



Beach Center on Disability

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REAL STORY - Expecting a Baby with Down Syndrome: One Couple's Story of Coping ...and Carrying

The names of family members in this story have been changed to protect their privacy.

Lynn and Greg Taylor's life had clicked along perfectly. A young couple in their late 20s, they had college degrees, promising careers, and a new home. Best of all, they were expecting their first child. But a routine blood test during Lynn's first trimester changed everything. They were told their baby might have Down syndrome.

Had Lynn and Greg known what a double-edged sword pre-natal screening can be, they might have worried more. But with no family history of genetic disorders, Lynn had every reason to believe the pregnancy would go smoothly and that their baby would be fine. "They're always doing blood tests when you're pregnant," Lynn recalled. "I like to know what to expect and didn't think that much about it."

Screening for Risk Factors

What Lynn had was a triple AFP test. AFP (alpha-fetoprotein) is a protein made by all developing fetuses. AFP levels in an expectant mother's blood can identify spina bifida, low birth weight, or the presence of more than one baby. Lynn's triple AFP also measured hormone levels and screened the fetus for other characteristics, such as Down syndrome.

After an AFP test, parents are given an equation that represents risk factors for a specific anomaly. Following her blood test, Lynn learned her AFP was 1:166, which was unusual for her age. Lynn and Greg were then referred to a genetic counselor for more testing.

"I knew that the ratio should have been more like 1:1000," Lynn said. "The genetic counselor was having a difficult time explaining false positives and false negatives along with the probability that the child would have Down syndrome. We were very confused by what the true likelihood was of having a baby with Down syndrome."

Lynn agreed to a follow-up test to explain why her AFP ratio was so low. She underwent amniocentesis, a common but more invasive a procedure in which fluid is removed from the sac surrounding the fetus. This fluid contains fetal skin cells that can be used to perform a profile of the baby's chromosomes. An extra #21 chromosome indicates Down syndrome.

Lynn worried while waiting for the results of her amniocentesis but was determined to continue the pregnancy. She had just started to feel better after weeks of constant nausea. She broke out the maternity clothes.

Hearing the Results

Lynn called her doctor, who said the amniocentesis had confirmed their baby was a girl. And the baby had Down syndrome. The test was conclusive.

What the doctor went on to say still clings to Lynn's memory. "She just kept saying how really sorry she was, over and over again. I'm sorry, so sorry." Then her physician offered to give her another woman's phone number, "...where you can have the procedure."

"The procedure?" Lynn asked.

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"Termination," her doctor explained.

Lynn told her physician that she wanted time to think about it. "By then I was 19 weeks along. We were told we had only one week to decide what to do."

When Greg came home around 9:30 p.m., Lynn broke the news.

"We didn't know if our baby would ever be able to walk or talk. We didn't know anyone with Down syndrome and knew nothing about it except what we'd learned in biology about the 21st chromosome. I think I had it confused with other disabilities, such as cerebral palsy. It never occurred to us to go to the library to get information and our dial-up connection at home was really slow. We had just moved half-way across the country. We had no family near us. We were in shock."

A Traumatic Perspective

On Sunday Lynn called her OB, peppering her with questions about Down syndrome. Her physician cautioned them against continuing the pregnancy and said their child might be institutionalized.

"That was the most awful part of what the OB told us when we were asking for information," Lynn said. "I had grown up near a state hospital and had visited the children's ward for Christmas parties each year. This was terribly traumatic information for me and for my husband."

Their physician agreed to leave information about Down syndrome for them at the front desk of the hospital. Greg made a special trip into the city to pick it up, finding only two poorly photocopied handouts. One, in Lynn's words, "was a litany of frightening medical issues associated with Down syndrome." The other was a photocopied excerpt from a book about "How to Grieve for Your Deceased Child."

The pregnant women featured had all either miscarried or terminated. "I couldn't believe that was the information to OB gave us since we had originally told her we would continue the pregnancy. We really wanted information about Down syndrome, not terminating."

Lynn and Greg called family members for advice. Most said they would support them whatever their choice. "I didn't think I could go through with termination," Lynn said. "I just didn't want to be pregnant anymore."

"We Can Do It"

Racing against time, Greg and Lynn made another appointment with the genetic counselor, losing more days because the counselor worked part-time.

"When we arrived, the counselor was holding a book about Down syndrome on her lap. I could see pictures of babies on it. She held onto the book, like she wasn't sure she wanted to show us. I grabbed the book right out of her hands. I thought it would be terrible but the kids were so cute."

The counselor also told them that, if they wanted to continue the pregnancy, there was a long waiting list of couples wanting to adopt children with Down syndrome. "I thought if that's the case, why would we not keep the baby? That's when we realized we could do it."

REAL STORY Cont..

They were given the name of a Carl Cooley, a pediatrician in the region who specializes in serving children with special health care needs and himself the father of a child with Down syndrome. To this day Lynn praises the time Dr. Cooley spent with them on the phone, which convinced them that their decision to continue the pregnancy was right.

Throughout the remainder of the pregnancy, Greg and Lynn scoured the shelves of bookstores for information about Down syndrome. They read everything they could get their hands on. They connected with a family who had a child with Down syndrome. They contacted The Arc (Association for Retarded Citizens) and set up intervention services for after the baby was born.

But the pregnancy was an emotional roller coaster. They learned that several health conditions often accompany Down syndrome, such as heart defects and respiratory and gastrointestinal tract problems. At work people kept gushing over the pending birth of Lynn's first child. "I didn't want to tell them what we knew. I wasn't even sure that the baby wouldn't die, that it wouldn't be stillborn." The future was filled with questions and worries.

Emma Is Born

Four months later Lynn and Greg became the proud parents of a girl with Down syndrome, Emma, 5 pounds, 13 ounces. "I was ecstatic as any first-time mother," Lynn says. "I was so relieved that she made it."

As it turns out, Emma was born with a hole in a heart and ended up in the hospital a few weeks later for respiratory problems. At the age of four months she underwent heart surgery and then, according to Lynn, "became 100 percent better."

