did it] because I wanted to kind of relieve the stress of the pregnancy, because wondering all the time, and waiting to find out if the baby’s going to be healthy or not, it was very stressful... once we got the results, then we could kind of smoothly sail through the pregnancy.”*

*woman with genetic disease (interview)*

When town hall participants were asked to name and then rank the most important benefits to parents of being able to identify the genetic characteristics of their children, the ability to plan and prepare for the challenges of having a special needs child was always mentioned and ranked at or near the top. Focus group and interview participants also mentioned that prenatal testing gives parents time to prepare emotionally, financially and medically for the birth of a special needs child.

*“I think for us, not only just in terms of the intellectual piece of learning about the disease in advance and how to cope with it, but the actual grief process of feeling the loss of a healthy child — I think it was valuable to go through part of that, even while pregnant, so that by the time the baby was born, some of that was over. Because I think that could be brutal. If you had postpartum depression, [you might be] completely overwhelmed by all this information.”*

*mother of child with genetic disease (interview)*

Preparations might include learning more about the disease, identifying health-care specialists, making sure health insurance will cover the child’s medical costs, moving to a location with the best climate and medical care for that disease, rearranging employment and/or working hours, and mobilizing their support system of friends and family.

*“...I would want to know if [the baby] had cystic fibrosis, if that test was positive, because then I would be finding everything in the world out that I could about cystic fibrosis, and preparing to give that baby the best, even if it is five months, the best life that that baby could have...”*

*participant from female Evangelical focus group, Colorado*

### **Avoiding Non-fatal, Adult-onset Diseases**

*“[Y]ou have to start looking at which [diseases] are you going to fix... cystic fibrosis, and the colon cancer, and the depression... Where do you stop?”*

*female participant from mixed sex/race focus group of people over 55, California*

Survey participants were asked about the appropriateness of using reproductive genetic testing to avoid adult-onset diseases like cancer. Similarly, focus group participants were asked to consider use for adult-onset disease like cancer, obesity and depression. Focus group participants often considered the severity of the disease, disability, or condition. If the disease is fatal and has an early onset, respondents were more likely to view using the technology as appropriate. In contrast, there was less approval for testing for adult-onset diseases, risk of disease, diseases influenced by behavior or the environment, and those for which a treatment exists.

Among survey respondents, 60 percent approved of using prenatal testing to identify fetuses at risk of adult-onset disease, and 58 percent approved of using PGD to avoid transferring embryos that have an increased risk of developing an adult-onset disease (Figure 3.1). The split between those who approved and disapproved of this use was evident in the focus group discussions; in fact, individual participants frequently were ambivalent about this use. Of those focus group and town hall

participants who did not support PGD for adult-onset diseases, many stated that they objected because people with these diseases could still live full lives and because treatments were available or might become available.

*“It gets into a very gray area when you’re saying ‘Now we’re going to have a child who is going to be sick from day one, and it’s going to be sick for it’s whole life’ versus ‘Now we’re going to have a child that’s going to be healthy for 40 years, and maybe by then we’re going to have a cure for cancer.’”*

*female participant from mixed sex/race focus group, Massachusetts*

This opinion was not unanimous, however. Some members questioned why using reproductive genetic testing to avoid the birth of a child at risk of cancer was ethically less acceptable than other technology aimed at eliminating cancer. Those who expressed these opinions were more often men, and frequently had a personal experience with an adult-onset disease.

*“It’s kind of interesting that it would be okay for us to solve colon cancer in 40 years, but why couldn’t we solve it before it started? Why is that not acceptable? I mean, if we have a cure for it, isn’t this truly a cure? It’s a preventative cure, like living my life differently so I don’t get colon cancer. Then your life was different from the beginning, we selected it that way, so you didn’t have that. It’s an interesting thought.”*

*participant from male focus group, Colorado*

Many focus group, interview, and town hall participants characterized using prenatal testing or PGD to avoid having children with obesity or depression as “too much picking and choosing” and “like shopping for kids.”

*“I am very uncomfortable with [using reproductive genetic testing to avoid] obesity, depression, those types of things...that is too big of a decision to give those parents, I mean, to say this child can't exist because of these things or those things.”*

*participant from Mexican American female focus group, California*

While many focus group participants initially expressed disapproval of the use of genetic testing to identify genetic risks for obesity or depression, further discussion often led to greater ambivalence about these uses. For example, the discussions about the use of reproductive genetic testing for obesity might begin with one participant calling it “vain” and others countering that it was a legitimate health concern, leading some group members to express the opinion that both points of view were defensible. Similarly, participants would use terms such as “quality of life,” “life-threatening” and “severe” only to discover that they each defined these terms differently.

## Sex

Genetic testing can be used to identify the sex of embryos and fetuses. Information about the sex of embryos can be used to select

which embryos to transfer into a woman’s uterus. Information about the sex of a fetus is most often obtained to satisfy parental curiosity but may also be the basis for a decision to have an abortion. Attitudes about genetic testing for sex are particularly interesting since it is the only reproductive genetic test currently in use that identifies a genetic characteristic unrelated to health.<sup>2</sup> All study populations were asked to comment on the use of PGD for sex selection, and survey and town hall participants were also asked about whether they approved or disapproved of prenatal genetic testing to identify sex.

Focus group participants and particularly families affected by genetic diseases tended to group sex with socially desirable traits and were generally unsupportive of using PGD for this purpose. A woman who had not yet had a successful outcome following PGD had a strong negative reaction to the use of PGD for non-medical sex selection.

*“I think that’s completely stupid. In a case like [hemophilia], where the sex of the child affects the health of the child, yes. But not for any other reasons. That would be horrible.”*

*PGD patient (interview)*

Health-care providers also had reservations about the use of PGD for non-medical sex selection.

*“I went into medicine and into science to diagnose, and treat, and hopefully cure disease. And the last time I checked, gender wasn’t a disease.”*

*PGD provider (interview)*

*“We have spoken and discussed this extensively at our team meetings because we are torn between denying a patient care that they ask us for, and the somewhat distasteful idea that one gender is preferred to another in some cultures.”*

*PGD provider (interview)*

While most of the participants in focus groups and interviews were quite negative about sex selection, fully 40 percent of surveyed Americans said that it was appropriate to use PGD to select the sex of a child (Figure 3.1). A discussion of who these “approvers” are follows below in the discussion of demographic characteristics. Participants in the online town halls were asked about their approval for using PGD for sex selection before and after the online discussions. There was a marked decline in the number of participants “approving” of this use of PGD after the discussions, with numerous participants changing their opinion from “agree” to “strongly disagree.”

## Trait Selection

All data indicate that most Americans disapprove of the use of hypothetical reproductive genetic testing to select socially desirable traits such as intelligence, strength, or hair and eye color. Focus group and interview participants described these uses as “selfish,” “vain,” “greedy,” “egotistical” and “frivolous.” Similarly, town hall participants objected to using these tests for traits because they viewed these uses to be “trivial,” “narcissistic” and “elitist.”

*“If you are going to get pregnant to have a baby just because it is going to have blue eyes and it is going to be perfect, I think there is something wrong with you because you should have a baby [to love it]...If you are going to be very selective as to aesthetic, that’s not right. You shouldn’t even be considering being a parent.”*  
 participant from Mexican American female focus group, California

*“I think if parents are doing it for selfish reasons — like if they want to have the best-looking kids on the block — I think there should be a line drawn there. That’s not for the health of the child: that’s for the vanity of the parents...[If] I want the tallest kids because I want my kid to be a basketball player - that, I think, is over the bounds.”*  
 PGD patient (interview)

In spite of these strong sentiments, more than one-quarter of survey participants supported the use of prenatal genetic testing to find

out whether a fetus has desirable characteristics like intelligence or strength, and more than one-quarter support the use of PGD to select for these traits (Figure 3.1). The discussion on demographic characteristics that predicted approval for trait selection is below.

### The Slippery Slope

*“[T]o me, it’s like the slippery slope, O.K., so we start [with] mental, physical deformities — what’s next, you know? Oh, we don’t like kids with blond hair.”*  
 participant from Mexican American male focus group, California

Three-quarters of survey respondents agreed or strongly agreed with the statement that “Technology will inevitably lead to genetic enhancement and designer babies” (Figure 3.2). After controlling for other variables, agreement with this statement varied very little, with the exception of education. Higher levels of education were associated

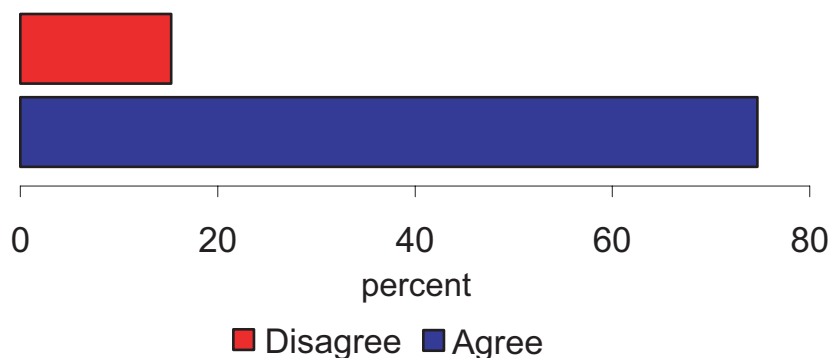
with a lower likelihood of agreement that genetic technologies would inevitably lead to “designer babies.”

Focus group and town hall participants were clear that it is not the technologies themselves that people fear, but rather that unrestrained human selfishness and vanity will drive people to use reproductive genetic testing inappropriately. They believed that the technology is being developed for good purposes, but human vices will result in consumer demand for capricious uses.

*“You’re trying to get rid of this terrible burden on your children, but at the same time, I don’t put as much faith in humanity, because people are greedy. I mean, we’re just inherently greedy people and it’s never going to be enough.”*  
 participant from young male focus group, Tennessee

*“I would be lying if I said I hadn’t encountered parents who made choices based on delusions and dreams. We’re not computers. It’s not only factual, logical issues we take into account.”*  
 health-care provider from Seattle town hall

**Figure 3.2: Percent Who Agreed with the Statement “Reproductive Genetic Technology will Inevitably lead to Genetic Enhancement and Designer Babies.”**



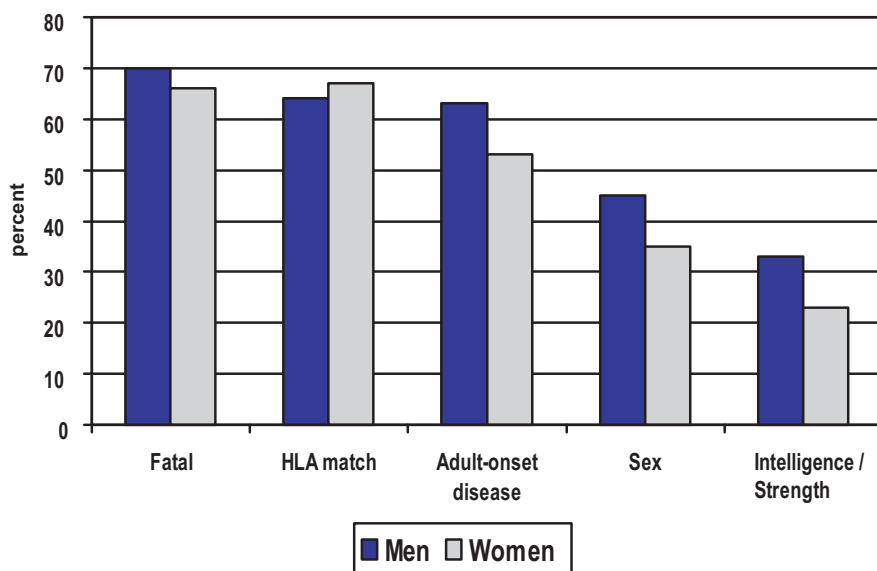
Source: 2004 survey

### What Explains Differences in Opinions about Appropriate Use?

There is huge diversity of opinion about which uses of reproductive genetic testing are and are not acceptable, but what accounts for this diversity of views? In order to understand this diversity, we looked at the frequency of responses by a variety of socio-demographic



**Figure 3.3: Approval of PGD for Different Purposes by Sex**



Source: 2004 Survey

characteristics to see what characteristics were associated with particular views about reproductive genetic testing.

### Sex, Race and Age

Approval for reproductive genetic testing for a fatal childhood disease and for tissue-matching is universally high (Figures 3.3 and 3.4, and Tables 3.2 and 3.3). When a multi-variate regression was performed, differences in sex, race and age did not explain differences in attitudes about the use of reproductive genetic testing for fatal disease and tissue-matching. The only statistically significant difference was that women were slightly more approving than men of prenatal genetic testing for tissue matching. Support was lower for reproductive genetic tests for adult-onset diseases, sex and desirable traits; however, there were some

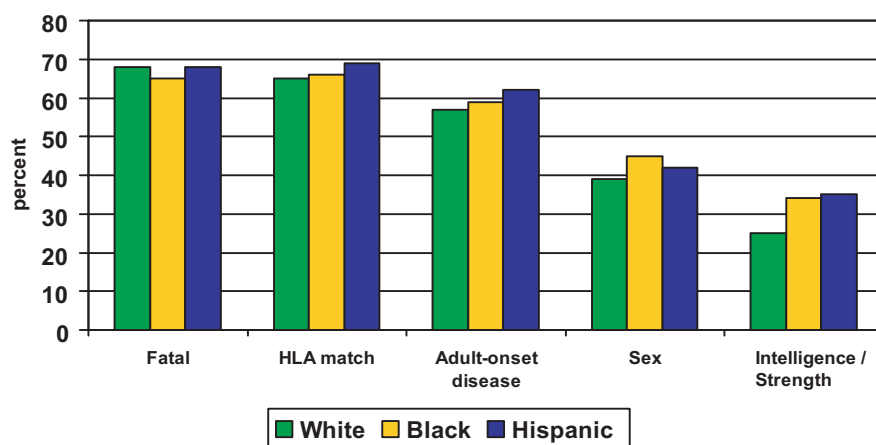
interesting differences by sex, race and age. Men and Hispanics had a higher level of approval for testing for adult-onset diseases. Men were more supportive than woman of using prenatal genetic testing and preimplantation genetic diagnosis

for sex. Whites were least supportive of using reproductive genetic tests for sex and hypothetical traits.

### Religion

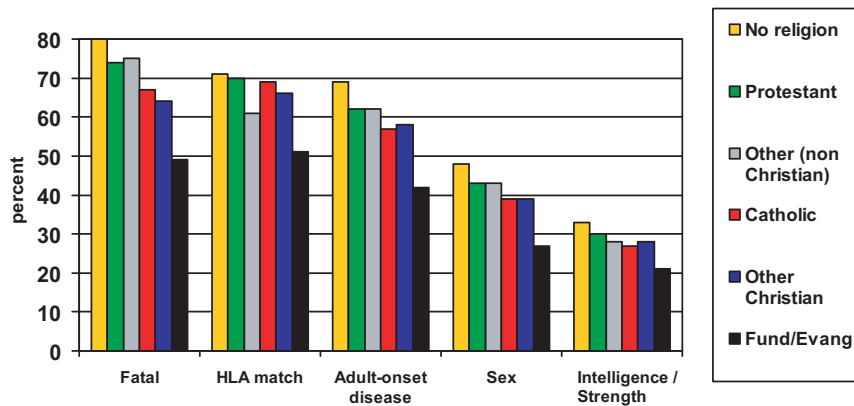
Among religion groups, Fundamentalist and Evangelical Christians were the least supportive of using these technologies for any reason. After controlling for other variables, being a Fundamentalist or Evangelical Christian was associated with a greater likelihood of disapproval for all uses of reproductive genetic testing. The differences in attitudes between Fundamentalist and Evangelical Christians and all other religion groups is largest for PGD or prenatal genetic testing for fatal and adult-onset diseases and shrinks for testing for hypothetical traits (Figure 3.5 and Tables 3.2 and 3.3). While support for testing for traits is lowest among Fundamentalist and Evangelical Christians, fully one-fifth still approve of this use of PGD.

**Figure 3.4: Approval of PGD for Different Purposes by Race**



Source: 2004 Survey

**Figure 3.5: Approval of PGD for Different Purposes by Religion**



Source: 2004 Survey

Respondents who did not have a religious affiliation had the highest levels of support for the use of both prenatal genetic testing to find out the sex of a fetus and PGD to select sex of an embryo. Protestant participants reported higher levels of approval for testing for traits than other religious affiliations.

**Income and Education**

Some interesting differences were observed by education and income. As the level of education increased among respondents, approval for the use of both prenatal genetic testing and PGD to identify fatal childhood disease increased (Tables 3.2 and 3.3). In contrast, respondents with either no or only some college education showed greater levels of approval for reproductive genetic testing for sex or hypothetical traits. Once adjusted for other demographic characteristics, these differences remained significant. Approval for reproductive genetic testing was relatively constant across income groups, with two notable exceptions. First, approval for

both prenatal genetic testing and PGD for a fatal childhood disease increased as respondents' income increased. Second, approval for testing for hypothetical traits was inversely related to income, such that a greater number of participants

in lower-income groups approved of reproductive genetic testing for hypothetical traits (Tables 3.2 and 3.3). Both of these observations remained statistically significant after adjusting for other demographic characteristics.

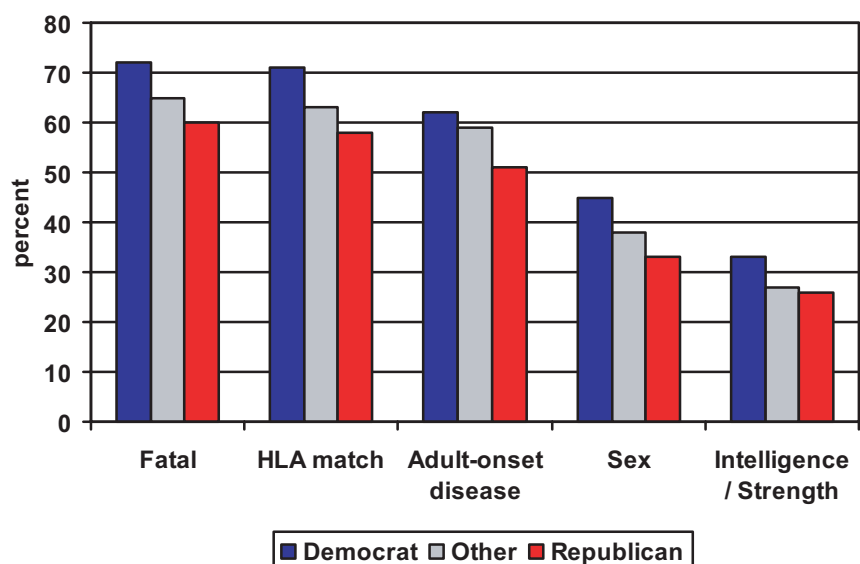
**Political Affiliation**

Republicans are less approving than Democrats and "others" of all uses of reproductive genetic testing, though a majority approved of PGD and prenatal genetic testing for health-related purposes (Figure 3.6).