Today Emma is an eight-year-old blue-eyed blonde who loves to dance, swim, and travel. Tall and agile, she excels at gymnastics and looks fit and confident. "One of her strengths is academics," Lynn proudly explains. "She started reading at age three and by four or five had mastered more than 400 words."

Speech will likely be a lifetime challenge to Emma because of her small oral space. She also has ear problems. But Emma displays great tenacity. She taught herself to jump rope at the age six, a task that can be difficult for children with Down syndrome. "Her friends in kindergarten were always jumping rope at recess," Lynn says. "It was important to her and she figured it out."

Lynn sits on the Board of her statewide Down syndrome organization. She and Greg had a second child two years after Emma, a son born without disabilities. This time they had just the minimum of prenatal screening to test for health problems.

Liability Issues

Lynn's obstetrician was affiliated with one of the nation's most highly ranked hospitals on the east coast. Yet, their interaction with the health care community was fraught with insensitivity and ignorance. After deciding to continue with her pregnancy, Lynn returned to her original OB before finally deciding to change physicians.

While taking her blood pressure, the nurse looked puzzled. "You know, you don't have to do this. You don't have to keep coming if you're not pregnant anymore." Lynn realized the nurse had read the chart that indicated her baby had Down syndrome and assumed that Lynn had terminated.

REAL STORY Cont.

"How can they have been so misinformed?" she wonders. Yet, she acknowledges that many physicians are preoccupied with liability issues. "It's easier for them to recommend that parents should terminate than to deal with complications of birth and post-natal treatment."

The Debate Continues

Eight years have passed since Emma's birth. In that time the genetic counseling community has developed standards on how information should be disclosed to expectant parents. Still, roughly 80 percent of women who learn they are carrying a baby with Down syndrome decide to terminate.

The pros and cons of genetic testing are often linked to the national debate over abortion. Neither the National Down Syndrome Society nor the National Down Syndrome Congress has taken a stand on abortion. Lynn and Greg's family and friends indicated they would be supportive, whatever the outcome. But the debate continues on how health care personnel can deliver test results in ways that are positive and realistic.

Lynn says her best advice for parents facing the same situation as hers is to collect as many facts as possible so they can make their own decision. "It's easy to feel outside pressure from your physician or family and friends who may not have accurate information based on your own personal situation."

She quotes Dr. Carl Cooley. "There's the hope of couples that one more piece of information will help. But it ends up being a personal decision."



ARTICE- Ethical, Legal, and Social Implications of the Human Genome Project

The Human Genome Project (HGP) is a source of both hope and concern for people with disabilities and their families. It offers hope for improved understanding, identification, treatment, and prevention of disabilities. Yet, it creates concern about discrimination, privacy, eugenics, high costs, and other quality of life issues for persons with disabilities and their families. Unfortunately, the disability community's voice is still underrepresented in the public debate about genetic research. Too few know what the human genome project is and why it is important to persons with disabilities.

This article will provide an introduction to the HGP and outline a related research program underway at the Beach Center--the Ethical, Legal, and Social Implications of the Human Genome Project (ELSI). It also will review the research on the potential benefits and dangers of genetic research.

What Is the Human Genome Project?

The goal of the Human Genome Project, which began in 1990, is to identify all the genes possessed by human beings. Genes are biological units that help determine our personalities, health, appearance, and abilities. Genes determine what traits we inherit from our parents and those we pass along to our children. There are, of course, many environmental factors that also affect our personalities, health, appearance, and abilities. Where we live, what we eat, what we do, and with whom we interact play a major role in our development. We are not our genes, and our genes don't automatically predetermine our future. But genes do play a significant role in

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human development, and understanding the nature of that role is the goal of the HGP (U.S. Department of Energy, 2005).

What Is the ELSI project?

If understanding the role of genetics in human biology is the goal of the HGP, the ELSI program within the overall National Human Genome Research Institute (NHGRI) is about understanding the implications of the research. When Congress authorized HGP research, it recognized that such research also raises several issues including protection of human subjects, genetic information and privacy, discrimination and diversity, cost and benefits, and beliefs and autonomy. Accordingly, Congress mandated that a portion of HGP research funds be dedicated to studying these concerns.

The ELSI program funds research on the effects that genetic research may have upon individuals, stakeholder groups, and society in general. It also provides education on genetics and genetic issues and brings people together to discuss implications. ELSI encourages proactive responses to genetic research to ensure that the benefits of the research are realized and any potential harm from it minimized.

With NHGRI funding, the Beach Center began its own ELSI research project in 2003 to investigate the perspectives of the disability community on human genetic research. Our research attempts to bring the perspectives and opinions of underrepresented, grassroots members of the disability community into the genetics dialogue using focus groups and interviews. Our goal is to identify the hopes and fears of persons with disabilities about genetic research and technology. We also seek to explain the context of those hopes and fears and identify possible responses in policy and in practice.

What Are the Potential Benefits of Human Genetic Research?

The HGP has tremendous potential to improve medical care.

- **Improving Diagnosis:** Genetic tests and knowledge of the genetic roots of health, disease, and disability will allow early and better identification of health conditions. Genetic research may even allow us to identify our risks for future health conditions. More than 900 genetic tests already are available (U.S. Department of Energy, 2005a).
- **Improving Treatment:** New methods of treating disease and disability are possible if we know more about their genetic components. That knowledge fosters the development of new, more effective drugs and may allow us to cure some genetic diseases through gene therapy. Gene therapy clinical trials are currently underway for such diseases as Alzheimer's (Seppa, 2005), cancer, Severe Combined Immunodeficiency (SCID), and HIV/AIDS (U.S. National Institutes of Health, 2005). None has been approved outside of research settings.
- **Allowing Individualization:** In addition to helping develop new drugs and treatments, genetic research will allow the types and doses of drugs and other treatments to be tailored for each person and each condition. While this new science is still in its infancy, progress has been made in identifying genes that cause adverse reactions to some drugs (U.S. Department of Energy, 2005b).