**Awareness of the Technology**

Survey respondents who reported they had heard about PGD prior to the survey were slightly more likely to approve of the use of PGD for all purposes. There were no differences

**Figure 3.6: Approval of PGD for Different Purposes by Political Affiliation**



Source: 2004 Survey

**Table 3.2: Percentage of Approval for PGD by Purpose and Demographic Characteristics**

| Demographic Characteristics |                       | Fatal | HLA Match | Cancer | Sex  | Traits |
|-----------------------------|-----------------------|-------|-----------|--------|------|--------|
| Total                       |                       | 67.6  | 65.5      | 57.8   | 39.9 | 27.9   |
| Sex                         | Men                   | 69.8  | 64.1      | 62.7   | 45.2 | 33.1   |
|                             | Women                 | 65.6  | 66.7      | 53.3   | 35.0 | 23.2   |
| Age                         | 18-29                 | 68.9  | 64.4      | 59.0   | 41.0 | 27.4   |
|                             | 30-49                 | 69.3  | 65.8      | 57.5   | 41.1 | 27.0   |
|                             | 50+                   | 65.1  | 65.7      | 57.6   | 37.9 | 29.2   |
| Race / Ethnicity            | White                 | 68.3  | 65.3      | 56.6   | 38.6 | 25.3   |
|                             | Black                 | 65.3  | 65.5      | 59.3   | 44.7 | 33.9   |
|                             | Hispanic              | 67.5  | 69.0      | 62.3   | 41.6 | 34.8   |
| Religion                    | Protestant*           | 73.5  | 70.2      | 61.5   | 43.0 | 30.0   |
|                             | Fund/Evang**          | 48.6  | 51.2      | 42.3   | 27.2 | 20.7   |
|                             | Roman Catholic        | 67.1  | 68.6      | 57.0   | 39.4 | 27.3   |
|                             | Other Christian***    | 64.3  | 66.4      | 58.3   | 39.4 | 28.1   |
|                             | Other (Non Christian) | 74.8  | 61.4      | 62.1   | 43.4 | 28.3   |
|                             | No Religion           | 79.9  | 71.0      | 69.2   | 48.0 | 32.7   |
| Income                      | Under 25k             | 64.9  | 67.3      | 58.1   | 41.1 | 32.0   |
|                             | 25k-49k               | 67.4  | 65.4      | 57.7   | 38.4 | 26.6   |
|                             | 50k-74.9k             | 66.9  | 61.2      | 57.3   | 39.6 | 26.0   |
|                             | 75+k                  | 74.6  | 66.7      | 58.4   | 40.8 | 24.3   |
| Education                   | No College            | 63.8  | 65.5      | 57.3   | 39.2 | 30.4   |
|                             | Some College          | 68.3  | 65.0      | 58.1   | 40.3 | 27.5   |
|                             | College               | 72.5  | 66.6      | 58.0   | 37.2 | 21.9   |
|                             | Post Grad             | 76.9  | 64.5      | 60.0   | 46.8 | 26.5   |
| Political Affiliation       | Republicans           | 60.1  | 57.6      | 51.1   | 32.6 | 25.5   |
|                             | Other                 | 64.6  | 62.8      | 58.5   | 38.3 | 26.6   |
|                             | Democrats             | 72.2  | 70.5      | 61.8   | 45.0 | 32.4   |
| Aware PGD                   |                       | 73.1  | 69.3      | 62.8   | 43.8 | 32.6   |

Source: 2004 Survey

\* Protestant includes respondents who self-identified as Protestant, excluding those who additionally self-identified as Fundamentalist or Evangelical.

\*\* Fundamentalist/Evangelical includes all Protestant or Other Christian respondents who additionally self-identified as either Fundamentalist or Evangelical.

\*\*\* Other Christian includes all who self-identified as Other Christian, excluding those that additionally self-identified as Fundamentalist or Evangelical.

in approval for the use of prenatal testing for each of the given purposes based on prior awareness of prenatal genetic testing (Tables 3.2, 3.3).



**Table 3.3: Percentage of Approval for Prenatal Genetic Testing by Purpose and Demographic Characteristics**

| Demographic Characteristics |                       | Fatal | HLA Match | Cancer | Sex  | Traits |
|-----------------------------|-----------------------|-------|-----------|--------|------|--------|
| Total                       |                       | 73.2  | 71.5      | 59.9   | 51.3 | 28.4   |
| Sex                         | Men                   | 73.7  | 68.8      | 64.1   | 56.9 | 33.8   |
|                             | Women                 | 72.6  | 73.9      | 56.0   | 46.0 | 23.5   |
| Age                         | 18-29                 | 74.5  | 71.9      | 62.6   | 55.3 | 27.3   |
|                             | 30-49                 | 74.0  | 70.5      | 59.5   | 51.5 | 26.9   |
|                             | 50+                   | 71.5  | 72.3      | 58.7   | 48.6 | 30.7   |
| Race / Ethnicity            | White                 | 73.8  | 71.5      | 58.9   | 49.8 | 25.2   |
|                             | Black                 | 72.0  | 73.4      | 62.1   | 58.4 | 36.0   |
|                             | Hispanic              | 73.5  | 73.5      | 64.1   | 51.6 | 35.4   |
| Religion                    | Protestant*           | 76.9  | 76.3      | 62.2   | 53.1 | 30.1   |
|                             | Fund/Evang**          | 57.7  | 60.4      | 46.6   | 43.2 | 22.7   |
|                             | Catholic              | 74.9  | 75.9      | 60.2   | 50.0 | 27.1   |
|                             | Other Christian***    | 69.4  | 70.4      | 56.1   | 49.8 | 26.3   |
|                             | Other (Non Christian) | 79.4  | 64.3      | 66.1   | 54.8 | 31.1   |
|                             | No Religion           | 82.9  | 74.4      | 71.7   | 58.8 | 34.4   |
| Income                      | Under 25k             | 71.1  | 72.0      | 59.1   | 53.2 | 34.6   |
|                             | 25k-49k               | 73.4  | 72.0      | 61.7   | 48.5 | 26.4   |
|                             | 50k-74.9k             | 72.3  | 71.2      | 59.3   | 53.2 | 25.6   |
|                             | 75+k                  | 77.9  | 69.5      | 58.1   | 50.7 | 22.9   |
| Education                   | No College            | 70.2  | 72.1      | 59.9   | 50.9 | 32.4   |
|                             | Some College          | 73.5  | 71.5      | 60.6   | 52.0 | 27.2   |
|                             | College               | 77.6  | 73.3      | 57.7   | 48.7 | 19.8   |
|                             | Post Grad             | 79.9  | 65.3      | 61.1   | 55.5 | 26.5   |
| Political Affiliation       | Republicans           | 67.5  | 65.4      | 54.9   | 45.4 | 23.0   |
|                             | Other                 | 69.1  | 67.0      | 57.3   | 48.8 | 28.9   |
|                             | Democrats             | 76.4  | 74.6      | 63.3   | 54.5 | 33.6   |
| Aware Prenatal Testing      |                       | 75.7  | 72.7      | 61.0   | 51.4 | 27.5   |

Source: 2004 Survey

\* Protestant includes respondents who self-identified as Protestant, excluding those who additionally self-identified as Fundamentalist or Evangelical.

\*\* Fundamentalist/Evangelical includes all Protestant or Other Christian respondents who additionally self-identified as either Fundamentalist or Evangelical.

\*\*\* Other Christian includes all who self-identified as Other Christian, excluding those that additionally self-identified as Fundamentalist or Evangelical.

**NOTES:**

<sup>1</sup> Having a child with a specific tissue type is important to some parents because such a child could provide stem cells, usually from the umbilical cord, for an older sibling who is sick and in need of a stem cell transplant. Stem cells from a matched sibling donor are less likely to be rejected and more likely to be effective than stem cells from an unrelated donor.

<sup>2</sup> The situations presented to research participants were to identify sex in the absence of a sex-linked genetic disease such as hemophilia.



# Chapter 4: Views About Embryos and Fetuses

*“I guess it depends on where you really think your baby starts. Does it start at the egg and the sperm or does it start once it actually starts looking like a little baby at nine weeks old...”*

*participant in Black female focus group, Tennessee*

Americans have deeply held, and widely divergent, views about the moral worth of both the human fetus and embryo, and it is often assumed that those beliefs determine people’s perspectives about various forms of reproductive genetic technologies. The notion that people’s views about the appropriateness of using reproductive genetic testing are determined by their views of the moral status of embryos and fetuses – was explored in both the qualitative and quantitative research.

During the focus groups, participants were asked to comment on hypothetical situations in which termination of a pregnancy and destruction of embryos were potential outcomes following genetic testing. In the discussion about prenatal testing, participants were asked to talk about what a hypothetical couple should do with information that their fetus has a specific genetic disease. Next, they were asked to discuss what they thought about the use of preimplantation genetic diagnosis (PGD) to produce healthy children. Finally, participants were asked what a couple ought to do with excess embryos – both affected and unaffected – following PGD. During the town hall meetings, participants expressed their views on the moral status of embryos and fetuses and the role that plays in decision making.

Although the moral status of fetuses and embryos is an important part of people’s assessment of the acceptability of using reproductive genetic testing, numerous additional issues (discussed in Chapters 3, 5, 6 and 7 of this report) seemed to influence focus group and town hall participants’ opinions. Thus, to obtain a quantitative assessment of the relationship between people’s views about the moral status of embryos and the acceptability of using PGD, survey respondents were asked about their views on abortion, the beginning of life, the moral status of embryos and fetuses at various stages of development and appropriate uses of prenatal testing and PGD. Responses to these questions were then cross-tabulated.

## The Moral Status of the Fetus

Prenatal genetic testing has been a routine part of prenatal care for decades. The number of conditions that can be tested for continues to grow, and the stage in pregnancy when testing can occur is being pushed back into the first trimester. In very rare instances, information about a genetic abnormality in utero can facilitate early intervention. Additionally, some families find value in early identification of a genetic abnormality because it gives them the opportunity to plan for the birth of a special-needs child. What concerns some people, however, is that if prenatal testing identifies an affected fetus, parents may consider terminating the pregnancy, or even be encouraged by others to do so. Of greater concern to some is the possibility that a woman might choose to terminate a pregnancy because the fetus does not have the

desired genetic characteristics, such as the “right” sex.

To begin exploring Americans’ opinions about the use of prenatal genetic testing and how that may or may not correlate with their views on the moral status of the fetus, focus group participants were asked to talk about a hypothetical scenario in which a pregnant woman discovers through prenatal testing that her fetus is affected with a genetic disease. Participants were told that, in addition to preparing for the birth of an affected child, terminating the pregnancy was also a potential choice. Some participants in almost every focus group expressed the view that abortion under these circumstances is immoral and that once pregnant, carrying to term and giving birth is the only option. This viewpoint was held frequently but not exclusively by individuals who defined themselves as Christians.

*“I approach this from a non-religious point of view...I don’t really believe in abortion, and it’s not a religious view; it’s just a view that I think life is great, and I think everybody should be alive. I think the more life the better, you know? And let the life run its course.”*

*male participant from mixed sex/race focus group of people 55 yrs and older, California*

Many focus group participants who were opposed to abortion said they would personally refuse prenatal testing if there were no treatment options, such as fetal surgery, and abortion was the only available intervention. Some participants also pointed out that carrier testing and prenatal maternal

serum screening seem harmless because they are “just blood tests,” but they can lead to invasive prenatal genetic testing. Prenatal genetic testing, if positive, could result in a very profound and difficult decision to terminate a wanted pregnancy. Some participants were concerned that routine prenatal genetic testing might create the “temptation” for women to abort if the results are positive.

For other focus group participants, abortion was perceived to be a tragic, yet acceptable, alternative, particularly when its goal is perceived as preventing the suffering of a child. Numerous focus group and interview participants stated that abortion might be the best choice when a fetus is diagnosed with a severe, life-threatening disease.

*“I probably would abort because I wouldn’t want to see the baby suffering...when I know I could have...[given] the baby their wings and just let them just avoid that suffering.”*  
participant from Black female focus group, Michigan

Both points of view – that ending a pregnancy is taking a life and that it is the best choice to make when the alternative is the birth of a child with a severe, life-threatening illness – were expressed by individuals with all socio-demographic characteristics.

Many focus group participants, without prompting, considered ways that couples could avoid this choice, and recommended that carrier testing be available prior to

pregnancy so that couples can know their risk before they are “already pregnant.”

For a very small minority, even a full-term fetus does not have the same moral worth as a born baby and, therefore, abortion is not a morally laden choice.

*“...brace yourselves, ladies, some of you are not going to agree with me. I do not think an embryo is a baby. A baby is not a baby until it is born and it is alive. That’s my view, and that’s why I don’t put my view on anyone else. That’s mine.”*  
participant from White female focus group, Michigan

## The Moral Status of the Embryo

PGD was originally developed to create an alternative to prenatal testing and abortion for couples at known risk of having a child with a genetic disease. To better understand Americans’ views about the moral status of embryos, and how the American public views PGD in comparison with prenatal testing followed by abortion, focus group participants were asked to discuss a scenario in which a couple at risk of having a child with a genetic disease was considering whether or not to use PGD. They were then asked to compare the two approaches to avoiding having a child with a genetic disease.

Some focus group participants stated their belief that from the moment of conception embryos have the same moral value as all human beings, and therefore rejecting some embryos through PGD is unacceptable.

*“[Y]ou formed a child. The sperm and the egg have come together and essentially [through PGD] you get rid of a child, to me. Not to everybody because eight cells might not make up a child to you, but to me, I have to really think through it. I mean where is my kid going? Are you going to flush him down the toilet?”*

participant from Black female focus group, Tennessee

In fact, some focus group participants who adamantly believe that embryos have the full moral worth of a child argued that PGD is ethically less acceptable than prenatal testing followed by abortion, because it may result in the destruction of multiple embryos.

*“I think the difference is that when you’re testing the embryo at four months, you’ve only created one potential life there. When you do it in the dish, five, six, seven, eight? Those are all potential children. So to me, that’s the difference. You have now created more that are going to be destroyed.”*  
female from mixed sex/race focus group, Massachusetts

*“What I would call [PGD] is selective abortion because I believe that life begins at conception, which is when the sperm and the egg unite. So, whether it is eight to ten cells, or a fully developed baby, I think what you have done is scientifically produce twenty embryos, which I would call a baby.”*  
participant from Evangelical female focus group, Colorado

Other focus group and interview participants, including some who

had concerns about the morality of aborting an affected fetus, thought that there was a distinction between abortion and the loss of embryos through the PGD process. They perceived PGD as ethically preferable because PGD does not require termination of a pregnancy. This view was expressed by many members of the general public in focus groups, health-care providers, families affected by genetic diseases and all of the PGD patients.

*“[P]reimplantation genetics has almost redefined that life, in my opinion, would start upon implantation and not upon conception. Because it’s in a lab. An embryo at that stage cannot be sustained by itself. If it’s not implanted or frozen it will not turn into a human being. It needs to be implanted into a woman in order for it to become a human, so that’s why I don’t have a problem with preimplantation genetics.”*  
*Adult with genetic disease, interview*

*“I just keep thinking of embryos and implanted embryos. Those are very different things.”*  
*female participant from mixed sex/race group, Massachusetts*

A PGD specialist described in detail why he believes PGD is different ethically from prenatal genetic testing:

*Well, I think definitely there is [an ethical difference]...When we look at the embryo, the embryo is at the eight-cell stage, which is three days after the fertilization. Morphologically, this is a very much undifferentiated situation. And this embryo, unless you transfer to the uterus, is not a viable embryo”*  
*PGD specialist, interview*

PGD patients were even more adamant about the ethical differences they perceived between abortion and PGD.

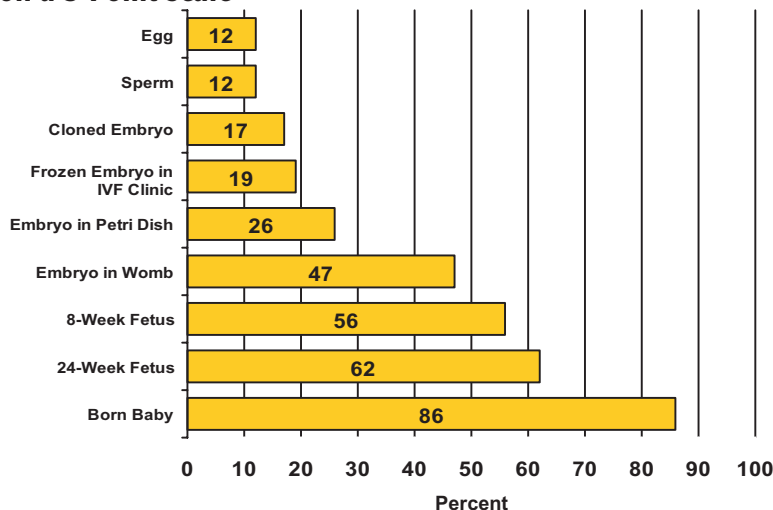
*“[N]either of us felt that the embryo was a living thing until it was living inside me.”*  
*PGD patient, interview*

*“PGD...is more costly; almost as emotionally draining; and more painful, physically, than doing the prenatal testing, but ethically, I feel better about doing it. Because I know that I’m not ending a life...to me, a ball of cells is not a child until it takes root and starts growing, so I don’t feel that I’m doing something bad or evil or unethical by not using certain embryos. So I just feel I’m doing everything I can to create a healthy, happy child, rather than wait and find out if I’ve created a healthy and happy child.”*  
*PGD patient, interview*

In their discussions about PGD, focus group and interview participants were asked to think about what to do with both affected and unaffected embryos left over from the PGD process. The majority believed that the whole point of PGD was to avoid the transfer of affected embryos, so these embryos should not be used for reproductive purposes. Participants repeatedly suggested that affected embryos should be donated for disease research. The most common suggestion for what to do with extra unaffected embryos was to freeze them for future transfer.

Occasionally a participant would recognize the ethical dilemma inherent in valuing affected embryos less.

**Figure 4.1 Percent of Respondents Assigning Maximum Moral Worth on a 5-Point Scale**



Source: 2004 Survey

“What happens [once embryos are created through PGD]?...I acknowledge it is a child, but then I don’t acknowledge it is a child. When it turns out to [be affected], flush it or whatever; or I do acknowledge it is a child when you want to put that good child in my body, and the bad children, you know? [W]hat gets me is that ethical part of she has got those five sickle cell kids and the one that doesn’t have it, you want that one. That is your desire, and we live happily ever after. But what happens to them?”

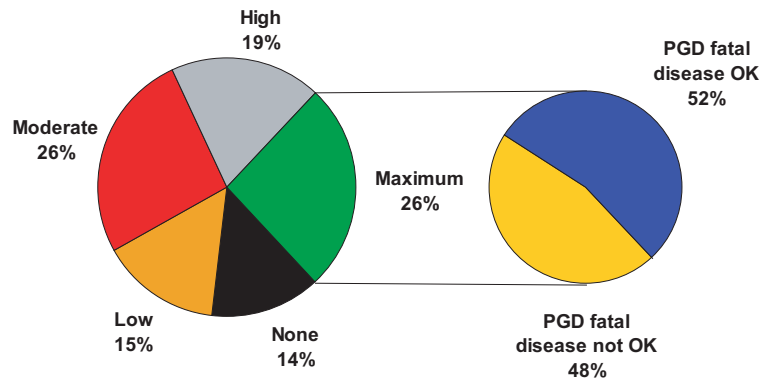
participant from Black female focus group, Tennessee

### Views about the Moral Worth of Embryos and Fetuses

Views about the moral status of embryos clearly play a part in people’s thinking when they assess the acceptability of using PGD, but how big a part? Do people’s views about the moral status of embryos predict their opinions about the appropriate use of PGD, or are there other factors at play?

To assess Americans’ views on the moral status of human embryos and fetuses in the general population, respondents to the 2004 survey

**Figure 4.2: Moral Worth of an Embryo in a Petri Dish**



Source: 2004 Survey

were asked to rank, on a five-point scale, the moral worth of an embryo, a fetus at various stages, and a born baby (Figure 4.1). Survey results indicate that the stage of development makes a difference in people’s assessment of moral worth. In rating moral worth, the proportion of respondents assigning maximum moral worth increased with increasing developmental age. As expected, a large majority (86 percent) ranked a born baby as having maximum moral worth on a five-point scale. Forty-seven percent of respondents assigned an embryo in the womb maximum moral worth compared to 26 percent who rated

an embryo in a petri dish as having maximum moral worth.

Because the use of PGD generally involves the destruction of human embryos,<sup>1</sup> if opinions about PGD are principally driven by views on the moral status of the human embryo, one would predict that those who believe that an embryo in a petri dish has maximal moral worth would disapprove of PGD regardless of why it is being used; however, this is not the case.<sup>2</sup>

Those who felt that embryos in vitro have maximum moral worth were less likely than those who

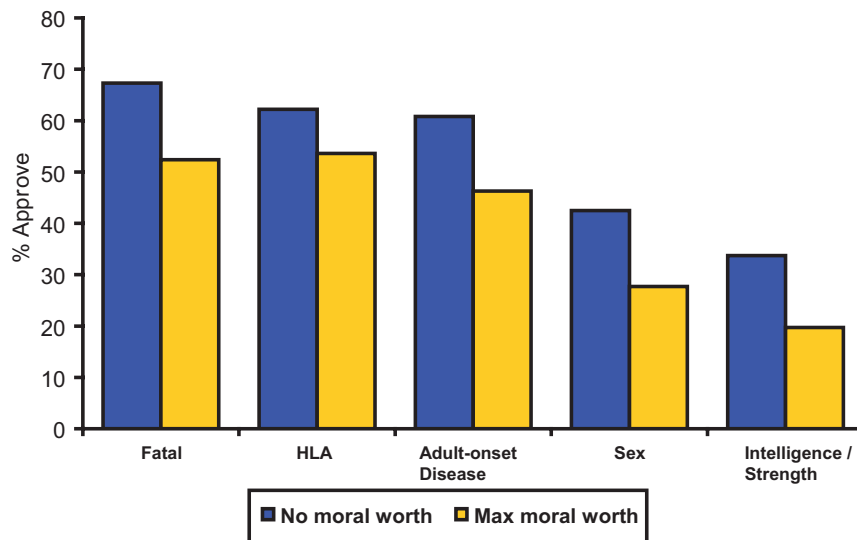
**Table 4.1 Perceptions about the Moral Worth of an Embryo and Approval for Different Uses of PGD**

| Moral Worth of Embryo in Petri Dish | PGD for Fatal Childhood Disease |            | PGD for HLA Match |            | PGD for Adult-onset Disease |            | PGD for Sex Selection |            | PGD Traits |            |
|-------------------------------------|---------------------------------|------------|-------------------|------------|-----------------------------|------------|-----------------------|------------|------------|------------|
|                                     | approve                         | disapprove | approve           | disapprove | approve                     | disapprove | approve               | disapprove | approve    | disapprove |
| Less Than Maximum                   | 73.0                            | 27.0       | 69.8              | 30.2       | 62.2                        | 37.8       | 44.3                  | 55.7       | 30.7       | 69.3       |
| Maximum                             | 52.4                            | 47.6       | 53.6              | 46.4       | 46.3                        | 53.7       | 27.7                  | 72.3       | 19.7       | 80.2       |

Source: 2004 Survey



**Figure 4.3: Level of Approval for PGD by Purpose: Comparing Respondents who Assigned Embryo in a Petri Maximum Moral Worth vs. No Moral Worth**



Source: 2004 Survey

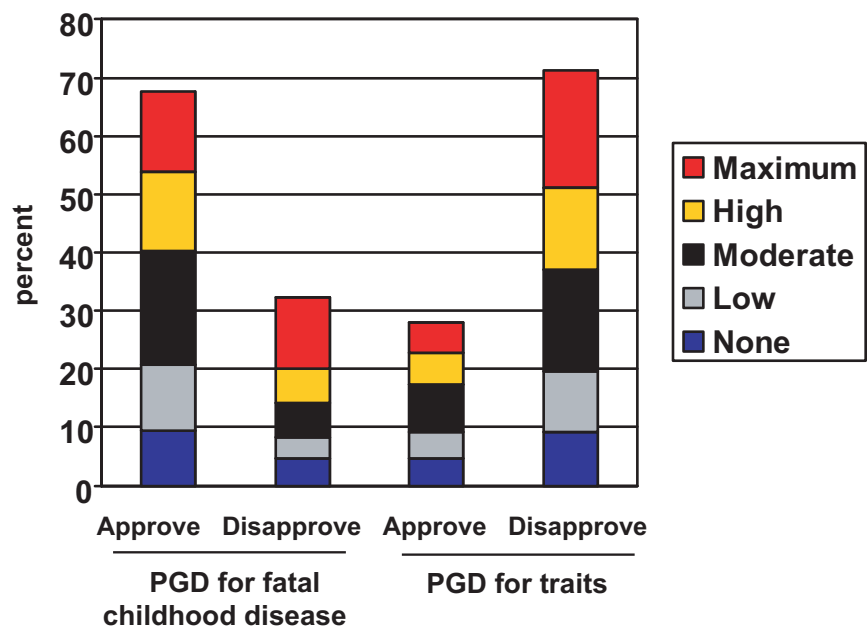
of attitudes towards PGD. Among those ranking embryos with maximum moral worth, approval for PGD to ensure a child will not have a fatal childhood disease was more than twice as high as approval for using PGD to select hypothetical traits such as intelligence or strength (Table 4.1). A similar pattern was observed in responses from those who ranked embryos in a petri dish as having high, moderate, low or no moral worth (Table 4.1; Figure 4.3).

Further support for the notion that views about moral worth are not the primary drivers for views on PGD comes from those who disapprove or strongly disapprove of PGD. A third of respondents disapproved or strongly disapproved of the use of PGD for a fatal

ranked embryos with less moral worth to approve of any use of PGD (Table 4.1). However, slightly more than half of the respondents ranking embryos with maximum moral worth approved of PGD for a fatal childhood disease (52 percent), for HLA matching (54 percent) and nearly half (46 percent) approved of PGD for an adult-onset disease (Figure 4.2, Table 4.1). Thus, this level of approval of PGD does not support the notion that people who attach a high moral worth to the embryo necessarily reject PGD; other factors must be playing a strong role.

Approval for the five proposed uses of PGD varied considerably among those who ranked embryos as having maximum moral worth, providing further support for the existence of factors other than moral worth in the determination

**Figure 4.4: Distribution of Views on Moral Worth of Embryos Based on Approval of PGD**



Source: 2004 Survey

childhood genetic disease. Yet only 38 percent of this group rated a human embryo in a petri dish as having maximum moral worth (Figure 4.4).

These data demonstrate that while views on the moral status of human embryos influence attitudes toward PGD, other factors are playing a major role in shaping these attitudes.

## NOTES:

<sup>1</sup> In the survey, preimplantation genetic diagnosis was defined as “genetic testing that is done on embryos produced through in vitro fertilization before they are transferred to a woman’s womb. Based on the test results, parents can select which embryos to transfer into the woman’s womb. For example, they may want to select only embryos with no genetic diseases, those of a specific sex, or those that have other characteristics. Left over embryos may be discarded, frozen and stored for future use, donated to other couples, or used for research.”

<sup>2</sup> Similar analysis using prenatal genetic testing and views about the moral status of a human fetus is not possible because the questions about prenatal genetic testing were framed differently. We asked whether it was appropriate to use prenatal genetic testing to find out whether a fetus has a genetic alteration that causes illness, etc. Finding out is not the same as making a decision to terminate and thus does not necessarily have the same moral implications.



# Chapter 5: Human Control Over Reproduction

*“Do we leave it to God, or is it up to us?”*  
*participant from Mexican American male focus group, California*

Americans’ beliefs about how much we ought to attempt to control human reproduction and the genetics of the children we bring into the world fall across a very broad spectrum. At one end are people who believe that using genetic testing to make reproductive choices amounts to “playing God.” Those in the middle believe that some uses may be justified but that humans need to be cautious stewards of any new technology. At the other end of the spectrum are those who believe we should be using technology in every possible way that might advantage humans, including enhancing and improving the human species.

*“[I]t feels like we’re taking this incredible gift and process of giving birth to a child, and turning it into a scientific process, and that completely goes against what I believe. I want to leave [the sex of a baby] up to whatever the Creator decides He wants to give me, and trust that there is a reason that I’m going to have a boy instead of a girl.”*  
*participant from White male focus group, Colorado*

When focus group participants discussed the use of reproductive genetic testing, the notion of humans overstepping their appropriate role in the reproductive process was always mentioned. This concern was expressed in either religious terms, for example, “playing God,” or in

secular terms, such as “tampering with Mother Nature” or “interfering with natural selection.”

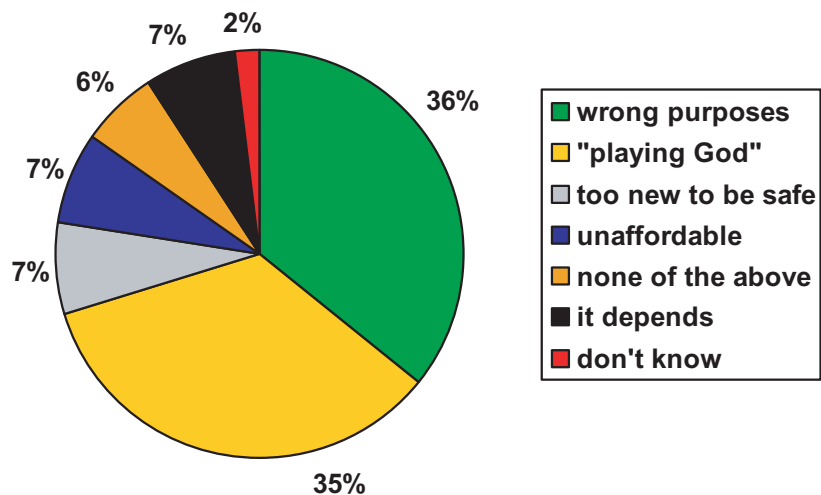
In the 2002 survey, participants were asked what worried them most about the use of reproductive genetic technologies (Figure 5.1). When given the choice of four alternatives, 34 percent of Americans said that using reproductive genetic technology was too much like “playing God.” The only issue (among those choices offered) that appeared to concern participants more was that the technologies could be used for the wrong purposes.

The idea of “playing God” was most frequently mentioned by Evangelical Christian focus group participants, but was spontaneously mentioned during many of the other focus groups. It is important to note that in all of our discussions with Americans, this phrase was consistently used as an expression of concern.

Focus group discussions revealed that “playing God” means different things to different people. As discussed in Chapter 4, some focus group participants equated the destruction of embryos and/or fetuses with murder. For this group, “playing God” meant deciding who lives and who dies.

*“I don’t think that you can just discard an embryo that has been fertilized, or change that in any way because I just don’t believe that that is the way God intended it to be...Promote a healthy baby, I am all for it, but I just don’t think isolating and taking [embryos] out, deciding which ones to take and which ones you shouldn’t take — I think that’s an ethical thing, and I think that’s God choice and not mine, or the doctor’s or anybody else’s.”*  
*participant from female Catholic focus group, Michigan*

**Figure 5.1: What Worries You the Most?**



Source: 2002 Survey

Others were concerned that these technologies can result in people making value judgments about

who is fit to be born. This sends an inappropriate message that there are some lives not worth living. This

concern was expressed predominantly by Evangelicals and by Catholics.

**Table 5.1: Suffering is a Part of What Makes Us Human**

| Demographic Characteristics |                       | Percent Of Those Who Agreed Or Strongly Agreed |
|-----------------------------|-----------------------|--|
| Total                       |                       | 79.3   |
| Sex                         | Men                   | 79.0   |
|                             | Women                 | 79.6   |
| Age                         | Age: 18-29            | 83.3   |
|                             | Age: 30-49            | 80.3   |
|                             | Age: 50+              | 76.0   |
| Race/ethnicity              | White                 | 79.8   |
|                             | Black                 | 78.2   |
|                             | Hispanic              | 78.0   |
| Religion                    | Protestants*          | 78.8   |
|                             | Fund/Evang**          | 86.2   |
|                             | Roman Catholic        | 82.1   |
|                             | Other Christian***    | 76.4   |
|                             | Other (Non Christian) | 73.8   |
|                             | No Religion           | 74.5   |
| Income                      | Under 25k             | 80.6   |
|                             | 25k-49k               | 81.3   |
|                             | 50k-74.9k             | 78.9   |
|                             | 75+k                  | 72.9   |
| Education                   | No College            | 81.0   |
|                             | Some College          | 79.1   |
|                             | College               | 77.8   |
|                             | Post Grad             | 74.1   |
| Political Affiliation       | Republicans           | 79.8   |
|                             | Other                 | 78.7   |
|                             | Democrats             | 76.6   |

Source: 2004 Survey

\* Protestant includes respondents who self-identified as Protestant, excluding those who additionally self-identified as Fundamentalist or Evangelical.

\*\* Fundamentalist/Evangelical includes all Protestant or Other Christian respondents who additionally self-identified as either Fundamentalist or Evangelical.

\*\*\* Other Christian includes all who self-identified as Other Christian, excluding those that additionally self-identified as Fundamentalist or Evangelical.

*“...I would draw the line anytime that a life is being ended because of its assumed quality.”*  
*participant from Evangelical female focus group, Colorado*

*“[W]e wanted to send all of our children the message that quality of life is not measured by how many minutes you get on this planet, or how many of those minutes are disease-free. But rather by how much you have loved, and by how much you have been loved. And in that respect, we feel that our children have a rich, happy life.”*  
*mother of child with cystic fibrosis who declined to use PGD (interview)*

Numerous participants pointed out that we may not understand why people are affected by genetic disease, but everything that happens in life, including having a genetic disease, has a purpose as a part of God’s divine plan.

*“[D]o you trust God to have the best will, that what he has given you is the best thing that you can have, and to do the best you can with it, or do you want to keep intervening in situations, and change things, and not knowing whether you have the best wisdom or not?”*  
*participant from Evangelical female focus group, Colorado*

*I don't agree with making your baby while it is in the womb because that is part of the enjoyment... You can't just go in and be like I want a baby with blue eyes, brown hair, can it be six foot tall, can it be like Omar Epps and look like Morris Chestnut... it all comes back to [the] religious. No matter what you have, God has blessed you with it. And you should never be ashamed of the way you look or your appearance or anything like that.”*  
*participant from Black female focus group, Tennessee*

Additionally, some focus group participants made clear that, for them, suffering, disability and physical, mental and emotional challenges are a valuable part of life and contribute something special to individual lives, families and, collectively, to society. These people argued that human suffering teaches individuals about overcoming obstacles and growing as human beings and contributes to a more humane world.

*“I think there are things we need to learn from our own trials... Maybe compassion as human beings, and that's how we learn it.”*  
*participant from Mexican American male group, California*

The idea that suffering is an essential part of life was explored in the 2004 survey. Respondents were asked whether they strongly agreed, agreed, disagreed or strongly disagreed that “Suffering is a part of what makes us human” (Table 5.1).

A greater number of Fundamentalist and Evangelical Christians and Catholics agreed with this statement compared to other religion groups. Americans over 50, and those with higher education and income, were slightly less likely to think suffering is a part of what makes us human. Interestingly, there were virtually no differences by sex, race or political affiliation in the way people think about the purpose of suffering.

In addition to perceptions about the purpose of suffering, many Evangelical and other Protestant focus group participants said having a child affected by any disease has deep spiritual meaning. It may be an opportunity to learn compassion, a test of faith for the parents, a testimony of the family's faith to others as they learn to live with the burdens and blessings of having an affected child or an opportunity for God to perform a miracle. Using technology to avoid these situations could be interpreted as a lack of faith in God's plan for your life.

*“...I believe that everyone is created differently, and there is a reason that people are born with whatever. Even if it is cystic fibrosis, there is a reason that God has intended that person to have that, whether it be a testimonial kind of a thing, or maybe it would make the quality of life better, knowing that you could die within like ten years, because I think a lot of people just live like they can live forever... So I think everything has a purpose.”*  
*participant from Evangelical female focus group, Colorado*

*“God doesn't put anything on you that you can't bear. And sometimes pain is just something you have to bear through... it is just something that everybody has to learn to live with...”*

*(Protestant) participant from Black female focus group, Tennessee*

*“To me, [parents of an affected child] were blessed with a child, and it's God's will how that child comes out. It might be a test for the parents.”*

*participant from Mexican American male focus group, California*

Other focus group and town hall participants expressed their discomfort with reproductive genetic testing in secular rather than religious terms. They stated their belief that using these technologies to influence who is born is tampering with nature or fate and could have repercussions we cannot begin to understand.

Some participants said there is divine wisdom in the design of the world, or in secular terms, that there is a balance to nature. Similarly, the idea was expressed that human wisdom is flawed, and that we may think we are using sound judgment when we use these reproductive genetic testing technologies, but we will be tempted to use them for “selfish” reasons and in ways that reinforce harmful stereotypes. Additionally, participants stated that the ability to select for or against specific traits is unlikely to turn out the way people plan because too

many factors work together to create a whole person. For instance, a person selected for genetically high intelligence may contribute little to the world without ambition and moral values.

*“I don’t know if I can put my finger on it, but there is something that just seems kind of off about the whole process of us pulling out sperm and eggs, and mixing them all up and picking the one we like best, without even trying to take it to a really deep religious or philosophical level.”*  
participant from White male focus group, Colorado

*“[A] lot of this stuff is, in my own personal opinion, mankind trying to step above God or natural order, the way things were supposed to be created, how things were naturally created within the Bible. Man is trying to take it to his own context, and as a result, man is going to doom himself because of trying to go above and beyond God, and go against natural order, and the way things are supposed to be done.”*  
participant from young male focus group, Tennessee

*“You have a doctor who is picking the cells that are going to be implanted, as opposed to the body naturally picking what’s going to happen.”*  
participant from female focus group, Massachusetts

When challenged by other participants, however, some of the participants who thought that using reproductive genetic testing was unnatural or “playing God” agreed that taking control of reproduction to limit disease is not radically

different from other medical interventions.