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- ***Fostering Prevention and Wellness:*** Understanding our genetic health risks will allow each of us to anticipate, prepare, and sometimes avoid or reduce those risks. Personal health may benefit as the effect of various toxins in the environment are better understood (Sharp & Barrett, 2000).

Improvements in medical technologies are more than empty promises. Research already has identified and created tests for genes that cause many common disabilities, such as Fragile X (the most common genetic cause of intellectual disabilities) and Cystic Fibrosis (the most common fatal genetic disease). While research has not yet developed treatments for these and other genetic conditions, early identification of genes for some conditions allows for preventive interventions. For example, children diagnosed with PKU may benefit from dietary changes (U.S. Department of Energy, 2005a). For the vast majority of other genetic conditions, early identification may mean more timely use of educational and supportive services to reduce the impact on a child's abilities (Wolery & Bailey, 2002). Early identification may also foster greater inclusion and community participation.

Other potential benefits of genetic research are less certain, such as a shift in public attitudes toward persons with disabilities, public health benefits, and long-term health care savings. Genetic research alone cannot ensure such societal benefits. It can only offer us, as a society, the opportunity to do so.

What Are the Potential Dangers of Human Genetic Research?

As with the societal benefits, the potential harms of genetic research depend largely on how we conduct and use genetic research and technologies. In other words, the harms and whether they come to pass depend upon on what we as a society think, say, and do. It is important to understand the potential danger of misusing genetic research. Some of the primary concerns about genetic research include the following:

- ***Genetic Attitudes:*** Genetic research may lead to expanding the stigma of disability to individuals with particular genetic characteristics. Family members of persons with disabilities may themselves be viewed as having a disability or deemed guilty of carrying or passing on faulty genes. Hype and misinformation about genetics may lead people to equate an individual's worth with his or her genetics or to believe that genetics determines one's future. Even religious and philosophical beliefs and moral and ethical standards may be affected by an inappropriate search for genetic answers to non-genetic problems (Phelan, 2002).
- ***Loss of autonomy:*** Health care, reproductive, and service decisions may increasingly be made on the basis of public, rather than individual, health concerns. Misplaced desires to make decisions for persons with disabilities based on genetic information "for their own good" or "for the good of society" may limit individuals' freedom of choice. Forced treatments, coercion, or even inadequate opportunities to make informed decisions undermine the right to make personal health care decisions (Wetz, 1992).
- ***Research Exploitation:*** The drive to apply new genetic knowledge may undermine human research protections. Persons with disabilities may be exploited by being treated as human guinea pigs without access to full information about experimental trials or possible treatment (Chadwick, 1999).

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- **Research Insufficiency:** One concern is that genetic research will be slowed, limited, or halted and its benefits unrealized for some groups. Another is that side effects and other medical harms from genetic technologies will not be foreseen or addressed in research. Some fear that genetic research will overshadow other important research on environmental causes of disability (Mowat, 2002).
- **Privacy and Discrimination:** With increased use of technologies to identify an individual's genes comes the concern about what is done with that information. Employers, insurers, adoption agencies, and others might use information to deny employment, insurance, and other benefits eligibility or otherwise to discriminate against individuals and families based on their genetic information (Caperna & Curley, 2003).
- **Unequal Access and Cost:** Genetic research is not cheap. Who will bear the cost of new genetic technologies and who will receive the benefits? The concern is that only the rich or upper middle class will be able to afford many of the benefits of research that has been funded, in part, by public funds (Elias & Annas, 1992).
- **Drive to Perfect Persons:** Genetic technologies offer increased understanding and control over traits we pass on to our children. As such technologies become more available, there is concern that there will be a push for "perfect" babies through forced or coerced sterilization of the genetically "unfit," selective abortion, or genetic engineering (Otlowski & Williamson, 2003).

While many concerns are somewhat speculative, some have already come true. Cases of genetic discrimination have been documented. Federal legislation is currently being considered to prohibit some types of discrimination based on genetic information. ([Link to What the Law Says](#)). Research also has revealed that an estimated 80 percent of women terminate their pregnancies following a prenatal diagnosis of Down syndrome and that health care provider communications may play a strong role in those decisions (Kramer et al., 1998). ([Link to Real Story](#))

The Voice of the Disability Community: Recommendations

People with disabilities and their families are, and will be, one of the main groups that benefit from, or are harmed by, the application or misapplication of genetic technologies. So far, the disability community's engagement in public discussion over genetics has included the following:

- Some traditional disability advocacy organizations (e.g., The Arc) have participated in the public debate over genetic technologies (Davis, 1997).
- Some ELSI research has reflected the views of some in the disability community (Parens & Asch, 2003).
- The number of disability advocacy organizations represented in genetics advocacy groups, such as the Genetic Alliance, has increased as has their advocacy efforts. ([Link to Groups](#).)

While these steps are significant, many advocacy organizations are not yet actively engaged in the genetics debate. This fact might reflect the perception that genetics is a medical rather than social issue or that many of the benefits or potential harms have yet to materialize. Policy and

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advocacy, after all, generally address current rather than potential issues. But, for the first time in history, the disability community has the opportunity to proactively address discrimination before it occurs. The opportunity should not be missed.

Some organizations have focused only on the potential for harm and resisted genetic research without considering the possible benefits to persons with disabilities. Certainly, much of this resistance may be due to the dark chapters of medicalization of disability, which focused on cure and medical treatment without regard to quality of life. Resistance also may stem from the history of institutionalization, involuntary sterilization, discrimination, and abuse that those dark ages fostered. But it is this history and the opportunity to guide policy makers and practitioners in the conduct and use of future research that makes genetic advocacy so important for persons with disabilities and their families.

The ELSI program (especially as carried out at the Beach Center) provides a means for the disability community to engage the medical community and policy-makers in discussions of the ethical, legal, and social implications of genetic research. The challenge is to make the disability community's voice heard so that the benefits of genetic research are available to all and the potential for harm prevented.

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**THE LAW: The Genetic Information Nondiscrimination Act of Nondiscrimination Act of 2005**

Extraordinary medical advances such as The Human Genome Project can benefit individuals and the public, yet still carry the risk of misuses. Now that it is possible to identify someone's genetic tendencies for certain diseases, insurers, employers, and others could use that information to deny employment, insurance, or other benefits.

Although federal and state laws prohibit some misuse of genetic information by health insurance providers and employers, the existing laws are limited in their scope and many apply only on a state-by-state basis. The Genetic Information Nondiscrimination Act of 2005 (H.R. 1227), which aims to nationally prohibit misuse of genetic information, is currently being considered in the House of Representatives. The Senate unanimously passed an identical bill, S.B. 203, earlier this year.

Gaps in the Current laws

Many federal and state laws address genetic discrimination either directly or indirectly. Among these are the The Health Insurance Portability and Accountability Act (HIPAA), The Employee Retirement Income Security Act (ERISA), The Americans with Disabilities Act (ADA), and Title XVIII of the Social Security Act (Medicare/Health Insurance for the Aged and Disabled). However, gaps exist in each of these laws. Depending on where a person lives or what a

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person's particular genetic information issue is, adequate protection may not be available. For example;

- The ADA, which prohibits discrimination solely on the basis of disability, does not contain language specific to genetic traits. The one court decision that may suggest ADA protection extends to genetics is *Bragdon v. Abbott*¹. In *Bragdon*, the Supreme Court held that a person infected with HIV, even in the absence of AIDS, qualified for ADA protection. While this may suggest that the ADA could cover genetic "disabilities" even in the absence of an existing condition, the genetic characteristic would have to be "regarded as" a disability by the employer or insurer for it to be covered.

The Court's test for whether a condition or trait is regarded as a disability is exceptionally narrow and unlikely to offer protection in all cases of genetic discrimination. The Supreme Court has never directly addressed this issue. In other cases such as *Sutton v. United Airlines*², *Murphy v. United Parcel Service*³, and *Albertsons v. Kirkingburg*⁴, the Court has substantially limited what is and is not a disability under the ADA and generally required that a disability be presently existing, not potentially or hypothetically existing, casting serious doubt about whether genetic discrimination would be covered by the ADA.

- HIPAA prevents group health insurers from using genetic information to make rules for insurance eligibility. It does not prevent group health insurers from requiring or requesting genetic testing or from disclosing a person's genetic information without getting prior authorization to do so.
- State laws vary greatly with regard to scope and coverage. Some state laws such as those in California and New York are as comprehensive or more comprehensive than the proposed federal legislation. Other states, such as Pennsylvania, have no provisions for genetic nondiscrimination. This means that citizens of one state may have significant protection while citizens of other states have none at all.
- Existing state laws have not carefully defined terms such as "employer", leaving questions as to whether employment agencies, labor organizations, and similar entities are affected by the law. Similarly, many laws have not specifically indicated whether health insurance provisions cover group plans, individual plans, or state-run plans.

What Does H.R. 1227 provide?

H.R. 1227 is divided into two titles: one prohibits genetic discrimination by *health insurance issuers* and the other prohibits genetic discrimination by *employers*. It will amend and add prohibitions to the use of genetic information in several ways.

The Bill

- Prohibits discrimination by group and individual health insurance issuers, including providers of Medicare supplemental policies.

¹ *Bragdon v. Abbott*, 524 U.S. 624 (1998).

² *Sutton v. United Airlines*, 527 U.S. 471 (1999).

³ *Murphy v. United Parcel Service*, 527 U.S. 516 (1999).

⁴ *Albertsons v. Kirkingburg*, 527 U.S. 555 (1999).

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- Prevents group health insurers from requiring or requesting genetic testing of applicants.
- Expands the definition of employers to include employment agencies and labor organizations.
- Prevents genetic discrimination in employment, including failing to hire, firing, or discriminating in the terms, conditions, or privileges of employment.
- Prohibits an employer, employment agency, or labor organization from requesting genetic information about an employee except when:
 - Acquisition of the information is inadvertent.
 - The employee voluntarily agrees to participate in the employer's wellness program and the genetic information is given as a result.
 - The employer makes the request to comply with the Family and Medical Leave Act.
 - The information is already publicly available.
 - The employer gathers the information in connection with monitoring employee's exposure to toxic substances at the workplace.
- Classifies genetic information as medical information, placing it under the umbrella of medical privacy and confidentiality rules to prevent unauthorized disclosure.
- Will not pre-empt any state laws but will supplement state laws, many of which, have inadequate genetics protections.
- Guarantees some level of protection to all U.S. citizens without reducing protection in the states that provide adequate coverage now.
- Expands the definition of genetic information beyond the individual alone, to include information about an individual's family, such as the presence or absence of familial disorders or diseases. Without such safeguards, entities such as insurance companies could discriminate against someone without any personal genetic disorders on the basis of genetic disorders in that person's family.
- Authorizes money damages, injunctive relief (in which the court orders someone to cease an action), and other remedies.

Opponents have argued that the patchwork of protection available under current federal and state law is sufficient. A comprehensive approach such as that proposed by H.R. 1227, would eliminate the need for individuals with genetic information issues to search through the maze of existing laws and piece together a solution. Legal clarity is especially important since none of the patchwork remedies have been clearly established in a court of law. Having clear and thorough policies in place will make the law more understandable to the average person.

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Evidence has shown that many people avoid participating in research for fear that their genetic information will be widely and detrimentally disclosed. This not only hampers the benefit that a research participant could potentially receive but thwarts the advancement of science.

H.R. 1227 appears to be an effective way to safeguard the interest of patients who are seeking genetic services or participating in genetic research.

What Are H.R. 1227's limitations?