A few focus group participants argued that God has given us these tools and leaves it up to humans to use them wisely. Eliminating serious genetic disease is a wise and an appropriate use of the technology.

*“[I]f we’re going to leave it to God, God’s putting this knowledge in our path... God’s giving us the knowledge to figure it out.”*  
participant from Protestant female focus group, Massachusetts

*“You know what it is? It’s the old argument, you know, if God wanted you to fly, he’d give you wings. Well, you know, we got past that. We fly now.”*  
male participant from older mixed sex/race focus group of people over 55, California

*“We eliminated small pox and I didn’t see anybody crying about that.”*  
participant from Mexican American female focus group, California

*“How is stopping it [technology] not playing God?”*  
participant from young female focus group, Colorado

### **Is This the Next Step in Human Evolution?**

*“Down the road, and this is very far down the road, I think this is the way the human species is going to evolve. We have... met the limits of our evolution in the old fashioned ways.”*  
PGD provider (interview)

At the other end of the spectrum were focus group participants, mostly male, who argued that human intervention in reproduction can lead to efficient and vast improvements in human health, and we have an obligation to pursue technological progress.

*“I think if the question on the table is should they be allowed to increase intelligence, I say yes... I agree... people who are more intelligent generally are more aware; they live life a little bit more fully... [I]f we can make children more intelligent, sure, make them more intelligent. Let them really live life; enjoy things; let them stop and smell the roses, and know what that means, and not just be brutish louts walking down the streets stealing hubcaps, you know?”*  
male participant from older mixed sex/race focus group of people over 55, California

*“It’s kind of funny that I guess humans will do this to animals to make more productive cows, more productive chickens that have bigger breasts for meat and stuff like that, and we can look at that as an improvement of the animal for a variety of purposes, but we kind of refuse to put ourselves in that animal category, and we refuse to say ‘why don’t we make a smarter kid?’ As a teacher, I would love to have a room full of smart kids. I have plenty on the other side, you know?”*  
participant from White male focus group, Colorado

**Table 5.2: Reproductive Genetic Technology is Potentially the Next Step in Human Evolution**

| Demographic Characteristics |                       | Percent Of Those Who Agree Or Strongly Agree |
|-----------------------------|-----------------------|--|
| Total                       |                       | 53.6   |
| Sex                         | Men                   | 55.6   |
|                             | Women                 | 51.7   |
| Age                         | Age: 18-29            | 52.2   |
|                             | Age: 30-49            | 52.2   |
|                             | Age: 50+              | 55.9   |
| Race/Ethnicity              | White                 | 52.4   |
|                             | Black                 | 60.0   |
|                             | Hispanic              | 57.0   |
| Religion                    | Protestant*           | 56.7   |
|                             | Fund/Evang**          | 41.0   |
|                             | Roman Catholic        | 53.8   |
|                             | Other Christian***    | 54.4   |
|                             | Other (Non Christian) | 56.7   |
|                             | No Religion           | 60.9   |
| Income                      | Under 25k             | 57.1   |
|                             | 25k-49k               | 52.5   |
|                             | 50k-74.9k             | 50.7   |
|                             | 75+k                  | 52.0   |
| Education                   | No College            | 56.5   |
|                             | Some College          | 51.7   |
|                             | College               | 49.4   |
|                             | Post Grad             | 51.6   |
| Political Affiliation       | Republicans           | 45.6   |
|                             | Other Affiliation     | 52.2   |
|                             | Democrats             | 58.4   |

Source: 2004 Survey

\* Protestant includes respondents who self-identified as Protestant, excluding those who additionally self-identified as Fundamentalist or Evangelical.

\*\* Fundamentalist/Evangelical includes all Protestant or Other Christian respondents who additionally self-identified as either Fundamentalist or Evangelical.

\*\*\* Other Christian includes all who self-identified as Other Christian, excluding those that additionally self-identified as Fundamentalist or Evangelical.

*“[I]f there is a possibility of a way that you can actually have a better person, I don’t see how come we would not want to select to have a better person.”*

*participant from Black male group, Tennessee*

This notion was tested in the 2004 survey, in which Americans were asked whether they strongly agreed, agreed, disagreed or strongly disagreed with the statement: “Reproductive genetic technology is potentially the next step in human evolution.” Americans are almost evenly split between agreeing and disagreeing with this statement (Table 5.2). There was very little variation by demographic characteristics with two notable exceptions. Sixty-one percent of people who had no religious preference agreed with this statement, while only 41 percent of Fundamentalist or Evangelical Christians agreed. There was a 12 percentage point difference between Democrats and Republicans, with 58 percent of Democrats agreeing, compared to only 46 percent of Republicans agreeing. In addition, Whites were slightly less likely than Blacks or Hispanics to agree with this statement.





# Chapter 6: Implications for Individuals, Families and Society

*“I generally think this is marching down the road of the end of mankind.”*

*participant from young male focus group, Tennessee*

The American public has both hopes and fears about the implications of using reproductive genetic testing. Many are extremely optimistic about the potential to enable families to have healthy children and reduce the physical and emotional burdens caused by genetic diseases. Some even believe the technology is a step towards improving the human condition by leading to increased life spans and improved quality of life. But many are troubled by the potential for adverse social consequences of widespread use of reproductive genetic testing.

Will a society that can “pick and choose” the genetic characteristics of the next generation become less accepting of genetic differences, neglect those with genetic disease, view children as products and hold parents responsible for the birth of less than perfect children? Additionally, many are concerned that selecting for or against certain genetic alterations might inadvertently make humanity more vulnerable. For example, we might make humans more susceptible to infectious disease. Finally, many fear the possibility that if the government controls these technologies, they could be used for nefarious purposes such as the Nazi eugenics movement or as genocidal weapons.

To uncover and further explore people’s perceptions about the social implications of reproductive

genetic testing, participants in the focus groups, interviews and town hall meetings were asked to discuss their hopes and fears about this technology. Subsequently, survey respondents were queried about their levels of concern about these issues.

## Will We Lose Diversity?

*“What are we going to do, go through and clean out every single one of these until we have this perfect person? What’s the fun in that? What are we going to do, be all bland, homogenous white people? Where is going to be the diversity? I like diversity in my life.”*  
*participant from young male focus group, Tennessee*

Focus group participants were worried about a world in which we scrutinize DNA to see who passes over the genetic bar and is allowed to gain entry into the world.

A common remark among focus group and town hall participants was that they did not want a world of “blonde haired, blue-eyed people.” They thought that the world was a better place for being diverse, and they feared that reproductive genetic technologies could lead to a narrowing definition of who is fit to be born and a loss of the beauty and richness of human diversity.

Some focus group and town hall participants pointed out that much of what we consider extraordinary about some individuals could also be interpreted as genetic flaws. Using reproductive genetic technologies to eliminate these flaws means eliminating these individuals, who

can make major contributions to society.

*“What about someone like [physicist] Stephen Hawking? Someone might have chosen not to continue that pregnancy, and we would have missed out on a genius.”*  
*participant in Kalamazoo town hall*

Some Americans, especially those in families affected by genetic diseases, were concerned that routine use of genetic testing would eventually reduce the number or even lead to the elimination of people with genetic diseases.

*“And people with genetic conditions have wonderful lives, and they can lead productive lives, and it’s not a reason to really eliminate a genetic condition...because then you start to eliminate a different segment of the population that deserves to be there.”*  
*adult with genetic disease (interview)*

The potential that use of these technologies could result in a loss of human diversity is of concern to three-quarters of survey respondents (Figure 6.1). This is of greatest concern for women of reproductive age, Republicans, and Fundamentalist and Evangelical Christians and Catholics.

Concerns about loss of diversity extended to the possible biological consequences of reproductive genetic technology. A few participants cited research linking a single sickle-cell gene mutation with resistance to malaria.

*“But we all know for a fact that humanity is strong because of diversity. Now it may not be as clean. Yes, we have kids with cystic fibrosis. We have kids with Down syndrome, but diversity is what makes us strong...we don’t know what the future implications of our eliminations are.”*

*participant from White Protestant female focus group, Massachusetts*

*“To have one copy of the [cystic fibrosis] gene actually offers protection against certain types of plagues...And in fact, that’s why cystic fibrosis is still with us today. Carriers have a survival advantage over people who are not carriers. When you change one thing in a very complex system, you sometimes inadvertently change things that you didn’t want to change.”*

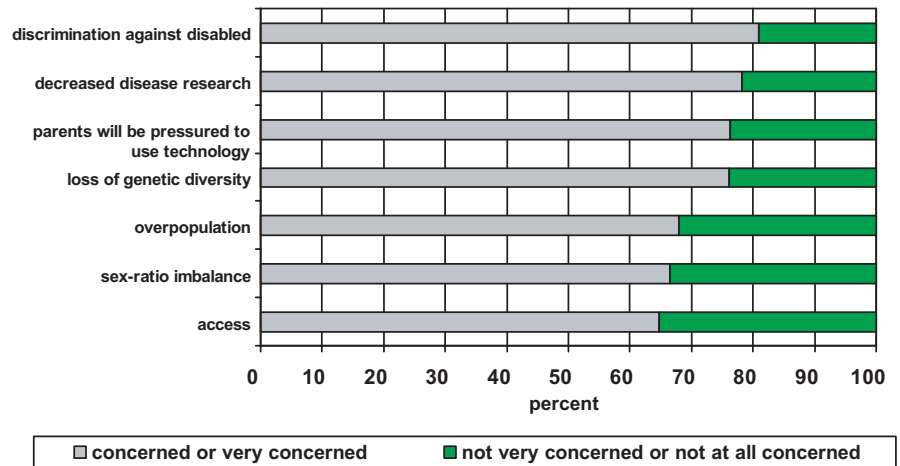
*mother of three children with genetic disease (interview)*

Some focus group and town hall participants also expressed the fear that widespread availability of reproductive genetic testing combined with a preference for male children in some cultures could lead to significant sex ratio imbalances. These imbalances could lead to societal dysfunction if most people selected one sex over the other.

*“There are so many examples of what’s already happened with people thinking that men are better than women and women are inferior. I mean in China, you know they were throwing away kids because they were girls, and now you’re giving people the power to just not even have to deal with accepting what they have.”*

*participant from young female focus group, Colorado*

**Figure 6.1: Level of Concern about Social Implications**



Source: 2004 Survey

Again, survey findings confirm that over two-thirds of Americans are concerned about use of this technology leading to an imbalance in the sex ratio (Figure 6.1).

### Discrimination and Stigmatization of the Disabled

*“I think socially we have to be very aware that we’re not trying to eradicate all diseases, because we don’t want it [to be] that we don’t accept people in our society that have a disease...I wouldn’t want to see a society that really further stigmatizes families or children or adults that do have a disease.”*

*genetic counselor (interview)*

Of the seven concerns identified in the qualitative research and tested in the survey, fear that use of this technology could result in discrimination and stigmatization of the disabled is of most concern to survey respondents. Fully 81 percent of surveyed Americans were very concerned or concerned that expanded use of reproductive genetic

testing could lead to increased discrimination against the disabled (Figure 6.1). Females, those with less education and Fundamentalists and Evangelical Christians were most concerned about discrimination. Members of different races were equally likely to be concerned about discrimination.

Additionally, data from the focus groups, interviews and town halls suggest that Americans are concerned that increased use of genetic testing could lead to a society in which there is an expectation that everyone could or should be “perfect” and where there is less tolerance for diversity, imperfections, diseases or disabilities.

*“Where is the point at which ‘otherness’ becomes ‘disability?’”*

*participant in Kalamazoo town hall*

Participants frequently referred to the film *Gattaca* and the book *A Brave New World* as a portrayal of a possible abhorrent future



brought about by reproductive genetic technologies. They stated that the world would be a poorer place if differences and disabilities were eliminated. Several told stories about the contributions that individuals with Down syndrome, cystic fibrosis and sickle cell anemia have made to their communities.

*“I know a ton of Down syndrome children that I can’t even imagine this world without. They’re just phenomenal children.”*  
female participant from mixed sex/race focus group, Massachusetts

*“Well, I think the negative implication [of PGD] is that we become less tolerant of people who are different and have disease... And it creates a false expectation that we all can be perfect.”*  
PGD specialist (interview)

Many preimplantation genetic diagnosis (PGD) providers and patients felt strongly that fears that PGD will result in a society where everyone is selected based on their genetic makeup are overstated and belong in the realm of science fiction. PGD patients felt that these fears pale next to the immediate concerns felt by families dealing with a genetic disease.

*“It’s not like we’re trying to create the supreme race here; we’re just trying to have healthy kids.”*  
father of a child with genetic disease (interview)

## Who Will Have Access?

*“[T]here may be a certain type of population who cannot afford [these technologies], so then you’re giving those with more money, more power to choose...”*  
participant from Jewish female focus group, Massachusetts

Cost and lack of insurance coverage were seen as major barriers to the use of reproductive genetic testing, particularly PGD. Focus group participants tended to view advanced reproductive technology as “something for rich people.” According to survey data, 65 percent of Americans were concerned or very concerned that even if the use of genetic technology became widespread, some people would be unable to afford it (Figure 6.1). Inequities in access were of greater concern for older Americans and Democrats. It was of less concern for young males, individuals with post-graduate degree, Whites, and Fundamentalist and Evangelical Christians.

This concern was shared by some health-care providers and many patients who were interviewed. Providers described repeated unsuccessful attempts to convince insurance companies to provide coverage for the costs of PGD. They stated that PGD is so new that insurance companies do not understand the technology. They also expressed the belief that insurers tend to be very shortsighted in their financial considerations and base coverage decisions on short rather than long-term savings. Some interview respondents expressed the belief that insurers are under political pressure not to underwrite

a technology that many see as controversial.

The majority of primary care and PGD providers said they felt insurance should pay for reproductive genetic testing, but several voiced concern about the burden that could be placed on the health-care system if it were covered. Many qualified their support for insurance coverage by saying that it should be reserved for cases in which it is being used to avoid a serious, early-onset disease.

PGD patients were quite passionate in their arguments that reproductive genetic testing should be covered by health insurance. They argued that, from a purely financial standpoint, not covering reproductive genetic testing was irresponsible because the financial costs of treating a child with a genetic disease are so high. They also stated that insurance coverage was needed so that everyone who could benefit from the technology could afford it.

*“I think that this should be available to everybody. I don’t think that insurance should make you suffer...I think that’s insane because what they paid for my son having been born with this [disease]...his first two years of life, he was hospitalized nine times. He almost died a few times. You know, they wouldn’t have had that cost if he had been born healthy...I don’t think they see the full picture.”*  
PGD patient (interview)

Focus group participants generally believed that carrier and prenatal testing should be widely available and covered by

health insurance, but they were split over whether PGD should be covered by insurance. While most empathized with families affected by genetic disease who want to have genetically-related, healthy children, many believed that people who want to use an expensive procedure like PGD that has such a high failure rate should bear the cost of it themselves. Expecting others to bear the cost was “selfish,” especially since couples have alternative paths to parenting like adoption.

*“[I]f the insurance is paying for it, that means I’m paying for it ultimately, because they’ve got to recoup that \$60, \$80 grand somehow, and it’s going to affect my rates...that’s great if they’ve got the inclination that that’s where they want to dedicate their resources, and their savings, and they really want children. I think that’s a choice that should be made available. But I don’t think the rest of us should pay for it.”*  
participant from White male focus group, Colorado

Some members of the general public and some primary care providers were reluctant to endorse widespread use of reproductive genetic testing because they did not think it was the best use of scarce health-care resources. A nurse midwife and a family practice physician stated that there were ethical implications to investing in PGD technology when so many people lack access to basic prenatal and other health-care.

While cost was the primary access barrier raised by focus group and town hall participants, they also expressed concern about additional barriers that might limit people’s access to the technology. They mentioned that many of these technologies are so new that patients do not know to ask about them, and providers do not know enough to offer them or refer patients to appropriate specialists.

*“...who is even caring that we are getting educated about possibly testing a child for sickle cell, or spina bifida...if you are going to do it for one, do it for all, or don’t do it at all...I mean if the doctor does not present this information to you, how do you know to ask?”*  
participant from Black female focus group, Tennessee

Additionally, people may not be able to take advantage of testing if they live in geographic areas where there are no providers.

### **Will Access Barriers Increase Class and Racial Disparities?**

*“I see a world where only poor people have diseases.”*  
participant from females with no children focus group, California

Americans are almost universally concerned that reproductive genetic technologies will only be accessible to the white and wealthy, leading to ever wider disparities in health. The public fears that unequal access to the technologies would enable those who can afford it even greater advantage because their offspring would be healthier or even

(futuristically) smarter and stronger than those without financial resources.

*“[I]t’s not the poor families in Africa that are going to be doing this, it’s going to be the very affluent who are going to at first have healthier children...and then it becomes the slippery slope, they will have stronger, faster, smarter children... Then you’ve got these two very disparate classes.”*  
participant from White male focus group, Colorado

*“[M]ost of the Black community is not going to have access to this.”*  
participant from Black male focus group, Tennessee

*“[T]he universe that I live in right now, it’s mostly rich, White, well-educated humans who are utilizing assisted reproductive technologies. And so that has the potential to really create inequities or exacerbate inequities that already exist.”*  
PGD provider (interview)

### **Decreased Efforts to Find Treatments or Cures**

Americans do not want genetic testing to become a substitute for continued research into cures for genetic disease. Some participants in the focus groups and town halls expressed concern that if the use of reproductive genetic technologies becomes widespread, it could lead to decreased research and development of treatments for diseases that can be detected before birth and the birth avoided.

*“There [would be] fewer people who are sick, but there’s less attention given to the sick people. Like there’s less...priority given to those diseases. I would want to make sure that, even though they’re a minority, that they’re still being taken care of somehow.”*  
*female participant from mixed sex/race focus group, Massachusetts*

Survey participants were asked how concerned they were that widespread use of genetic technology could result in decreased research to develop treatments for certain diseases, and 78 percent of surveyed Americans said they were concerned or very concerned about this possibility (Figure 6.1). Women, Democrats and all Christians (compared to non Christians and those with no religious affiliation) were more likely to be concerned about neglect of those with genetic disease. Survey respondents of different ages and races were equally likely to be concerned about this issue.

### **Will We Expect Perfect Children?**

*“[C]hildren aren’t products, you know?”*  
*participant from mixed sex/race focus group of people over 55, California*

Americans are enthusiastic about the possibility of using reproductive genetic testing to avoid genetic disease. Additionally, a small minority of focus group participants thought that society would benefit from using reproductive genetic testing to create smarter, stronger children.

At the same time, the majority of Americans are concerned that increased use of this technology could change the way we think of children and increase the chances that we view them as commodities. Participants in the focus groups, interviews and town halls recognized that it is a natural inclination for parents to want to provide the best possible opportunities for their children. Unfortunately, this drive may inevitably lead to competition to select for or against traits that may convey social advantage. This may lead to unrealistic expectations of what it means to be a “perfect child.”