- It contains no provisions to prevent genetic discrimination in adoption, foster care, or other similar family-focused systems where genetic information could be used to the detriment of an individual. The Act limits its protections to health insurance and employment.
- Currently there is no cause of action under the "disparate impact" theory of discrimination. A disparate impact results when criteria or standards are applied equally that none-the-less result in a disadvantage for a group or class of people with that characteristic. For example, if insurance covers only a limited number of screenings for cancer, people who have a predisposition toward cancer—and therefore need more regular screenings—may be harmed by the limitation. Thus, people with a genetically high-risk of cancer are unfairly affected by what is, on its face, equal treatment. Because this manner of discrimination is of great concern, the bill requires a Genetic Nondiscrimination Study Commission to be established to further investigate the need for a disparate impact cause of action under the Act.
- H.R. 1227 defines genetic information and "manifested disease" in such a way that it is difficult to know exactly what that term means. The manner of testing, the substance used to perform the test (such as proteins), and the nature of the results may dictate whether or not the extracted information is genetic information for the purpose of the Act. Depending on the manner of the analysis and the information obtained, a very slight difference between the two tests could render one test result protected and one unprotected by the very same legislation. (Schoonmaker and Williams, 2005)
- H.R. 1227 does not prohibit inadvertently garnered genetic information, referred to as the "water cooler issue" (meaning, personal information is often casually exchanged among co-workers).
- H.R. 1227 requires that those who assert claims of genetic discrimination must employ the state and Equal Employment Opportunity Commission (EEOC) measures before filing a suit. H.R. 1227 also places a cap on punitive damages.

Although this bill (and its Senate identical bill) does not address every form of genetic discrimination by every entity, it does provide significant protection against most forms of discrimination.

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Library of Congress



INTERVIEW: The Human Genome Project and the Disability Community: What Are the Concerns?

An ambitious research program underway at the Beach Center is beginning to show that the perception of disability is the disability community's biggest concern with the Human Genome Project (HGP).

Throughout several focus group sessions, Research Assistant Professor Matt Stowe and his colleagues have heard that family members worry more about how people with disabilities are perceived and treated than possible HGP outcomes, such as genetic discrimination, violations of privacy, or even a new eugenics movement.

"Participants are more concerned with stigma and discrimination," Stowe said. "They are concerned that people with disabilities are feared or pitied or seen as a drain on society and that this will lead to harm. Despite these concerns, the majority of our respondents want the Human Genome Project to continue. They believe that improved health care benefits will come out of it. They just ask that caution be used and potential harms anticipated and addressed."

Completed in 2003, the Human Genome Project identified all the 20,000-25,000 genes in human DNA and their sequences. It also launched a debate over the ethical, legal, and social issues (ELSI) that could evolve from identifying what genes carry specific disorders.

Funded by the National Human Genome Research Institute, the three-year ELSI project at the Beach Center is bringing together grassroots members of the disability community, individuals with disabilities, and their families in small focus groups. The researchers also are conducting interviews with key informants, including consumers of genetic services, advocates, service providers, and policy makers. Groups have been convened in Raleigh-Durham, North Carolina; New York City; Bethesda, Maryland; Kansas City, Missouri; and Kansas City, Kansas. An additional focus group is planned for the Washington, D.C. area. Interviews also will be conducted in these same locations.

Focus group participants have included individuals who have, or who advocate for individuals who have intellectual disabilities, physical disabilities, and other health impairments. Other groups have comprised individuals from underserved populations within the disability community, such as racial and ethnic minorities, women, and low-income families that include persons with disabilities.

Stowe, who holds a law degree, describes the focus group work as a process of collecting the "hopes and concerns" of the disability community. He said the sessions start with hopes but usually progress quickly to concerns.

"There is a fear that the 'medicalization' of disability will return and will emphasize curing and treating disability impairments exclusively rather than the quality of life of those with disabilities. Probably the greatest concern comes from the intellectual disabilities community. Historically, persons with intellectual disabilities were a primary focus of eugenics."

INTERVIEW Cont.

"Eugenics didn't just happen in the Holocaust," Stowe said. "It took place in the United States among well-meaning, educated people who were swayed by negative perceptions of persons with disabilities. The public viewed people with disabilities as a burden on society and believed that the fit masses should not have to support the unfit. Eugenics policies fed on fears of and pity for persons with disabilities."

Stowe says ELSI is an enormous step in the right direction. "The Human Genome Project recognized from the start that the social and political implications of science should be examined. The lesson to us from eugenics is that advances like the Human Genome Project should proceed with clear consideration of its implications and with caution."

Stowe and his colleagues, Jennifer Rack and Suzanne Schrandt, have carefully recorded the comments of focus group participants and coded them according to common themes that emerged. Some of the prevalent themes include the perception of and attitudes toward persons with disabilities. The researchers also are examining possible responses to such hopes and fears, including social responses to disability, educational initiatives, health care delivery practices, or laws. The researchers surveyed all state laws in the U.S. related to genetics and prenatal screening, including laws that pertained to genetic diseases, such as sickle-cell anemia, pre-natal screening, and genetic discrimination. They will report their findings in presentations and articles and by creating a data base that connects the hopes and fears of the disability community with the laws intended to address them. They hope to highlight areas where new federal and state policy is needed.

Stowe believes that the Genetic Information Nondiscrimination Act of 2005 is a positive step because it protects against most forms of discrimination. Other legislation that holds promise is the Brownback-Kennedy Prenatally Diagnosed Condition Awareness Act. Introduced by Senators Sam Brownback (R-Kan.) and Edward M. Kennedy (D-Mass.), the bill would allocate \$25 million to provide more complete information about conditions such as Down syndrome, including data on life expectancy and how to help parents of children with congenital syndromes or diseases.

"This bill would give people more accurate information about a genetic condition prior to birth," Stowe said. "It will allow parents to prepare for their child's needs before the child is even born and lead to better quality of life for the child and the family."

"That's the ultimate best hope for the Human Genome Project. It should be about getting good, accurate information to the people who need it."

Another beneficial outcome might be the realization that everyone carries a certain number of faulty genes, Stowe said. "It's important that disability is seen as a universal characteristic, a common part of human existence, if we are to address the perceptions that are the roots of discrimination.

Stowe feels that involving the disability community in the ELSI debate is critical. "The Human Genome Project offers a forum for people to bring issues of perception in public discourse. The motto 'Nothing about us without us' needs to be carried into the genetics age."



RELATED RESEARCH

Classification, social contracts, obligations, civil rights, and the Supreme Court: Sutton v. United Air Lines.