*“We always want the best for our children. But we always want the best children, too.”*  
*two Sacramento town hall participants*

*“[S]ome people, they push their kid. They want them to be the best... What if we all want our kid more intelligent. So your kid is 150 [IQ]— I find out, I want mine 180. Ech, no, don’t go there. That’s too far.”*

*participant from Chinese American female focus group, California*

*“[I]t’s unfortunate, but there probably would be this whole competition thing... people perceive that if you are more perfect or closer to perfection then you have more value as a human being. I think that there are certainly negative social implications there.”*  
*parent of child with genetic disease (interview)*

Participants in the focus group and town hall discussions were concerned that picking the genetic

characteristics of one’s children would lead parents to put even more pressure on children to live up to unrealistic expectations. Participants occasionally mentioned that dealing with disappointment from one’s children is part of parenting.

A town hall participant mentioned that with so much emphasis on genes, we may forget about the role nurturing plays in raising healthy, happy children. Other focus group and town hall participants feared that children selected to meet parents’ preferences would embody unhealthy prejudices and perpetuate them in future generations, further narrowing diversity and increasing ignorance about any other way to look or function.

*“Kids come in all shapes and sizes. And some aren’t perfect. And I think that they’re still valuable.”*  
*female participant from mixed sex focus group, Massachusetts*

Of survey respondents, 70 percent agreed or strongly agreed that they are concerned that the ability to control human reproduction will lead to treating children like products (Figure 6.2).

Religion, income and education were associated with the degree to which Americans agree that the ability to control human reproduction will lead to treating children like products (Table 6.1). Eighty percent of Fundamentalist or Evangelical Christians agreed with this statement compared to only 61 percent of those who had no religious preference. Of those with a post graduate degree, 55 percent

agreed compared to 73 percent without a college degree. Those with less income were also more likely to agree with this statement.

Conversely, participants in focus groups and town halls raised the concern that this technology could lead to a society in which children hold their parents accountable for their reproductive decisions.

*“As parents you would now be responsible for choices you made. There will be lifelong replaying of those choices. Children would say ‘why did you choose me to be like this, when you could have chosen me to be like that?’”*  
*participant in Seattle town hall*

### Privacy of Genetic Information

*“I think in another 20 years we’re going to have a bar code on our forehead, and they’re going to scan the damn thing and know everything about us.”*  
*male participant from mixed sex/race focus group of people over 55, California*

Americans see the potential for great benefit from reproductive genetic testing, but they also want the opportunity to decline reproductive genetic testing and control how the information is used. They are concerned that test results might be used in ways that are harmful rather than helpful for individuals and families.

Focus group, interview and town hall discussions demonstrate that people do not want to receive genetic testing without first being informed that testing is optional and that it

has implications beyond standard prenatal testing. This appears to be a valid concern since several providers admitted in interviews that they or their colleagues did not obtain informed consent prior to ordering carrier testing and mentioned test results only if they were positive.

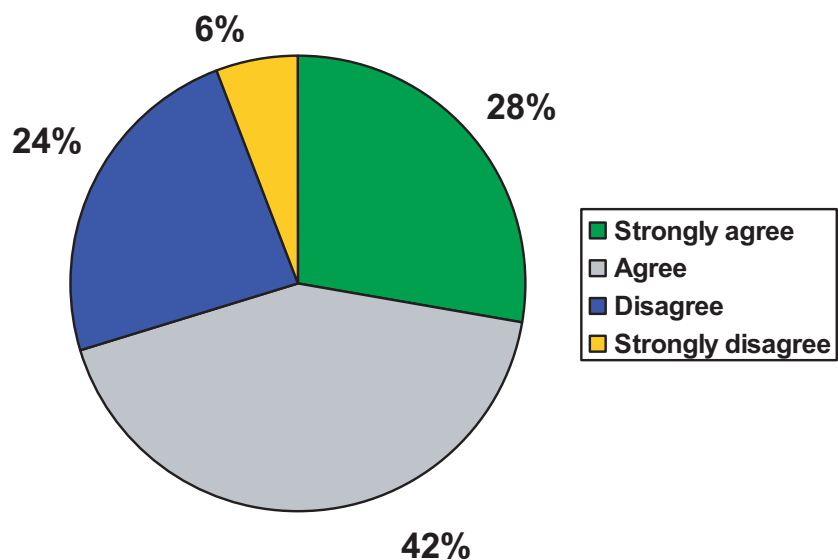
Americans want limits on who has access to test results because they are concerned about how disclosure might negatively affect them and members of their families. While over three-fourths of Americans surveyed in 2004 stated that the spouse of a person carrying a gene increasing the risk of disease has a right to know, and more than half stated that extended family members have a right to know, most oppose disclosing this information to an employer or health insurer. (Figure 6.3). Over time, and as

this issue has received more media attention, support for disclosure to a person’s employer or health insurer has declined, while support for disclosing to a person’s family members has increased (Figure 6.3).

People who are White, more educated and who do not have a religious affiliation were more likely to say that others do not have a right to know their genetic information.

Qualitative data indicate that the public is concerned about what insurers and employers might do with information obtained from genetic tests. The public is fearful that disclosure to employers could result in job loss or employment discrimination, and disclosure to insurers could result in being ineligible for or loss of both health and life insurance.

**Figure 6.2: The Ability to Control Human Reproduction Will Lead to Treating Children Like Products**



Source: 2004 Survey

**Table 6.1: The Ability to Control Human Reproduction Will Lead to Treating Children Like Products.**

| Demographic Characteristics |                       | Percent Of Those Who Agree Or Strongly Agree |
|-----------------------------|-----------------------|--|
| Total                       |                       | 69.5   |
| Sex                         | Men                   | 68.7   |
|                             | Women                 | 70.3   |
| Age                         | 18-29                 | 73.2   |
|                             | 30-49                 | 69.1   |
|                             | 50+                   | 67.9   |
| Race/Ethnicity              | White                 | 69.1   |
|                             | Black                 | 72.2   |
|                             | Hispanic              | 70.0   |
| Religion                    | Protestant*           | 68.0   |
|                             | Fund/Evang**          | 80.1   |
|                             | Roman Catholic        | 69.3   |
|                             | Other Christian***    | 70.1   |
|                             | Other (Non Christian) | 66.6   |
| Income                      | No Religion           | 61.4   |
|                             | Under 25k             | 72.3   |
|                             | 25k-49k               | 71.0   |
|                             | 50k-74.9k             | 68.9   |
| Education                   | 75+k                  | 61.2   |
|                             | No College            | 72.0   |
|                             | Some College          | 72.7   |
|                             | College               | 64.8   |
| Political Affiliation       | Post Grad             | 54.9   |
|                             | Republicans           | 73.0   |
|                             | Other                 | 68.6   |
|                             | Democrats             | 66.1   |

Source: 2004 Survey

\* Protestant includes respondents who self-identified as Protestant, excluding those who additionally self-identified as Fundamentalist or Evangelical.

\*\* Fundamentalist/Evangelical includes all Protestant or Other Christian respondents who additionally self-identified as either Fundamentalist or Evangelical.

\*\*\* Other Christian includes all who self-identified as Other Christian, excluding those that additionally self-identified as Fundamentalist or Evangelical.

*“Will you have trouble getting a job because you have this gene that may cause cancer, whether or not you have cancer?”*

*Sacramento town hall participant*

*“If insurers paid for tests, they would want to know the results and that could affect what they would be willing to cover.”*

*Fort Worth town hall participant*

**Will We be Able to Make Free Choices?**

*“You have to think about your health insurance...If the insurance company paid for the test that said that the baby had cystic fibrosis, could they say “We’ll pay for an abortion, but we won’t pay for the child’s [health] care?”*

*male participant from mixed sex/race focus group of people over 55, California*

Americans do not want families to be coerced into using reproductive genetic testing, and they especially do not want women to be pressured into aborting a fetus that has been diagnosed with a genetic disease. Focus group, interview and town hall participants were worried that social pressures, health-care providers and especially insurance policies have the power to create incentives to use the technology to prevent the birth of children that might be perceived to be a burden. They viewed such incentives as coercive. For instance, they worried that insurers could



require prenatal testing and, if a genetic disease was detected in a fetus, refuse to cover treatment for that specific genetic disease or raise the family's premium. Since treating genetic disease can be very expensive, families could feel coerced into having an abortion if they could not afford health-care for the resulting child. Additionally, people fear that insurers could simply terminate a family's policy if a genetic disease was detected.

*"Would insurance play into this? Are they going to limit me from further examinations? Are they going to stop payment? What is this going to do in the future? Would I be considered high risk?"*  
*adult with genetic disease*  
*(interview)*

Widespread fear of being coerced into using the technology is evidenced by survey findings. Three-fourths of Americans said that if the use of reproductive genetic technologies were to become more widespread, they would be concerned or very concerned that parents would be pressured to use this technology (Figure 6.1). Women, Whites and Republicans were slightly more concerned about parents being pressured to use this technology. Fundamentalist and Evangelical Christians expressed more concern about this issue than all other religions.

**Genocide**

*"Taken in the wrong direction, this is a potential technology for an alternative to ethnic cleansing."*  
*participant in Seattle town hall*

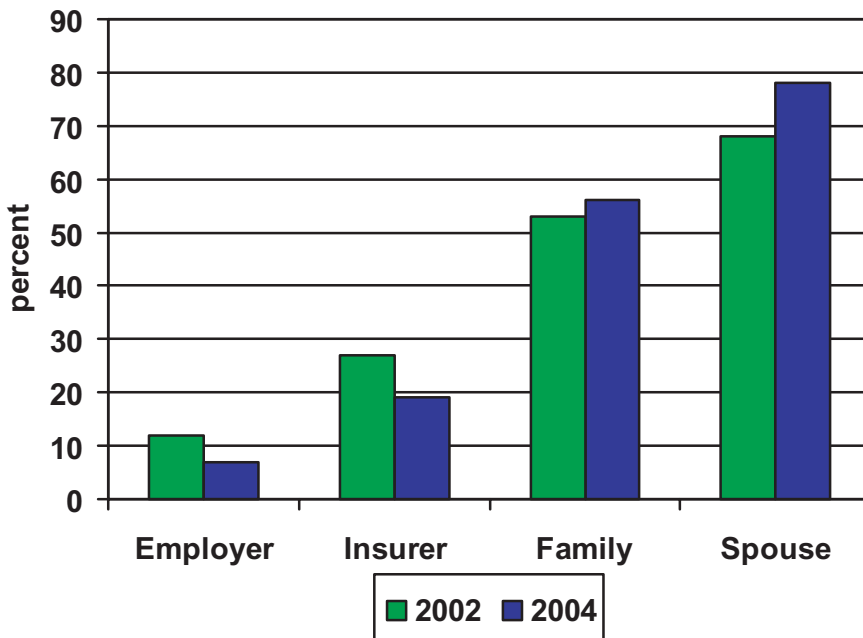
A less prevalent, but important, theme that emerged in focus group and town hall discussions was the fear that genetic testing and related technologies might be misused to attempt to create a "master race," or worse, eliminate certain groups. There were numerous references to Hitler and the eugenics movement as examples of the direction people feared. There was some concern that individual choices could result in large population changes but what most concerned participants was the possibility of eugenics campaigns sponsored by governments. Concerns about governments using the technology for social engineering were great enough for some of these participants to argue that government should stay out of all reproductive decision making.

*"What if they all of a sudden say, 'hey, let's just eliminate all Mexicans?' — [We're] gone."*  
*participant from Catholic Mexican American female focus group, California*

*"...go back to Hitler, the Aryan race. That was all that was supposed to survive in the world. Not one of us in here is blonde haired, blue eyes and six feet tall. We wouldn't be sitting here if his mentality ruled. So all I can see is that down the line we think it's our choice, but eventually someone is going to take over, and there is going to be a power struggle and oh, let's just recreate what race is supposed to look like."*  
*female participant from mixed sex/race focus group, Massachusetts*

**Figure 6.3: Genetic Privacy**

"If a genetic test shows that a person has an increased risk for a genetic disease, does the person's \_\_\_\_\_ have the right to know?"



Sources: 2002 and 2004 Surveys

*“[V]ery rarely has the majority instituted anything into our community that created a positive effect. This is dangerous.”*  
*participant from Black male focus group, Tennessee*

*“Our society could step in, and if the disease is in your family, they’ll say ‘no...you’re going to be sterilized. You can no longer give birth, because you’re going to give birth to somebody who has a disease, and we don’t want disease in our society.’”*  
*participant from male focus group, California*

## Overpopulation

*“Well, you know, disease is also like a natural selective evolution, and we need that because what is going to happen a hundred years from now when there is no disease? The world is going to be overpopulated.”*  
*participant from Catholic Mexican American female focus group, California*

Additionally, a common point of discussion in focus groups was that disease is a necessary part of population control. There was a concern that the world would become overpopulated if genetic diseases were eradicated through reproductive genetic testing.

*“Then 200 years from now, a thousand years from now, there is a race of perfect (people), and there are billions of us, because we’re all perfect. And I wish health for everybody of course, but I don’t know if having trillions and trillions of people on the earth is going to be a good thing in the end.”*  
*participant from young male focus group, Tennessee*

Survey findings confirm that this is an important concern for 68 percent of Americans (Figure 6.1). Young women, people with less formal education and Democrats tended to be more concerned about overpopulation while Fundamentalist and Evangelical Christians were less concerned when compared to other religious groups. In the interviews, health-care providers were less likely than focus group participants to express this fear and more likely to see genetic technologies as analogous to existing treatments for diseases.





# Chapter 7: Accuracy and Safety

*“The availability of testing should be as widespread as possible — but widespread testing without safety and accuracy, I can’t endorse.”*  
participant in Seattle town hall

Americans want to be sure that reproductive genetic testing is safe — that it does not result in physical harm to the mother or resulting child — and that it actually provides accurate, clinically-relevant information. People value accuracy because they understand that couples will make profound, life-altering decisions based on test results.

Most of the evidence that safety and accuracy of genetic testing are important to Americans comes from the focus group and town hall discussions. Focus group participants were presented with hypothetical scenarios and asked what issues a couple should consider before using reproductive genetic testing. Town hall participants were shown a background video on genetic testing and specifically asked to consider the issue of whether and how to regulate safety and accuracy of genetic testing.

The importance of safety and accuracy of reproductive genetic testing was addressed in the 2004 survey through questions about whether or not the government ought to regulate the quality and safety of reproductive genetic testing. These data are presented in Chapter Eight.

## Inaccurate Test Results Can Have Devastating Consequences

Participants in most of the focus groups brought up the importance of accuracy of reproductive genetic testing as a concern because the consequences of inaccurate test results — the transfer of an affected embryo, the abortion of a healthy fetus or, alternatively, the birth of an affected child — could be so devastating.

*“What is the reliability of the results of the test? Do they have a ninety-five percent, or higher, accuracy, or are they talking eighty percent, and there’s a wide range of discrepancy. There could be a mistake.”*  
participant from Catholic White female focus group, Michigan

Town hall participants were asked specifically to think about and discuss this issue. In every town hall, safety and accuracy of testing were listed as important factors to consider when setting limits on the use of reproductive genetic testing. Participants in the town halls pointed out that it is impossible to make truly informed reproductive decisions without accurate information. Some town hall participants called for limits on direct-to-consumer marketing of genetic tests to reduce the amount of misinformation.

Several focus group participants cited the importance of test accuracy

after sharing personal experiences about their own or other’s false-positive prenatal screening tests.<sup>1</sup>

*“I have heard many stories from other moms, that they were told that their baby had a certain percentage to survive or to have this and then they decided to either terminate the pregnancy or keep it, and the baby is healthy, and the doctors were wrong.”*  
participant from Mexican American female group, California

Participants perceived the abortion of a wanted, healthy fetus based on a false-positive test result to be a horrendous outcome.

Participants also occasionally expressed concern about false-negative genetic test results, test results that indicate the absence of a gene mutation when in fact it is present, and the unexpected birth of an affected child.

Parents of children with cystic fibrosis (CF) raised the possibility of false-negative test results with carrier testing since the standard CF test used in carrier testing does not cover all CF mutations. They said that providers need to discuss the possibility of false-negative test results with couples considering carrier testing.

People who had used preimplantation genetic diagnosis (PGD) believed they should have

asked more questions about the likelihood that misdiagnoses could be made. Three PGD users experienced misidentifications in their PGD test results. Although in two cases the misidentifications were not clinically significant, they did cause the patients anxiety. In one case, the interview participant was pregnant with a fetus affected by the disease she was trying to avoid by using PGD. It was unclear whether this resulted from a misdiagnosis in PGD or a mix up in the embryos that were transferred.

*“And who does [PGD]? It can be only in a few places around the world. But do you have results on how these are turning out? My feeling is, okay, there’s always a chance of a mistake when they test these embryos.”*

*participant from Evangelical female focus group, Colorado*

### **Miscarriage is a Substantial Risk of Prenatal Testing**

Most focus group participants perceived carrier testing to be safe since it is “just a blood test” similar to other routine blood tests during pregnancy. Prenatal testing through CVS or amniocentesis was perceived to be more invasive, and some participants considered the risk of miscarriage unacceptable. A few parents of children with genetic diseases and all the women who became pregnant following PGD were especially wary of the miscarriage risk from invasive prenatal testing.

*“[W]e got scared about doing the CVS. I mean we knew there was potential for miscarriage, and we had just gotten pregnant. We didn’t want to lose this child.”*

*PGD patient (interview)*

When considering whether or not using prenatal genetic testing is acceptable, focus group participants weighed the statistical risks of miscarriage against the perceived risk of having a child with a genetic disease. They also considered what they would do with the information. Some participants who would not consider abortion or would not want to be faced with the dilemma of whether or not to continue a pregnancy said they thought there was value in prenatal testing only if treatments were available that could be used before birth.

### **Is PGD Harmful for Children?**

*“[Y]ou are guaranteeing that the kid won’t have sickle cell. But through [PGD] and all of this manipulation, what other diseases or malfunctions or disfigurements will this child have?”*

*participant from Black male focus group, Tennessee*

Many focus group and town hall participants were concerned about whether PGD has been adequately researched and is truly safe. Some wondered if PGD could cause birth defects or other abnormalities and worried that there may be insufficient knowledge about the dangers for the resulting child.

*“[They need to ask] what kind of side effects that procedure might have on the baby...will [PGD] affect it as it’s growing up? Look at Dolly that sheep that was cloned. It grew up to have the worst kind of arthritis a sheep could have, and they ended up killing it.”*

*participant from White male focus group, California*

Interview participants who had experience with PGD also questioned if it could lead to birth defects or long-term problems for the child related to the hormones given as a part of in vitro fertilization (IVF), the biopsy, the embryo culture or the transfer procedure. These interview participants also raised the issue of the increased likelihood of multiple births following IVF. Some focus group participants, PGD providers and PGD patients raised the concern that the PGD biopsy could result in embryo loss. One PGD patient said she harbored lasting concerns that the biopsy process would have long-term negative effects on her child.

Providers were also concerned that, because PGD laboratories are not adequately regulated, not all providers who are offering PGD have the expertise needed to perform the procedure safely and accurately.

### **The Limited Effectiveness of IVF**

Even if PGD were completely safe and accurately identified genetic alterations, a number of focus group participants stated that the chances

of having a live, healthy baby seemed too low to warrant the expense, discomfort, time and risks associated with PGD.

PGD providers and patients who had undergone PGD focused heavily on the need for anyone considering using PGD to have realistic expectations of the technology to fully understand its limitations. They felt couples need to know that the PGD process may result in only a very few or no viable embryos free of the disease-causing alteration, and that testing for one genetic disease does not guarantee that a baby will be born without genetic abnormalities.

*“I think they really need to know the limitations - that this isn’t going to guarantee a healthy baby and that we’re not testing for everything. We can’t test for everything.”*

*Genetic Counselor (interview)*

Several PGD patients said they felt they may have had too much faith in the technology when they started PGD. Many reported feeling that they had been overly optimistic, both about the number of healthy embryos that would be available for transfer and about the likelihood that PGD would result in a viable pregnancy. Because they were not infertile, they believed their chances of success with IVF would be greater than the statistics quoted by the clinics.

*“I think [what is important is] knowing the true success rates of IVF - how many embryos you’re likely to have - I think just the real stats. I don’t feel that someone was trying to hide the stats; I just don’t think anyone worked really hard to make them available to us.”*  
*PGD patient (interview)*

## NOTES:

<sup>1</sup> Most women who relayed experiences with false positive test results were talking about maternal serum screening, which identifies fetuses at higher risk for genetic and other anomalies but has a high false positive rate. Maternal serum screening is not diagnostic, and women with positive screening results are generally offered prenatal genetic testing to establish a diagnosis.



# Chapter 8: Oversight of Reproductive Genetic Testing

The term “oversight” means different things to different people, and encompasses many different approaches. Deciding what kind of oversight might be appropriate or desirable for reproductive genetic testing requires consideration of several questions: What do we seek to prevent or, alternatively, to promote through regulation? What values do we wish to preserve? Whom are we trying to benefit? And, perhaps most importantly, in whom do we want to place our trust to make these decisions?

Oversight of reproductive genetic testing could come from a variety of different entities, working alone or in combination. The federal government, state governments and scientific and medical societies are all potential sources of oversight. Insurance companies could also have a regulatory role through their reimbursement policies – lack of coverage for certain tests would likely deter many from using them, whereas providing coverage would likely lead to increased use. Decisions about reproductive genetic testing could continue to rest solely with patients, in consultation with their health-care providers. Each of these oversight approaches has benefits and drawbacks.

The Center’s accompanying report, *Reproductive Genetic Testing: Issues and Options for Policymakers*, addresses current oversight of reproductive genetic testing and presents a range of distinctly different oversight options that could be adopted depending on one’s answers to the questions posed above.

This chapter discusses Americans’ opinions about the oversight of reproductive genetic testing, based on both our qualitative and quantitative studies. Focus group participants were asked to discuss whether and how these technologies should be regulated. Participants in the town halls discussed in detail whether these technologies ought to be regulated and were asked to react to a list of potential consequences of regulation. Survey respondents answered a series of questions about how to regulate prenatal genetic testing and preimplantation genetic diagnosis (PGD) as well as questions about their views of government regulation and personal liberty. Together, these data paint a detailed picture of the diverse views among the American public about the appropriate means of governing the development and use of reproductive genetic testing.

## Who Decides?

*“It’s easy to say testing shouldn’t be used for this reason or that reason, but who will decide which purposes are OK? A mother could say, ‘I want testing for disease,’ but actually be thinking ‘I don’t want another boy.’ Setting limits would be impossible. To find out the real reasons would be a huge invasion of privacy.”*  
Seattle town hall participant

In discussing the possible means of overseeing reproductive genetic testing, focus group, interview and town hall participants primarily discussed the proper balance between governmental involvement and individual and family decisionmaking. They identified a number of difficulties

the government might have in trying to regulate the appropriate use of these technologies. First, many highlighted the difficulties in reaching consensus, in a pluralistic society, on ethically appropriate uses. Second, many felt that there were conflicting values and interests that would thwart efforts to set limits.

*“But I despair. I don’t think that we have the will to limit what we unleash... The profit motive is too strong. And I think that we live in a society where people say that they deserve to have what they want. And I think that combination of profit motive, and a feeling of entitlement means a society that will not agree on appropriate limits for this technology.”*  
mother of three children with genetic disease (interview)

Third, many participants, especially women, feared that government limits on the use of reproductive genetic testing would eventually erode reproductive rights. Fourth, there was skepticism that laws could be enforced adequately because people could travel outside regulated areas and technology could go “underground.”

*“There is no way to avoid people abusing the advances. That’s the problem. And even if there were laws and things like that, when there are people with money, anything can be done.”*  
participant from Jewish female focus group, Massachusetts

Finally, there was concern that politicians and legislators do not adequately understand reproductive genetic testing, which may lead to



laws based on knowledge gaps and misperceptions. In addition, they felt that the policymaking process itself is subject to pressure from those with particular agendas.

*“I don’t want people from any particular political administration to decide.”*

*Seattle town hall participant*

A theme repeated across the focus groups and some interviews was that any governmental regulatory decisions about reproductive genetic testing ought to be made or informed by a diverse group that includes “average people,” regulators, policymakers, scientists, patients, families affected by genetic disease, health-care professionals and religious leaders. This preference stemmed from a general lack of trust in politicians or scientists to make decisions that are in the best interest of the public.

*“I think you should have some kind of committee, like in a court. Like a jury. Like...the American Medical Association has one person. Somebody from the public, somebody from the state, somebody from everything... a panel. And if they do not all agree, then it doesn’t go through.”*

*participant from Mexican American male focus group, California*

*“I think that in a perfect world,... majority rules. Take a societal type of survey, for lack of better terminology.”*

*mother of child with genetic disease (interview)*

Some focus group participants were troubled by the practical difficulty of trying to regulate reproductive genetic testing based on moral considerations, while others argued that the government has no place regulating moral decisions that can have such a profound impact on individuals’ lives.

*“We have to depend on people’s morality to draw their own lines. We cannot legislate it... We can’t legislate any of this stuff.”*

*participant from White Protestant female focus group, Massachusetts*

*“Why would you want somebody else involved... what about your privacy?... You have to have the permission of the government to do what you want to do with your sperm and egg?”*

*participant from female with no children focus group, California*

*“[T]he individual is going to make that determination. It all comes down to us. It does not come down to the government; it does not come down to somebody else making the decision for us.”*

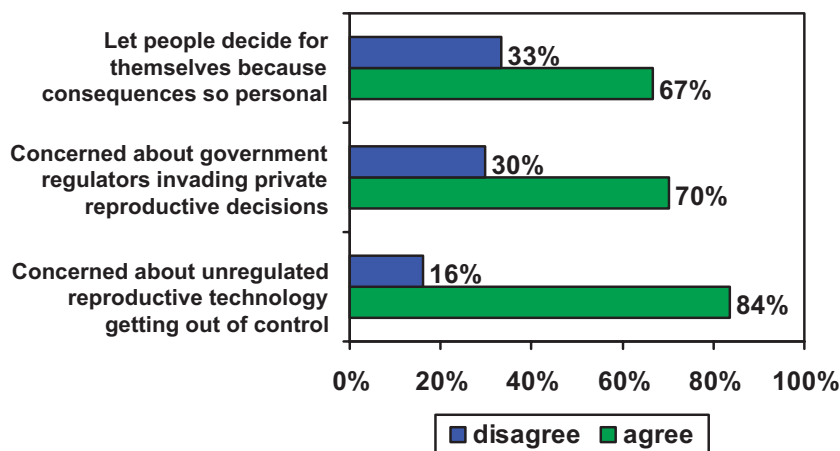
*participant from Mexican American male focus group, California*

Many focus group participants made it clear that while they had concerns about the development and use of these tests, they were also uncomfortable with the notion of the government imposing a single view on everybody. The belief that moral decisions need to be left to individuals rather than the government crossed all races, ages, education levels and religions.

Similarly, when given a choice of who should set limits (professional medical societies, individuals, government or patient groups), after discussion and debate, a third of town hall participants said these decisions should be left to individual patients and their doctors.

A series of questions in the 2004 survey further explored this tension. A majority of survey respondents agreed or strongly agreed with the statements: “I am concerned about unregulated reproductive genetic technology getting out of control” (84 percent) and “I am concerned about government regulators invading private reproductive decisions” (70 percent). At the same time, a majority of respondents (67 percent) agreed or strongly agreed with the statement “We ought to let people decide for themselves when it is appropriate to use reproductive genetic technologies because the consequences are so personal” (Figure 8.1).

Survey respondents’ views about respect for personal autonomy – meaning letting people decide for themselves – were consistent with their views about regulating reproductive genetic testing. For example, those who did not support any regulation of PGD or wanted regulation based only on considerations of safety and quality of testing placed the most emphasis on personal autonomy (82 percent of those who favored no regulation or regulation of only safety and quality agreed with the statement that people should decide for themselves). Those who wanted to ban the technologies placed the

**Figure 8.1: Who Decides?**

Source: 2004 Survey

least emphasis on personal autonomy (only 40 percent of those who favored banning PGD agreed that people should decide for themselves). Those who wanted to regulate based on ethics and morality fell in the middle with 63 percent agreeing that people should decide for themselves.

### Alternative Ways to Limit Use

Focus group participants discussed two alternative ways to limit the use of reproductive genetic technologies that did not involve government regulation. These included using health insurance coverage policies and limit-setting by health-care providers.

Focus group discussions about insurance company coverage policies typically centered on the fact that they might present a barrier to access to genetic testing technology if the costs were not reimbursed. Occasionally, however, participants

mentioned that insurers' coverage policies might serve to limit inappropriate uses of the technology by reimbursing only for appropriate uses.

*"I just think it is inevitable that we come down to who can pay for it, or can get their health insurance to pay for it. So, I can see it being regulated by the health insurance companies being willing to cover certain diseases."*

*participant from female Evangelical focus group, Colorado*

*"Insurance determines what is going to be done. The insurance company says, 'well, you can have this done for this, but not for this.'"*

*participant from female Catholic focus group, Michigan*

Occasionally focus group and interview participants, particularly parents of children with a genetic disease, suggested that physicians and professional societies should

put limits on when and how they themselves market and provide this technology.

*"I think you set procedures, you set guidelines for it and these specialists... hopefully can tell if the person is doing this for the right reasons, and keeping them within that guideline, and making them understand that you aren't going to have a perfect child, where you're just going to try to take care of this life-threatening disease, and you don't get to pick and choose the eye color."*

*participant from Chinese American female focus group, California*

*"I think that there should be limits, and I don't think that somebody should say they want to go have PGD because they have enough money to do it, and they want to have a girl. I think that there should be a doctor that says, 'I can't do that for you.'"*

*mother of child with genetic disease (interview)*

Town hall participants discussed and debated who ought to set limits (medical professional societies, individuals, government or patient groups) and one-third chose medical professional societies as the best group to set limits.

However, some focus group participants were skeptical that medical professionals could police themselves, and said that there would still be unethical individuals willing to violate professional standards.

*“And, that’s where I start worrying. Because some doctors when you say, ‘That’s not what the test is for. I’ll [only] tell you if your kid is going to be healthy or not.’ But again, there are some doctors out there who will be shady and will say, ‘Look, you can have the short kid or you can have the tall kid. Which one do you want?’”*  
*participant from Black male focus group, Massachusetts*

In fact, PGD providers saw more benefit in expanding the uses of PGD than other respondents in the studies. Those interviewed were loath to be regulated by government, yet admitted that their field did have the potential to advance rapidly and without limits. Some were already making decisions about the circumstances under which they were willing to provide testing. For example, one PGD provider said he refused requests to test embryos for sex because of his personal morals, even though there are no state or federal regulations guiding his decision.

### Attitudes About Government Oversight

The level of support for or opposition to government oversight of reproductive genetic testing was further explored in the 2004 survey (Figure 8.2, Tables 8.1 and 8.2). Survey respondents who disapproved of all proposed uses of prenatal genetic testing or PGD (see Chapter 3) were asked if they thought prenatal genetic testing or PGD should be allowed at all. If they said no, they are represented in this report as supporting a ban on testing. Respondents who

approved of one or more uses of prenatal genetic testing or PGD and those who disapproved, yet said it should be allowed, were asked if the tests should be regulated by the government based on both quality and safety, and if the tests should be regulated by the government based on ethics and morality. Those who responded no to both questions about possible roles for government regulation are represented as favoring no government regulation.

### Banning Reproductive Genetic Testing

Twenty percent of survey respondents said that PGD should not be permitted, and 11 percent said that prenatal genetic testing should not be permitted (Figure 8.2). Nearly three times as many Fundamentalist and Evangelical Christians supported a ban on prenatal genetic testing and PGD compared to those with no religious affiliation. Republicans and those in lower education groups were also more likely than Democrats and those with a college education to support banning both prenatal

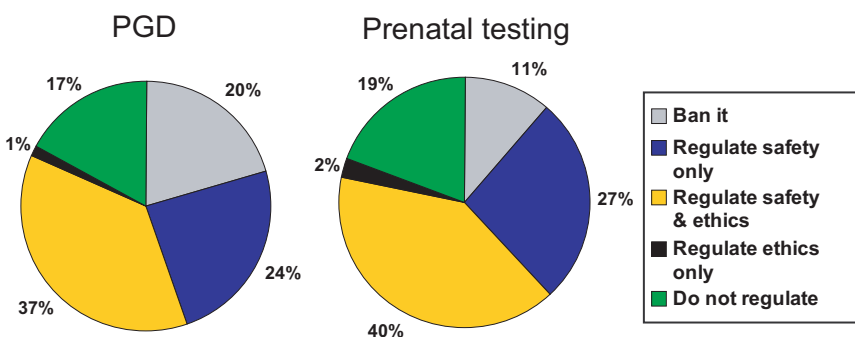
genetic testing and PGD (Tables 8.1 and 8.2).

### Ensuring Safety and Accuracy

In 2002, only 30 percent of survey respondents knew that the federal government does not review and approve reproductive genetic tests to ensure that they are safe and accurate before they are put on the market. In-person town hall participants were asked “as far as you know, does the government review and approve reproductive genetic tests to ensure that they are safe and accurate before they are put on the market.” Half (46 percent) thought, incorrectly, that the government reviews and approves tests while the other half (55 percent) responded correctly that the government does not currently play this role in oversight of reproductive genetic testing.

A majority of respondents in the 2004 survey agreed that the safety and quality of PGD and prenatal genetic testing should be regulated (61 percent and 67 percent, respectively). Thirty-seven percent agreed that PGD should be

**Figure 8.2: Attitudes about Regulation**

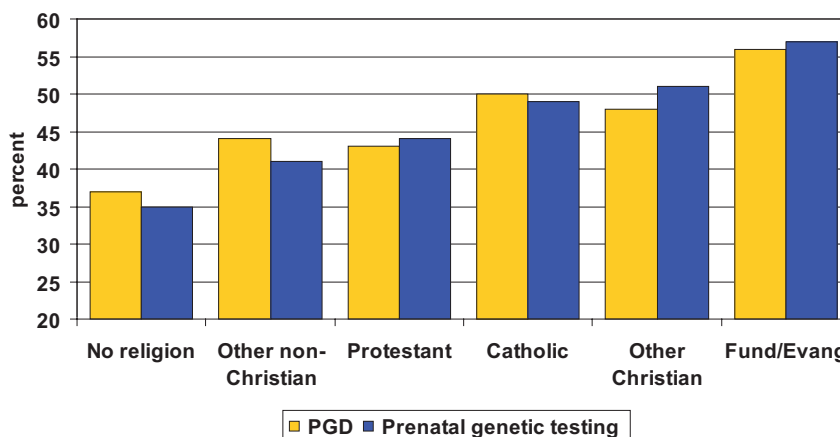


Source: 2004 Survey

additionally regulated for ethics and morality, while 40 percent stated the same for prenatal genetic testing. Interestingly, a greater number of young adults (66 percent and 77 percent, respectively) agreed that both PGD and prenatal genetic testing should be regulated for safety. Among religious groups, Fundamentalist and Evangelical Christians were the least likely to support government regulation of safety and quality; however, this is likely due to the fact that a significant proportion of this group preferred to ban PGD and prenatal genetic testing. As level of education increased, so did the number of respondents who endorsed safety regulation, although the majority within each educational group supported regulation based on safety and quality. More Democrats than Republicans supported government regulation of safety for both PGD and prenatal genetic testing, although a majority in both groups supported regulation based on safety and quality (Tables 8.1 and 8.2).

Even though there was strong support for regulation of safety, some recognized that such oversight could have a downside. Town hall participants were given a list of potential negative consequences of additional government regulation and asked how concerned they were about each. Delaying access to tests and increasing the cost of tests was of concern to about half of town hall participants. Fewer were concerned that regulation would be a burden to the biotechnology and laboratory testing industries or might not be effective in ensuring safety.

**Figure 8.3: Percent Who Support Regulating for Ethics and Morality by Religion**



Source: 2004 Survey

### Ethics and Morality

Thirty-eight percent of the 2004 survey respondents said the government should regulate PGD based on ethics and morality, while 43 percent said that the government should regulate prenatal genetic testing based on ethics and morality (Tables 8.1 and 8.2, sum of respondents who support regulation based on ethics and morality alone and those who supported regulation based on ethics and morality and safety and quality). Just over one percent stated that government should regulate based on ethics only.

The definition of “ethics and morality” was left to the survey respondent to define. Focus group data indicated that people had a broad range of ideas about what regulation of “ethics and morality” actually means; therefore, it is likely that these numerical data do not represent a uniform group. Instead, those who support regulation of

ethics and morality likely represent a broad spectrum of values.

Approval for regulating both PGD and prenatal genetic testing based on ethics and morality was highest among younger respondents, males and Evangelical or Fundamentalist Christians (Figure 8.3, Tables 8.1 and 8.2). Minorities were also slightly more supportive of regulating these technologies based on ethics and morality than Whites. No notable differences by political affiliation, education level, or sex were observed.

### No Regulation

A minority of survey respondents said that the government should not regulate reproductive genetic testing based on safety and quality or based on ethics and morality. Overall, 17 percent of survey participants did not want the government to regulate PGD and 19 percent did not want the government to regulate prenatal

testing. Proportionally, more Whites, people over age 50, those with less education and Republicans agreed that these technologies should not be regulated at all (Tables 8.1 and 8.2).