(2001) Turnbull, H.R. & Stowe, M.J. *Remedial & Special Education*, 22 (6), 374-382

In Sutton v. United Airlines, the airline refused to hire twin sisters as commercial airline pilots. Both sisters had severe myopia. The Airline refused because neither sister met its vision requirement for commercial pilots. The sisters sued stating they were discriminated against because of their disability. They felt they should be protected under the Americans with Disabilities Act (ADA). The United States Supreme Court ruled in the airliner's favor. The ruling has many implications for the future rights of individuals with disabilities.

OPTIONS:

a. Read more about [this article](#) or more about the Beach at:

<http://www.beachcenter.org/research/default.asp?intResourceID=1364&act=detail&type=General%20Topic&id=3>

b. Read more about the Beach Center's [Disability Policy](#) research in general at:

<http://www.beachcenter.org/default.asp?strResource=&Type=General%20Topic&act=view&id=3>



BOOK - Expecting Adam: A True Story of Birth, Rebirth, and Everyday Magic

Published by: Berkley Books 1999; Reissued August 1, 2000

Authors: Martha Beck, Ph.D.

OVERVIEW: Martha Beck and her husband were hard-working graduate students at Harvard when they received the diagnosis that their second child would be born with Down syndrome. Beck's book describes her own rebirth as she deals with the snobbery of Harvard, the bias of physicians, and her growing attachment to Adam.

AVAILABILITY:

At a college or university library or contact <http://www.proedinc.com/jpbi.html>



GROUP – Genetic Alliance

OVERVIEW: Genetic Alliance increases the capacity of genetic advocacy groups to achieve their mission. It leverages the voices of millions of individuals and families living with genetic conditions. Genetic Alliance is a coalition of hundreds of genetic advocacy organizations, health professionals, clinics, hospitals, and companies.

WEBSITE: www.geneticalliance.org

GROUP Cont.

ADDRESS: 4301 Connecticut Ave. NW Suite 404, Washington, D.C. 20008-2369

TELEPHONE NUMBER: (202) 966-5557

**TIP - Finding and Getting the Best Service from a Genetic Counselor**

The following steps may help you locate a genetic counselor and to receive the greatest benefits from your consultation.

1. Understand what services genetic counselors typically provide.

- Genetic counselors are health-care professionals. They help individuals and their families understand genetic issues and the impact of those issues on their lives.
- Genetic counselors typically do not have medical degrees. Genetic counselors have graduate degrees in areas related to medical genetics and counseling, but they are not medical geneticists.
- They typically have professional experience or degrees in biology, psychology, social work, or other similar fields.

2. Genetic counselors do not perform genetic tests. They interpret and convey information from tests performed by health care personnel. Genetic counselors primarily:

- Predict the likelihood of a genetic disorder by examining medical records, medical history, and test results
- Provide information and support regarding the results of genetic tests
- Help people and their families consider decisions surrounding genetic testing
- Refer individuals and families to additional resources

3. Before attending a counseling session, prepare the questions you want answered.

Genetic counseling varies depending on the type of questions an individual wants answered. There are three major types of counseling:

- a. Prenatal – assessing whether a fetus has a possible genetic disorder
- b. Pediatric – assessing if genetic issues are causing health, learning, or emotional problems for a child
- c. Adult– discovering if an adult has a genetic tendency toward a condition.

TIP Cont.

The type of inquiry will affect what type of supports a genetic counselor provides. For example, a genetic counselor may provide referrals to services for expectant parents if prenatal tests determine that their baby will be born with Down syndrome.

4. Genetic counselors also answer questions on the effects of a disorder by performing the following functions:

- Finding out whether a person carries genetic traits related to a medical condition
- Determining whether they will likely have the condition as they get older

Informing people if a possible course of treatment is available, including early identification and intervention services. For example, a genetic counselor can determine from test results if a woman has a high risk of breast cancer. The counselor can then advise her to get early and frequent screening to protect her against the disease.

5. Most people are referred to a genetic counselor by their physician. If you want more information on a certain condition before the first session, check out these online resources:

- The Genetic Alliance Disease Info Search (http://www.geneticalliance.org/ws_display.asp?filter=diseases)
- Genetics and Rare Conditions (<http://www.kumc.edu/gec/support/>)
- Jablonski's Multiple Congenital Anomaly/Mental Retardation (MCA/MR) Syndromes Database (*This site contains medical terms and scientific descriptions of conditions.*) (http://www.nlm.nih.gov/mesh/jablonski/syndrome_db.html)

6. You may want to ask the counselor's business office whether your insurance provider will cover the session. Genetic counselors can cost \$150 an hour or more.**7. If you want to find a counselor and do not have a referral, here are some tips:**

- Ask your insurance provider to help locate a local genetic counselor covered by your plan. By contacting your provider, you can obtain the names of counselors and information about your benefit plan at the same time.
- Ask your physician for information on local genetic counselors. Your physician's business office also can help you find out if the counselor is covered by your insurance plan.
- Locate a counselor on the web. Visit the National Society of Genetic Counselors' website – (<http://www.nsgc.org/>)

Some information for this tip was provided by the following informative websites:

- Genetic Education Center at the University of Kansas Medical Center (<http://www.kumc.edu/gec/>)
- The Genetic Alliance (<http://www.nsgc.org/>)

- Genetic Science Learning Center of University of Utah ('<http://www.nsgc.org/>)
 - The National Society of Genetic Counselors ('<http://www.nsgc.org/>')
-



BUZZ AT THE BEACH

Tragedy Turns to Hope for Beach Partners

Two long-time grassroots partners of the Beach Center were among those families who confronted personal tragedy when displaced by Hurricane Katrina.

New Orleans residents Ursula and D.J. Markey and their son, Teiko, were evacuated to Canton, Mississippi, but plan to rebuild their lives in New Orleans.

The Markeys co-direct the Pyramid Parenting Training, a non-profit resource center for families of children with disabilities. The Center serves hundreds of New Orleans families with one or more children with disabilities, the majority of them headed by low-income single African American women. The Center was destroyed by the hurricane and the flooding that followed. Many of the families Pyramid serves were evacuated to the Superdome or Convention Center.

Pyramid Parent Training has provided information, training, and one-on-one support to parents since 1991. The Markeys are charter members of the Grassroots Consortium on Disabilities, a national multicultural alliance of community parent resource centers.

Trust Established to Assist Pyramid Parent

Beach Center Co-directors Ann and Rud Turnbull have established a trust fund to assist the Pyramid Parent Training Center whose building was destroyed by Hurricane Katrina.

The Pyramid Parent Recovery Trust Fund will help Ursula and D.J. Markey continue their efforts to serve New Orleans families who have children with disabilities. According to Rud Turnbull, "Their offices and records are flooded; their staff is dispersed; the families they serve are in distress."

The trust will be used at the direction of the Markeys on behalf of parents and children.

Donations may be sent to:

Rud and Ann Turnbull, Trustees

Beach Center on Disability

3111 Haworth Hall

The University of Kansas

1200 Sunnyside Drive

Lawrence, KS 66045-7534.

For more information, call the Beach Center at 785-7611 or visit

<http://www.beachcenter.org/default.asp?act=DonatePyramid>

BUZZ Cont.**Several Beach Center Researchers Present at Summit**

Researchers at the Beach Center participated in a historic conference sponsored by the Alliance for Full Participation September 22-23 in Washington, D.C.

Summit 2005 represented one of the largest gatherings ever of advocates, families, service providers, researchers, public policy experts, and leaders in the disability field. Participation by Beach Center staff included the following:

- **Ann Turnbull** moderated a breakout session entitled "Individual Control of Budgets, Supports, and Services for Individuals with Significant Intellectual Disabilities: Supporting Families to Support Their Family Member." Also participating were **Denise Poston**, research associate, and **Matt Stowe**, research assistant professor
- Associate Director **Michael Wehmeyer** co-chaired the Kansas delegation and present on two panels, one on the future of research and the other on technology use.
- **Nina Zuna**, doctoral student, and **Denise Poston** presented their research on community integration and in a poster session.
- **Karrie Shogren**, doctoral student, participated in a panel on health disparities and people with intellectual and development disabilities. She also will receive the AAMR's Outstanding Student Award on September 20 at a special AAMR awards reception.
- **Matt Stowe**, **Suzanne Schrandt**, research associate, and **Jennifer Rack**, doctoral student, presented research on the disability community's perspectives on the Human Genome Project, trends affecting perceptions and attitudes towards disability, and the implications for disability policy and advocacy.
- **Susan Palmer**, research assistant professor, attended as part of the Kansas delegation.
- **Miguel Angel Verdugo Alonso**, a Beach Center adjunct researcher from the University of Salamanca, Spain, received the International Researcher award from the American Association on Mental Retardation at the AAMR awards reception.

Summit 2005 Includes Beach-Sponsored Meeting on Individual Control

The Beach Center was one of five organizations sponsoring a special meeting on Medicaid and individual/family control of funding during the Summit 2005 conference in Washington, D.C.

Co-sponsored by The Arc, the American Association on Mental Retardation, and the Kansas and North Carolina Developmental Disabilities Planning Councils, the meeting was designed to solicit information on past, current, and future activities related to individual/family control. The session preceded a Medicaid plenary session scheduled for the previous day.

The Beach Center plans to develop a national Community of Action on individual/family control issues.

BUZZ Cont.

Work Continues on Exchange Program

Rud Turnbull returns to China in November to continue work toward a faculty and doctoral student exchange program with two major Chinese universities.

Turnbull will spend 12 days conferring with officials at Beijing Normal University and East China Normal University in Shanghai. Beijing Normal is home to the oldest teacher preparation program at a Chinese university. East China Normal is the only university in China that grants a doctorate in special education.

Ann and Rud Turnbull visited China in July 2004 to plant the first seeds of a formal exchange program. A first step in the process was a recent six-month collaborative visit to the Beach Center by Fei Zan, assistant professor of special education at East China Normal.

Wehmeyer Appointed Journal Editor

Michael Wehmeyer has been appointed Editor-in-Chief of the journal *Remedial and Special Education*, which is published by PRO-ED.

Wehmeyer also is co-editor of a new text on teaching students with mental retardation. Published by Prentice Hall, the book is *Teaching Students with Innovative and Research-Based Strategies*. Co-editor is Martin Agran, University of Wyoming. The book's web site is <http://vig.prenhall.com/catalog/academic/product/0,1144,0131701576,00.html>

Research Program Launched with North Carolina Partners

Ann and Rud Turnbull visited two North Carolina communities in August to launch collaborative research programs on policies related to Medicaid and Home and Community Based Services (HCBS).

The Beach Center will collaborate with families, support team members, and other staff over the next several years to study policies that enable individuals and families to exercise control of services and the funds to pay for services. Specific contacts in the two communities are The Arc in Wilmington and Piedmont Behavioral Health in Concord, which serves five counties.

Other members of the Beach Center research team will return to North Carolina in October to conduct interviews and attend a conference for families to introduce them to individual control of services.

Turnbull Appointed to Kansas Advisory Committee on End-of-Life Issues

Rud Turnbull has been appointed to a special advisory committee of the Kansas Judicial Council that will advise the council and the Kansas legislature on possible amendments to Kansas guardianship statutes concerning life-sustaining treatment and end-of-life issues.

BUZZ Cont.**Families Textbook Debuts on the Web**

A textbook by **Ann Turnbull and Rud Turnbull**, Elizabeth Erwin, Queens College of the City University of New York, and Leslie Soodak, Pace University, is now detailed on a new website. The site describes *Families, Professionals and Exceptionality: Positive Outcomes through Partnership and Trust* along with materials available to students and instructors. Check out <http://www.prenhall.com/turnbull/>

Deaf-Blind Grant Featured in KC Star

Work by Beach Center researchers to help children with deaf-blindness learn to communicate was profiled in the July 7 issue of *the Kansas City Star*. The front-page story described efforts by Research Assistant Professors **Susan M. Bashinski** and **Joan Houghton** to teach gestures to a six-year boy who is blind and deaf using adapted Prelinguistic Milieu Teaching. The project is funded by a \$1.25 grant to Bashinski and Nancy Brady, associate research professor with the Life Span Institute, to examine adapted prelinguistic milieu techniques for communicating with children who are deaf-blind and have cognitive disabilities. For the complete story, see http://www.kansascity.com/mld/kansascity/living/education/higher_learning/12070872.htm

Recent and Upcoming Presentations

Ann Turnbull has been invited to speak at an October autism conference in Les Croisic, France. She will present "Family Quality of Life" at a meeting of the Association Pour la Recherche sur l'Autisme et la Prevention des Inadaptations.