### Other Possible Roles for the Government

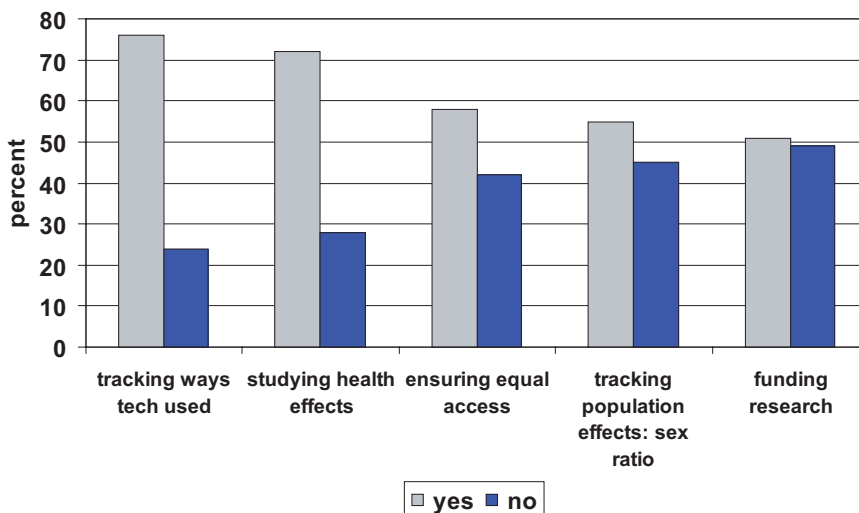
Discussions in focus groups and town halls identified areas in which some people thought the government could play a role in overseeing or tracking the effects of using reproductive genetic testing. These themes included:

- Tracking the different ways people are using these technologies
- Studying the long-term effects of these technologies on women and children
- Ensuring that people have equal access
- Tracking populations effects like changes in the sex ratio
- Funding genetic testing research

These themes were tested among survey respondents. A large majority of respondents (76 percent) said they think tracking the ways in which genetic testing technologies are being used is an appropriate role for the government (Figure 8.4). Nearly three-quarters also said that the government ought to be studying the long-term health effects of technologies like PGD on women and children. A slimmer majority (58 percent) said that the government ought to ensure that people have equal access to these technologies. In focus group and town hall discussions, participants suggested that the government could ensure greater access through insurance mandates for private insurers and by including reproductive genetic testing in publicly-financed health-care programs. Although a slim majority (55 percent) still supports the government tracking population effects such as changes in the sex ratio, support for this role is not as

strong as the mandate to track the ways the technologies are being used and the health outcomes. A number of focus group participants said that if there were demonstrable harmful populations effects, the government would have a more legitimate argument for setting limits on the use of reproductive genetic testing. Americans are divided about whether they want their tax dollars to fund research on reproductive genetic testing.

**Figure 8.4: Appropriate Role of Government?**



Source: 2004 Survey



**Table 8.1: Opinion on Regulation of PGD by Demographic Characteristics (%)**

| Demographic Characteristics |                       | Ban  | No Regulation | Regulate Ethics Only | Regulate Safety & Ethics | Regulate Safety Only | Safety Regardless Of Other Opinions |
|-----------------------------|-----------------------|------|---------------|----------------------|--------------------------|----------------------|-------------------------------------|
| Total                       |                       | 20.3 | 16.9          | 1.4                  | 37.0                     | 24.3                 | 61.3                                |
| Sex                         | Men                   | 19.5 | 16.6          | 2.0                  | 37.4                     | 24.4                 | 61.8                                |
|                             | Women                 | 21.0 | 17.2          | 0.8                  | 36.7                     | 24.2                 | 60.9                                |
| Age                         | 18-29                 | 21.2 | 11.0          | 1.4                  | 42.7                     | 23.5                 | 66.2                                |
|                             | 30-49                 | 19.6 | 13.7          | 0.8                  | 39.6                     | 26.2                 | 65.8                                |
|                             | 50+                   | 20.5 | 23.8          | 2.0                  | 31.0                     | 22.7                 | 53.7                                |
| Race/Ethnicity              | White                 | 19.7 | 17.6          | 1.2                  | 35.7                     | 25.6                 | 61.3                                |
|                             | Black                 | 21.9 | 13.8          | 1.7                  | 40.6                     | 22.0                 | 62.6                                |
|                             | Hispanic              | 20.1 | 16.9          | 2.3                  | 40.5                     | 20.2                 | 60.7                                |
| Religion                    | Protestant*           | 15.3 | 19.2          | 1.8                  | 36.5                     | 27.2                 | 63.7                                |
|                             | Fund/Evang**          | 35.6 | 15.5          | 1.0                  | 37.0                     | 11.0                 | 48.0                                |
|                             | Catholic              | 20.3 | 15.9          | 1.9                  | 39.5                     | 22.3                 | 61.8                                |
|                             | Other Christian***    | 20.5 | 15.9          | 1.0                  | 39.0                     | 23.5                 | 62.5                                |
|                             | Other (Non Christian) | 16.4 | 14.3          | 0.9                  | 38.5                     | 29.8                 | 68.3                                |
|                             | No Religion           | 12.5 | 16.6          | 1.0                  | 33.3                     | 36.6                 | 69.9                                |
| Income                      | Under 25k             | 19.1 | 18.7          | 1.8                  | 37.2                     | 23.2                 | 60.4                                |
|                             | 25k-49k               | 22.3 | 17.4          | 1.0                  | 37.0                     | 22.4                 | 59.4                                |
|                             | 50k-74.9k             | 22.9 | 14.5          | 1.3                  | 34.0                     | 27.2                 | 61.2                                |
|                             | 75+k                  | 15.2 | 15.1          | 1.5                  | 41.0                     | 27.4                 | 68.4                                |
| Education                   | No College            | 23.7 | 18.8          | 1.6                  | 36.2                     | 19.7                 | 55.9                                |
|                             | Some College          | 19.1 | 17.5          | 1.3                  | 37.0                     | 25.1                 | 62.1                                |
|                             | College               | 15.9 | 12.6          | 1.2                  | 38.5                     | 31.8                 | 70.3                                |
|                             | Post Grad             | 14.1 | 13.5          | 0.7                  | 38.9                     | 32.8                 | 71.7                                |
| Political Affiliation       | Republicans           | 26.7 | 20.9          | 1.4                  | 32.5                     | 18.4                 | 50.9                                |
|                             | Other                 | 22.2 | 17.4          | 1.2                  | 40.0                     | 19.2                 | 59.2                                |
|                             | Democrats             | 17.0 | 16.9          | 1.6                  | 35.3                     | 29.3                 | 64.6                                |

Source: 2004 Survey

\* Protestant includes respondents who self-identified as Protestant, excluding those who additionally self-identified as Fundamentalist or Evangelical.

\*\* Fundamentalist/Evangelical includes all Protestant or Other Christian respondents who additionally self-identified as either Fundamentalist or Evangelical.

\*\*\* Other Christian includes all who self-identified as Other Christian, excluding those that additionally self-identified as Fundamentalist or Evangelical.

Table based on responses to three questions.

(1) Should PGD be allowed at all?

(2) Do you think the government should regulate PGD based on quality and safety?

(3) Do you think the government should regulate PGD based on ethics and morality?

Ban=percent who responded 'no' to (1)

No regulation=percent who responded 'no' to (2) and (3)

Regulate ethics only=percent who responded 'no' to (2) and 'yes' to (3)

Regulate safety only=percent who responded 'yes' to (2) and 'no' to (3)

Regulate safety and ethics=percent who responded 'yes' to (2) and (3)



**Table 8.2: Opinion on Regulation of Prenatal Genetic Testing by Demographic Characteristics (%)**

| Demographic Characteristics |                       | Ban  | No Regulation | Regulate Ethics Only | Regulate Safety & Ethics | Regulate Safety Only | Safety Regardless Of Other Opinions |
|-----------------------------|-----------------------|------|---------------|----------------------|--------------------------|----------------------|-------------------------------------|
| Total                       |                       | 11.0 | 19.3          | 2.4                  | 40.3                     | 26.9                 | 67.2                                |
| Sex                         | Men                   | 11.4 | 17.9          | 2.6                  | 40.7                     | 27.3                 | 68.0                                |
|                             | Women                 | 10.6 | 20.6          | 2.3                  | 40.0                     | 26.6                 | 66.6                                |
| Age                         | 18-29                 | 10.5 | 10.4          | 1.9                  | 48.2                     | 28.9                 | 77.1                                |
|                             | 30-49                 | 10.9 | 16.1          | 2.3                  | 42.8                     | 27.8                 | 70.6                                |
|                             | 50+                   | 11.4 | 27.8          | 2.9                  | 33.0                     | 24.8                 | 57.8                                |
| Race/Ethnicity              | White                 | 9.9  | 20.4          | 2.3                  | 39.3                     | 28.0                 | 67.3                                |
|                             | Black                 | 11.6 | 15.5          | 2.1                  | 44.5                     | 26.3                 | 70.8                                |
|                             | Hispanic              | 12.4 | 18.8          | 4.2                  | 41.2                     | 23.4                 | 64.6                                |
| Religion                    | Protestant*           | 7.6  | 21.0          | 2.5                  | 39.9                     | 29.0                 | 68.9                                |
|                             | Fund/Evang**          | 19.7 | 19.1          | 3.1                  | 44.0                     | 14.1                 | 58.1                                |
|                             | Catholic              | 10.1 | 19.1          | 3.2                  | 42.0                     | 25.5                 | 67.5                                |
|                             | Other Christian***    | 13.9 | 17.7          | 1.1                  | 45.0                     | 22.3                 | 67.3                                |
|                             | Other (Non Christian) | 7.5  | 14.8          | 1.8                  | 38.4                     | 37.4                 | 75.8                                |
|                             | No Religion           | 7.0  | 18.4          | 1.9                  | 31.7                     | 41.0                 | 72.7                                |
| Income                      | Under 25k             | 11.5 | 19.5          | 2.6                  | 42.2                     | 24.1                 | 66.3                                |
|                             | 25k-49k               | 11.5 | 20.8          | 2.2                  | 39.3                     | 26.0                 | 65.3                                |
|                             | 50k-74.9k             | 11.4 | 18.0          | 2.6                  | 37.4                     | 30.6                 | 68.0                                |
|                             | 75+k                  | 8.5  | 16.8          | 2.3                  | 42.0                     | 30.3                 | 72.3                                |
| Education                   | No College            | 13.6 | 21.6          | 2.2                  | 40.3                     | 22.3                 | 62.6                                |
|                             | Some College          | 10.3 | 19.4          | 2.7                  | 39.7                     | 27.8                 | 67.5                                |
|                             | College               | 7.4  | 14.4          | 2.8                  | 41.0                     | 34.4                 | 75.4                                |
|                             | Post Grad             | 6.3  | 15.3          | 2.4                  | 41.2                     | 34.8                 | 76.0                                |
| Political Affiliation       | Republicans           | 14.6 | 23.7          | 2.5                  | 37.9                     | 21.3                 | 59.2                                |
|                             | Other                 | 15.0 | 20.0          | 2.5                  | 41.0                     | 21.4                 | 62.4                                |
|                             | Democrats             | 9.4  | 18.7          | 3.0                  | 37.4                     | 31.5                 | 68.9                                |

Source: 2004 Survey

\* Protestant includes respondents who self-identified as Protestant, excluding those who additionally self-identified as Fundamentalist or Evangelical.

\*\* Fundamentalist/Evangelical includes all Protestant or Other Christian respondents who additionally self-identified as either Fundamentalist or Evangelical.

\*\*\* Other Christian includes all who self-identified as Other Christian, excluding those that additionally self-identified as Fundamentalist or Evangelical.

Table based on responses to three questions.

(1) Should prenatal genetic testing be allowed at all?

(2) Do you think the government should regulate prenatal genetic testing based on quality and safety?

(3) Do you think the government should regulate prenatal genetic testing based on ethics and morality?

Ban=percent who responded 'no' to (1)

No regulation=percent who responded 'no' to (2) and (3)

Regulate ethics only=percent who responded 'no' to (2) and 'yes' to (3)

Regulate safety only=percent who responded 'yes' to (2) and 'no' to (3)

Regulate safety and ethics=percent who responded 'yes' to (2) and (3)

# Chapter 9: Conclusion

## Converging and Conflicting Values

As human genetics and reproductive medicine advance and move from the laboratory into the clinic, people will increasingly face decisions about what tests to have and what to do with the results. Reproductive genetic testing has the potential to change whether and how we have babies and, indeed, what kind of babies we have. Technologies that have the power to affect the most profound and meaningful of human activities can bring enormous hope, and deep concern. As the number and type of reproductive genetic tests increases, how are we as a society to ensure that their development and use is in keeping with our most deeply held values?

The public debate about these and other reproductive genetic technologies over the last half-century has suggested deep cleavages within American society mostly having to do with divergent views of the moral status of embryos and fetuses. Some have concluded that these differences are irreconcilable. Yet, a detailed, textured portrait of what Americans know, think and feel has been missing.

This report has presented the summary findings from The Genetics & Public Policy Center's effort to fully capture and understand American opinions about the appropriate uses of reproductive genetic testing and their thoughts about regulating this technology. This study, the largest ever on this topic, incorporated both qualitative and quantitative approaches and included 21 focus groups, 62 in-depth interviews, two surveys with a combined sample size

of over 6000 people, and both in-person and online town halls.

These data on the way Americans think about these issues demonstrate that there is significant agreement about some issues and incredible diversity about others. Deeply held and sometimes conflicting values, such as 1) preventing suffering, 2) living one's life in accordance with God's will, 3) respecting nature, 4) promoting social justice, 5) protecting individual privacy and autonomy, 6) respecting and protecting embryos and fetuses, and 7) limiting the reach of government – color and shape individual's views on these technologies and their oversight.

The specter of unchecked advances raises many fears, such as designer babies, eugenics and genetically modified human beings. These values and fears converge, and sometimes conflict, as Americans balance the potential benefits of advances in genetics with the possible negative consequences of their use.

When Americans think about the moral appropriateness of using reproductive genetic testing, they consider the individual's motives — what does the user hope to accomplish and is this an appropriate use of the technology. They also consider the means — the safety of the technology, the available alternatives and whether or not embryos or fetuses will be destroyed in the process. They also want to know about the overall consequences - what will be the long-term implications for the health of individuals who use the technology,

and how will widespread use affect society?

When Americans who participated in our studies evaluated possible uses of reproductive genetic testing, there was significant concordance of opinion at the ends of the spectrum of uses. A majority of surveyed Americans think it is appropriate to use reproductive genetic testing to avoid life-threatening diseases that affect children or to test embryos to determine whether they will have tissue that matches a sick sibling. Many study participants value preventing the suffering of a child above all, and some even perceive it to be an obligation. For a minority of surveyed Americans, suffering is a part of what makes us human and we need not use technology to avoid it.

At the other end of the use spectrum, most surveyed Americans think that using (hypothetical) genetic tests to identify and select traits like intelligence and strength would be inappropriate. Interestingly, however, one-quarter of surveyed Americans think it is appropriate to use genetic testing (both PGD to select embryos and prenatal testing to identify whether a fetus has certain desirable traits) for these purposes.

Our research indicates that Americans are divided about the use of reproductive genetic testing to avoid adult-onset diseases. For some, using these technologies to prevent diseases and conditions that many find burdensome is comparable to early-prevention programs. For others, there is deep concern that if we accept the use of

these technologies for less urgent or compelling reasons, it will lead down the slippery slope to even more capricious use.

While a majority of participants in our study objected to using hypothetical genetics test to identify non-disease related traits such as intelligence or strength, a substantial number approved of using PGD to select for sex. In focus group discussion, some participants stated that sex selection through PGD is simply a more effective means of doing what couples have tried to do for centuries and were unconcerned about possible population effects since they felt that the preference for male children that exists in other countries is not present in the U.S.. Some focus group and interview participants even think that use of sex selection methods could be advantageous to both families and their child. Finally, some said through PGD might avoid the abortion of fetuses perceived to be the wrong sex.

When evaluating the appropriateness of reproductive genetic testing, Americans also consider the means, or what actually has to physically happen in order to reach the desired outcome. Having children that are free from genetic disease may be a laudable goal, but, for some Americans, using reproductive genetic testing to reach this goal is troubling. Many Americans who participated in focus group discussions are concerned about the known and unknown risks to women and resulting children. They also question why people who want to be parents would choose PGD when alternative paths to

parenthood, such as adoption, are less expensive, more effective, and have less ethical baggage. For many Americans, using reproductive genetic testing in order to make decisions about who is fit to come into the world amounts to playing God, particularly if embryos and fetuses are destroyed in the process.

Finally, Americans are concerned about the ultimate consequences of widespread use of reproductive genetic testing. They fear a world in which children are expected to be perfect, and parents are expected to do everything possible to prevent children with genetic disease from being born. How might this affect the way we treat and care for those with disabilities? Because this technology is expensive and frequently not covered by health insurance, could its use result in greater health and economic disparities? Many of these fears are not unique to reproductive genetic testing. They echo deep concerns about how many advances in technology challenge the values that our society holds sacred.

The majority of surveyed Americans wants and expects oversight to ensure safety, accuracy and quality of reproductive genetic testing. Depending upon how the questions are asked, Americans both support and resist governmental limits based on ethics and morality. When Americans are asked about regulating each individual technology, one-third of respondents favor limits based on “ethics and morality.” Twenty percent and 11 percent favor a complete ban on PGD and prenatal testing, respectively; when respondents were asked whether they are concerned

about government regulators invading private reproductive decisions, however, 70 percent said they were concerned or very concerned. Wanting to have it both ways actually mirrors the ambivalence witnessed during the focus group and town hall discussions, and may also reflect variation in what people are thinking about when they speak of “ethics and morality.” Just under a fifth of all Americans think that the government should avoid regulating genetic testing completely. For a portion of these Americans, this discomfort with government regulation is so deeply held that they resist government regulation in spite of their concerns about these technologies.

The Americans that participated in the focus groups, interviews, and town halls were deeply interested and engaged in discussions about the appropriate use and regulation of reproductive genetic testing. They held sophisticated and nuanced discussions that mirrored those occurring in academic circles.

The analyses in this report represent the first look at the rich and textured data obtained from the opinion research conducted over the last two years. The Center looks forward to more in-depth analysis of these data to contribute to the public dialogue and to inform the development of policies to govern the development and use of reproductive genetic tests.

# Appendix: Methods

## Qualitative Research Methodologies

A team of researchers designed, implemented, and analyzed the qualitative research (Table 1). The study populations included: (1) members of the general public, most of whom had little experience with genetic technologies, and (2) key informants who had more experience with genetic technologies, including families affected by genetic diseases, people who have experience with PGD and health-care providers. Data were collected from the general public through focus groups and from the remaining study populations through in-depth interviews.

All focus groups and interviews were audio taped and transcribed. The transcripts were then imported into NVivo, a qualitative data management and analysis software program. Data were coded to enable analysis of themes that emerged from the data.

The study instruments and informed consent protocol were reviewed and approved by the Institutional Review Boards at Johns Hopkins University, Abt Associates Inc., and the University of Pennsylvania.

### Focus Groups

Twenty-one, two-hour focus groups were conducted with 181 members of the general public (8.6 people per group on average) between March 31 and April 22, 2003. Focus groups were conducted in cities located in five states (Massachusetts, Tennessee, California, Colorado, and Michigan) representing major U.S. geographic regions.

A national focus group vendor provided facilities, recruited participants from their existing database of potential focus group participants and collected minimal demographic data. People included in these databases have volunteered to participate in focus group research. They were recruited by word of mouth, telephone and the Internet. People were eligible to participate if they were fluent in English and had not participated in a focus group within the last 6 months. Participants received \$75 for their time. To ensure that a broad range of perspectives were solicited and the discussions in each group were rich and nuanced, participants were grouped in terms of gender, age, race/ethnicity, religion, parental status and education. These demographic characteristics were selected because they had been shown to be associated with people's attitudes toward genetic technologies in the national telephone survey conducted by the Center in 2002. The characteristics of each focus group are shown in Table 2.

An experienced moderator facilitated each focus group using a discussion guide. The guide consisted of a series of scenarios – realistic situations confronting fictitious couples involving choices about reproductive genetic technologies that might occur now or in the future – and included questions to get participants to react to the situations. Each scenario built on the technical information presented in the previous scenario(s). Scenarios first presented participants with the situations and technologies they were most likely to be familiar with and progressed to increasingly complex

**Table 1: Reproductive Genetics Qualitative Research Team**

|                                   |  |
|-----------------------------------|--|
| Genetics and Public Policy Center | Kathy Hudson, Ph.D.<br>Andrea Kalfoglou, Ph.D.<br>Joan Scott, M.S., C.G.C. |
| Johns Hopkins University          | Gail Geller, Sc.D.<br>Debra Mathews, Ph.D., M.A.                           |
| University of Pennsylvania        | Barbara Bernhardt, M.S., C.G.C.  |
| University of Louisville          | David Doukas, M.D.   |
| U. of California, San Diego       | John Evans, Ph.D.  |
| University of Michigan            | Nancy Reame, M.S.N, Ph.D., FAAN  |
| Abt Associates, Inc.              | Teresa Doksum, M.P.H., Ph.D.<br>Lisa LeRoy, M.B.A, Ph.D.                   |

**Table 2: Focus Group Characteristics**

| Group No. | No. of People | Location      | Sex    | Age   | Parent? | Race/ Ethnicity  | Religion    | Education                    |
|-----------|---------------|---------------|--------|-------|---------|------------------|-------------|------------------------------|
| 1         | 8             | Massachusetts | Mixed  | 25-40 |         |                  |             |                              |
| 2         | 7             | Massachusetts | Female | 35-45 |         |                  | Jewish      |                              |
| 3         | 5             | Massachusetts | Female | 25-34 |         | Mexican-American |             |                              |
| 4         | 7             | Massachusetts | Mixed  | 25-34 |         |                  |             |                              |
| 5         | 9             | Massachusetts | Male   | 25-34 |         | Black            |             |                              |
| 6         | 6             | Massachusetts | Female | 25-45 |         |                  | Protestant  |                              |
| 7         | 9             | Tennessee     | Female | 25-34 |         | Black            |             | College degree or >          |
| 8         | 9             | Tennessee     | Male   | 35-45 |         | Black            |             |                              |
| 9         | 8             | Tennessee     | Male   | 18-25 | No      |                  |             |                              |
| 10        | 10            | California    | Female | 35-45 | No      |                  |             |                              |
| 11        | 7             | California    | Female | 35-45 |         | Mexican-American |             |                              |
| 12        | 9             | California    | Male   | 35-45 |         | Mexican-American |             |                              |
| 13        | 9             | California    | Male   | 35-45 |         |                  |             | < or = a high school diploma |
| 14        | 9             | California    | Mixed  | 55+   | Yes     |                  |             |                              |
| 15        | 7             | California    | Female | 25-45 |         | Chinese-American |             |                              |
| 16        | 11            | Colorado      | Female | 25-34 |         |                  | Evangelical |                              |
| 17        | 11            | Colorado      | Female | 18-25 | No      |                  |             |                              |
| 18        | 8             | Colorado      | Male   | 25-34 |         | White            |             | College degree or >          |
| 19        | 10            | Michigan      | Female | 35-45 |         | White            |             | < or = a high school diploma |
| 20        | 11            | Michigan      | Female | 35-45 |         | Black            |             | < or = a high school diploma |
| 21        | 11            | Michigan      | Female | 25-34 |         | White            | Catholic    |                              |

and/or futuristic stories (Table 3). They also began with the use of reproductive genetic testing for serious, potentially fatal disease, then moving on to consider less serious, non-fatal health conditions, and finally asked participants to consider trait selection. The last section of the guide asked participants to reflect back on the technologies that had been discussed and consider the social, regulatory, scientific, and ethical implications of the technologies.

Focus group moderators were assigned to groups according to their own personal characteristics to maximize cultural appropriateness whenever possible. Center staff trained the moderators on genetic concepts related to the technologies in the discussion guide. A focus group methods report is available at [www.DNAPolicy.org](http://www.DNAPolicy.org).

## Interviews

In-depth interviews were conducted with 62 individuals including families affected by genetic diseases, people who had used PGD, and health-care providers between July 24, 2003 and March 4, 2004. Interviews were conducted over the telephone and lasted between 60 and 120 minutes (90 minutes on average). To ensure that participants with a broad range of perspectives on reproductive genetics were included, 12 types of families and providers were recruited (Table 4). The genetic diseases were chosen in part based on convenience sampling but also to ensure that the diseases were moderate to severe and not limited to a single racial/ethnic group.

Potential interview respondents were recruited primarily using the Internet beginning in July 2003 and ending in March 2004. All of the adults with a genetic condition had either achondroplasia or Marfan syndrome and were recruited via their providers. Parents of children with a genetic condition were recruited through a cystic fibrosis organization. PGD patients were recruited through either PGD providers or advocacy organizations' listservs (the cystic fibrosis and Fanconi anemia organizations). Other conditions represented by the PGD patient interviewees included Fabry disease, hemophilia, and congenital adrenal hyperplasia. PGD specialists were identified by the Genetics and Public Policy Center and recruited directly.

The research team developed separate interview guides for each group. Each guide consisted of a core set of questions based on scenarios from the focus group moderator's guide as well as questions specific to their personal experience or clinical practices.

Individuals first received a recruitment letter and a disclosure statement describing the study and eligibility criteria (such as fluency in English and recruitment criteria specific to each group). It directed interested potential interviewees to call a toll-free study hotline to find out more information about the study and to schedule an interview.

Interviews were conducted by one of three experienced interviewers who were trained in basic genetic concepts by Center staff. Limited demographic data were also collected. All groups except the PGD providers (PGD specialists, PGD nurses and assisted reproductive technology genetic counselors), received a \$50 token payment for their time. PGD providers were not offered a monetary incentive because we assumed that they would be willing to discuss their experiences without compensation as a professional courtesy. An interview methods report is available at [www.DNAPolicy.org](http://www.DNAPolicy.org).

**Table 3: Focus Group Scenario Progression**

|                         |
|-------------------------|
| Carrier testing         |
| Prenatal testing        |
| PGD                     |
| -serious disease        |
| -adult-onset disease    |
| -obesity and depression |
| Genetic modification    |
| -serious disease        |
| -adult-onset disease    |
| -obesity and depression |
| -intelligence           |
| Elective sex selection  |
| -genetic disease        |
| -family balancing       |
| - first born            |



Table 4: Recruitment Sources and Criteria for Interview Populations

| Group #   | Special Population                                  | # of Participants | Recruiting Source   | Date Recruitment Started | Recruitment Criteria   |
|---|---|-------------------|---|--------------------------|--|
| Individuals with a Genetic Condition in the Family        |   |                   |   |                          |  |
| 1   | Parents of a child with a genetic condition         | 5                 | Cystic Fibrosis Research Inc. listserv  | 9/03                     | Biological parent of a child with cystic fibrosis  |
| 2   | Adults with a genetic condition                     | 5                 | Providers for individuals with achondroplasia or Marfan syndrome                          | 8/03                     | Individuals with achondroplasia or Marfan syndrome   |
| Individuals with PGD Experience for Single-Gene Disorders |   |                   |   |                          |  |
| 3   | Successful PGD                                      | 3                 | PGD providers; Cystic Fibrosis Research Inc. listserv; Fanconi anemia information network | 11/03                    | Biological mother of a child born after using PGD for a single-gene disorder   |
| 4   | Unsuccessful PGD                                    | 7                 | PGD providers; Cystic Fibrosis Research Inc. listserv; Fanconi anemia information network | 11/03                    | Woman who was unsuccessful in using PGD to avoid the birth of a child with a single-gene disorder (or male partner of) |
| 5   | Declined PGD  | 3                 | PGD providers; Cystic Fibrosis Research Inc. listserv; Fanconi anemia information network | 11/03                    | Woman who considered, but declined using PGD to avoid the birth of a child with a single-gene disorder                 |
| Providers   |   |                   |   |                          |  |
| 6   | Nurse midwives                                      | 5                 | American College of Nurse Midwives regional listservs for SE and Midwest regions          | 7/03                     | Certified nurse midwives who delivered more than 30 babies last year   |
| 7   | Obstetricians                                       | 5                 | Obstetrician listserv   | 7/03                     | Board certified in Obstetrics and delivered more than 30 babies last year  |
| 8   | Family practice physicians                          | 5                 | Family Practice Obstetrics listserv   | 7/03                     | Board certified in Family Practice and delivered more than 20 babies last year   |
| 9   | Assisted reproductive technology genetic counselors | 5                 | National Society of Genetic Counselors ART Special Interest Group listserv                | 7/03                     | Certified genetic counselors who specialize in reproductive genetics and counsel PGD patients                          |
| 10  | Prenatal genetic counselors                         | 5                 | National Society of Genetic Counselors listserv   | 7/03                     | Certified genetic counselors who specialize in prenatal genetics and counsel prenatal patients                         |
| 11  | PGD Nurses  | 4                 | List of 62 nurses' e-mails from American Society for Reproductive Medicine                | 7/03                     | Nurses who provide care for patients using PGD for single gene disorders   |
| 12  | PGD Specialists (physicians and/or scientists)      | 10                | Genetics and Public Policy Center list of PGD specialists                                 | 7/03                     | Performs PGD for single gene disorders and/or provides clinical care for PGD patients                                  |
| TOTAL   |   | 62                |   |                          |  |

## Quantitative Research Methodology

The Public Awareness and Attitudes about Genetic Technology 2002 Survey (2002 survey) included telephone interviews with a nationally representative sample of 1,211 adults living in continental United States telephone households. The interviews were conducted in English between October 15 and October 29, 2002. Statistical results are weighted to correct known demographic discrepancies. Details on the design, execution and analysis of the survey are available on the Center's web site at [www.DNAPolicy.org](http://www.DNAPolicy.org)

The Study of Attitudes Towards Genetic Technologies 2004 Survey (2004 survey) collected data from 4,834 Americans about their attitudes toward reproductive genetic technologies between April 16 and May 9, 2004. This internet-based survey, administered by Knowledge Networks (Menlo Park, CA), is the largest survey of American opinions on this topic to-date. The respondents were randomly sampled from Knowledge Network's web-enabled research panel designed to be representative of the entire U.S. population. The panel is representative because it was selected using high-quality probability sampling techniques, and it was not limited to current Web users or computer owners. Households were selected using random digit dialing (RDD) and each household was provided with free hardware and Internet access as needed for research participation. More information about the Knowledge Networks methodology is located at [www.knowledgenetworks.com/ganp](http://www.knowledgenetworks.com/ganp). Research subjects for the 2004 Survey were U.S. residents over age 18. Blacks were oversampled. Statistical results are weighted to correct for known selection probabilities, demographic discrepancies, and to account for oversampling of Blacks. The overall survey completion rate of the survey was 73 percent. The survey instrument and research protocol were approved by the Johns Hopkins University Institutional Review Board.

Two types of statistical models were constructed based on survey data: ordinary least-squares (OLS) regression and binary logistic regression. All data reported as "significant" or "statistically significant" in the text of this document met criteria at  $p < .05$ . However, due to space limitations, regression models are not shown.

Independent variables for binary logistic regression models included: age: 18-29, 30-49, 50+, female gender, Black ethnicity, Hispanic, religious affiliation or not, income level: less than 25K, 25K-50K, 50K-75K, 75K+, political affiliation: Republican, Democrat or other affiliation, educational level: high school education, some college education, college graduate, post-graduate.

Independent variables for OLS regression models included: age: 18-29, 30-49, 50+, urban residence, male gender, Black, other races, Hispanic, Protestant, Fundamentalist/Evangelical Christian, Catholic, other Christian, other religion, income level: 25K-50K, 50K-75K, 75K+, high school education, some college education, college graduate.

## Public Engagement Methodologies

Using two different methodologies, The Genetic Town Hall: Making Every Voice Count took place in six U.S. cities using a town hall format, and with 15 discussion groups online using state-of-the-art Internet meeting capability during the summer of 2004. In both settings, participants were asked to consider three

### **Table 5: Chosen Children: Issues in Reproductive Genetic Testing**

Chosen Children: The Science of Reproductive Genetic Testing  
 Chosen Children: The Ethics of Reproductive Genetic Testing  
 Chosen Children: The Safety and Accuracy of Reproductive Genetic Testing  
 Chosen Children: Impact on Families and Society

major issues in reproductive genetic technologies: determining acceptable uses; examining the safety and accuracy of these tests; and considering the impact on individuals, families and society. Background information about the technology and views of a diverse group of experts were provided through educational videos developed by the Center entitled *Chosen Children: Issues in Reproductive Genetic Technologies* (Table 5). This ensured that the content delivered to each town hall was the same. Participants were queried at various times before, during and after the sessions to document changes in opinions as a result of participating in the town hall. Many of the questions were similar to the focus group, interview, or survey questions allowing for some comparison between groups. A separate report, *The Genetic Town Hall: Making Every Voice Count*, which summarizes the findings from this project, and copies of the *Chosen Children* videos are available at the Genetics and Public Policy Center.

### In-person Town Halls

Participants for the three-and-a-half hour town halls (Table 6) were recruited by local coordinators using a variety of outreach strategies including placing notices in high traffic locations such as public libraries, churches, hospitals, clinics and supermarkets; electronic e-vites to chambers of commerce, trade associations, neighborhood associations and community discussion or roundtable groups; targeted outreach to constituencies with varied educational, socio-economical and racial backgrounds; and media ads and news articles. The events were advertised as free and open to the public and as an opportunity to learn more about reproductive genetic testing and voice opinions. Individuals interested in participating were asked to pre-register online so that recruitment efforts could be monitored.

At the town hall, participants could choose to sit at any table. Each table of 8-10 individuals had a facilitator who was either invited as a local expert resource or was recruited from the pool of pre-registered participants. Table facilitators were provided with a guide to facilitate the small group discussions. Participants were equipped with an electronic keypad to register their responses to demographic and survey questions and to rank order major areas of concern and optimism that were generated during the discussions. Responses could be immediately tallied and seen by the group for further discussion.

See Table 7 for the content and format of a typical town hall. At the end of the program, participants had an opportunity to hear from members and leader of their own communities. Theologians and clergy, parents with firsthand experience of the technologies, medical professionals, community activist, elected officials and those in the biotech industry gathered as local expert resources and shared their views with the audience in panel discussions.

Demographic and survey data, as well as data ranking the list of issues identified during the discussions were captured electronically and could be linked to individual demographic data, but not to personally identifying data. In some cases, the same survey questions were asked both before and after the discussions to capture any shifts in opinions as the result of the engagement. All six engagements were audiotaped to assist in identifying and reporting dominant themes and to capture representative quotes.

**Table 6: In-person Town Hall Schedule**

|   |
|---|
| Sacramento, CA<br>- Tuesday, June 29, 2004    |
| Seattle, WA<br>- Thursday, July 1, 2004       |
| Kalamazoo, MI<br>- Monday, July 19, 2004      |
| Fort Worth, TX<br>- Saturday, July 31, 2004   |
| New York City, NY<br>- Monday, August 2, 2004 |
| Nashville, TN<br>- Monday, August 4, 2004     |

**Table 7: The Genetic Town Hall - Content and Format**

|            |   |
|------------|---|
| 9:00 a.m.  | Welcome   |
| 9:10 a.m.  | Overview of the Process   |
| 9:20 a.m.  | Initial Impressions: eFORUM Session<br>Using keypads, participants responded to questions from the moderator on their opinions and values concerning reproductive genetic testing.  |
| 9:30 a.m.  | The Science of Reproductive Genetic Testing<br>Participants viewed a video that explained the basics of reproductive genetic testing.   |
| 9:40 a.m.  | The Ethics of Reproductive Genetic Testing<br>Using keypads, participants responded to questions from the moderator, viewed a video on the ethics of reproductive genetic testing and then engaged in a “table talk” discussion about setting limits on acceptable uses of testing. Using keypads, they rated issues to consider when setting limits. |
| 10:25 a.m. | The Safety and Accuracy of Reproductive Genetic Testing<br>Using keypads, participants responded to questions from the moderator, viewed a brief video on safety and accuracy. The moderator then facilitated a question and answer discussion.   |
| 10:55 a.m. | Impact on Families and Society<br>Following the video, participants engaged in a “table talk” discussion on the impact these technologies may have on families and society. Using keypads, they rated their level of concern on the top responses developed at each table.  |
| 11:40 a.m. | Impressions: eFORUM Session<br>Using keypads, participants responded to many of the same questions about their opinions and values concerning reproductive genetic testing as asked earlier in the session.   |
| 12:00 p.m. | Community Panel Discussion<br>Regional leaders participated in a moderated panel discussion to reflect on the themes that emerged from earlier discussions.   |
| 12:30 p.m. | Concluding Remarks  |

### Online Town Halls

The online version of the genetic town halls took place in July and August 2004. Participants were recruited from Knowledge Network’s web-enabled panel. This panel is representative of the U.S. population because it is recruited using high-quality probability sampling techniques, and is not limited to current Web users or computer owners. Knowledge Networks selects households using random digit dialing (RDD) and provides selected households with free hardware and Internet access.

An e-mail invitation was sent to a subset of the web-enabled panel who were 18 years or older and who had a personal computer and home Internet connection. The e-mail introduced the project and screened for technical qualifications to verify that the potential participant's computer would work with the Lotus Sametime discussion software. Sametime requires an Internet connection, a multimedia-capable PC with Windows 98 or later and Internet Explorer 6.0 or greater. Sametime might also not function with certain Internet firewalls and 'pop-up' blockers; participants who indicated that they had these features were asked if they would be willing to disable them during the discussion sessions. Once agreeing to participate, participants completed an 80-item pre-intervention survey and selected their preferred times for the discussion groups. A stereo headset with microphone, step-by-step user's guide on how to login and use the Sametime discussion group software, and two CD-ROM discs containing the *Chosen Children: Issues in Reproductive Genetic Testing* videos were sent to participants.

Group discussions were one-hour long and scheduled for the same time each week for three weeks. A moderator who was also conversant in the content was assigned to moderate each group. Groups and moderators were kept intact for all the meetings so that the participants would be discussing topics with the same individuals throughout the project. If a participant had a schedule conflict, they were allowed to view an archived session or to move to another group for that week.

Moderators followed a discussion guide that was based on the in-person town hall script. Each week one of the major issue area – determining acceptable uses, examining the safety and accuracy of tests, and considering the impact on individuals, families, and society - was the topic of discussion. Participants were told which of the *Chosen Children* videos to watch before each session and used a combination of voice chat, text messaging, and online polling to discuss the topic that week with their group members.

Within a week of completing the last of the three live discussions, participants responded to a 76 item post-intervention survey. A randomly selected control group of 403 respondents completed identical pre- and post-survey instruments during the same field periods as the group that participated in the engagement.