Wayne Sailor, Beach Center associate director, presented "Schoolwide Applications Model" at the Arizona TASH Inclusion Conference in Flagstaff, Arizona, in June. In addition, Sailor has been asked to serve as a primary grant reviewer for the Institute of Education Sciences in Washington, D.C. in late October.

Wayne Sailor and PBS research colleagues **Amy McCart**, **Nikki Wolf**, **Peter Griggs**, and **Rachel Freeman** will present at a PBS Implementation Forum October 20-21 in Chicago. Their breakout session is entitled "Developing Structures for Family/Community/ Student Involvement."

Wayne Sailor will present the keynote address, "Positive Behavior Support and a Universal Design for Learning," at the 9th Annual Beyond Access Inclusion Conference in Memphis, Tennessee, on October 27. He also will lead a breakout session entitled "Critical Features of the Schoolwide Applications Model (SAM): Planning, Implementation, and Measurement."

Denise Poston and Susan Palmer will present "Transition to the Community: The Promise of Self-Determination" at the Annual InterHab Conference October 5-7 in Overland Park, Kansas. InterHab is a resource network for Kansans with disabilities.

Matt Stowe will join Missouri attorney Nancy Huerta on October 11 to present at a continuing education seminar in Lenexa, Kansas, on the 2004 Reauthorization of IDEA. The one-day seminar provides continuing education credits for special education teachers, directors, psychologists, principals, teachers, social workers, and attorneys, among others.

BUZZ Cont.

Several researchers and doctoral students from the Beach Center will present at the 43rd annual conference of the Kansas Federation of the Council for Exceptional Children October 13-14 in Wichita. The two-day conference will feature the following:

- **Denise Poston** and her son AJ, "My Life, My Way – Planning and Paying for a Life After High School"
- **Jean Ann Summers**, research associate, **George Gotto**, research assistant, and **Nina Zuna**, doctoral student, "Being Part of a Community: Activities, Barriers, and Strategies"
- **Suk-Hyang Lee**, doctoral student, "The Gap Between Theory and Practice of Access to the General Curriculum for Students with Disabilities: Implications from Teachers" (poster).

The work of three Beach Center researchers was presented at a poster session during the 2005 annual convention of the American Psychological Association held in August in Washington, D.C. A poster entitled "Development of perceptions of control in children and youth with mental retardation" represented recent findings by **Karrie Shogren**, **Michael Wehmeyer**, and **Susan Palmer**, along with James Bovaird, former research associate with the Life Span Institute.

Online Courses Completed for Indiana Project on Deaf-Blindness

Joan Houghton has developed four online courses for the Indiana State Department of Education. The courses cover several topics related to teaching children with deaf-blindness. They were developed through the Indiana State Department of Education, Special Education Services Division, with Indiana Deafblind Services Project at Indiana State University.

Student News

Five new doctoral students joined the Beach Center this fall. They are enrolled in the Systems Enhancement Leadership program in KU's Department of Special Education. The students who are working in the families and policies research area at the Beach Center are **Pam Epley**, **Anna Friend** (returning student), **Judith Gross**, and **Luchara Wallace**. **Hyun Jeong Cho** is a new student in self-determination. For profiles of both new and continuing students, see ([link here](#)).

Rashida Banerjee, doctoral student in special education, has been named one of KU's Women of Distinction by the Emily Taylor Women's Resource Center. Banerjee worked at the Beach Center this summer as a research assistant. She is a graduate of Jadavpur University in Calcutta.

Selected List of Recent Publications by Beach Center Researchers

Riffel, L.A., Wehmeyer, M.L., Turnbull, A.P., Lattimore, J., Davies, D., Stock, S., & Fisher, S. (2005). Promoting independent performance of transition-related tasks using a palmtop PC-based self-directed visual and auditory prompting system. *Journal of Special Education Technology, 20*(2), 5-14.

Schallock, R., Verdugo, M., Jenaro, C., Wang, M., Wehmeyer, M., & Xu, J., & Lachapelle, Y. (2005). Cross-cultural study of core quality of life indicators. *American Journal on Mental Retardation, 110*, 298-311.

BUZZ Cont.

Shogren, K. A., & Rye, M. S. (2005). Religion and people with intellectual disabilities: A study of self-reported perspectives. *Journal of Religion, Disability, and Health, 9*(1), 29-53.

Smith-Bird, E., & Turnbull, A.P. (2005). Linking positive support outcomes to family quality of life outcomes. *Journal of Positive Behavioral Interventions, 7*(3), 174-180.

Summers, J.A., Hoffman, L., Marquis, J., Turnbull, A., Poston, D., & Lord Nelson, L. (2005). Measuring the quality of family-professional partnerships in special education services. *Exceptional Children, 72*(1), 65-81.

Turnbull, A.P., & Turnbull, H.R. (2005). Parent-professional relationships. In M.E. Snell & F. Brown (Eds.). *Instruction of students with severe disabilities* (6th ed.). Upper Saddle River, NJ: Merrill/Prentice Hall.

Turnbull, H.R., Stowe, M.J., & Huerta, N. E. (2005). *The Individuals with Disabilities Education Act as amended in 2004*. Columbus, OH: Merrill/Prentice Hall.

Umberger, G.T., Stowe, M.J., & Turnbull, H.R. (2005). The core concepts of health policy affecting families who have children with disabilities. *Journal of Disability Policy Studies, 25*(4), 201-208.