

**HUMAN EMBRYONIC STEM CELLS: WILL *SHERLEY V. SEBELIUS*
EXPAND THE DEFINITION OF THE DISABLED INDIVIDUAL?**

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The D.C. Circuit decided Sherley v. Sebelius in favor of the National Institute of Health by holding that federal funding can be applied to human embryonic stem cell research. This decision will allow scientists to make strides in research, and it could allow for scientists to quickly characterize genetic abnormalities that predispose humans to develop particular diseases or disabilities. Individuals with genetic abnormalities may be characterized as disabled due to their genes alone, and they may be subject to discrimination. The Americans with Disabilities Act and the Genetic Information Nondiscrimination Act, the current legislation that could provide protection to this class of individuals, would provide only minimal benefit. However, the individuals may be able to establish themselves as a protected class under the Americans with Disabilities Act if the intersex community is successful in arguing that it should be given the protections provided by the Americans with Disabilities Act.

I. INTRODUCTION

As science has advanced, we have discovered that many diseases and physical disabilities are linked to genetic abnormalities.¹ The ideal human being would have maximum

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¹ *Frequently Asked Questions About Genetic Disorders*, NAT'L HUMAN GENOME RESEARCH INST., <http://www.genome.gov/19016930> (last updated Feb. 27, 2012). For example, a mutation in exon 4 of apolipoprotein CIII has been shown to have a high correlation to abnormalities of plasma triglycerides and HDL transport. D.J. Galton & G.A.A. Ferns, *Genetic Markers to Predict Polygenetic Disease: A New Problem for Social Genetics*, 92 QJM 223, 223 (1999). This mutation has been linked to a predisposition in individuals to develop coronary artery disease and an increased occurrence of heart attack. *Id.*

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genetic fitness such that the manifestation of physical disease and disability does not occur. Indeed, scientists have already developed procedures by which a fetus's genetic fitness can be assessed.²

Human embryonic stem cell research has become an important part of medicine only in the last several decades.³ The technique has proven to be a very useful tool for scientists in characterizing genetic abnormalities, and it has been hypothesized that it will be useful in mitigating the physical manifestations of some of the resultant disorders.⁴ However, our federal government has been unable to reach a long-term consensus in policy directing human embryonic stem cell research. In September 2012, the D.C. Circuit decided *Sherley v. Sebelius* ("Sherley")⁵ and thus passed down an important decision finding that federal funding can be used for human embryonic stem cell research.⁶ While this decision will almost certainly lead to advancements in medicine and the biological sciences and may improve the quality of life for many, it

Additionally, mutations in more than 60 proto-oncogenes have been linked to the development of cancers, including breast and ovarian cancers. *Id.*

² PETER J. RUSSELL, *GENETICS: A MOLECULAR APPROACH* 80–81 (Jim Smith et al. eds., 2d ed. 2006). A couple can undergo genetic testing before a pregnancy, or the fetus can be tested during pregnancy. *Id.* Prior to pregnancy, a couple can make an appointment with a genetic counselor who will examine the genetic histories of both the mother and the father and report to the couple the likelihood of emergence of particular genetic traits. *Id.* During a pregnancy, an amniocentesis can be performed on the fetus. *Id.* In the procedure, a sample of the amniotic fluid of the mother is extracted. *Id.* Because this fluid contains some of the fetus's skin cells, it can be screened to yield a report of the genetic fitness of the fetus. *Id.* An amniocentesis is usually only performed on mothers who are high-risk pregnancies because the procedure is expensive, complicated, and can be risky. *Id.*

³ See Junying Yu & James A. Thomson, *Embryonic Stem Cells*, NAT'L INSTS. OF HEALTH, http://stemcells.nih.gov/info/Regenerative_Medicine/Pages/2006Chapter1.aspx (last updated Sept. 16, 2010).

⁴ *See id.*

⁵ 689 F.3d 776 (D.C. Cir. 2012).

⁶ *See id.* at 785.

could also lead to some unwanted consequences affecting the scope of the current disability legislation.

The aim of this Recent Development is to put Congress and the courts on notice that the decision in *Sherley* could lead to an expanded definition of the disabled individual that could produce issues with which our current legislation is not equipped to deal. Part II will give the basics of genetics and human embryonic stem cell research along with the legal and social background preceding the case. Also, Part II will show how the human embryonic stem cell debate has taken form in all three branches of the federal government and in popular culture. Part III explains *Sherley v. Sebelius*. Part IV shows how an expanded definition of the disabled individual could result from the case, explains the problems that might arise from the expanded definition, and analyzes the limitations of the current legislation applicable to the disabled community. Lastly, Part V draws an analogy between an individual who would fall into the expanded definition of “disabled” and an individual with an intersex condition. The analogy highlights how some of the shortcomings of current legislation could be resolved.

II. THE SCIENTIFIC, LEGAL, AND POPULAR BACKDROP

An understanding of the basic scientific principles of human embryonic stem cell research as well as an understanding of the legal and popular bases for the controversy are necessary in order to fully appreciate the weight of the D.C. Circuit’s decision in *Sherley*.

A. *Just the Basics: Genetics and Stem Cell Research*

Research has shown that each time DNA is reproduced and passed from generation to generation 100 to 200 new mutations occur.⁷ This means that each human being’s DNA contains a large number of mutations, but most humans do not manifest any

⁷ Elie Dolgin, *Human Mutation Rate Revealed*, NATURE (Aug. 27, 2009), <http://www.nature.com/news/2009/090827/full/news.2009.864.html#B1>.

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physical abnormalities due to their genetic mutations.⁸ One reason for this may be that many mutations are silent, which means that they have no physical manifestation.⁹ In contrast, some mutations in DNA are visible, meaning that the DNA abnormality will have some physical effect on the human.¹⁰ Even still, some DNA mutations predispose, but do not guarantee, that a human will develop the condition for which he or she is at an elevated risk.¹¹

Visible mutations in DNA lead to human genetic disease. It is possible for genetic diseases to be caused by either a single mutation in a gene, by multiple mutations across several genes, or

⁸ *Genetics Home Reference: Do All Mutations Affect Health and Development?*, GENETICS HOME REFERENCE (May 13, 2013), <http://ghr.nlm.nih.gov/handbook/mutationsanddisorders/neutralmutations>.

⁹ See RUSSELL, *supra* note 2, at 137. Another factor that can affect the physical manifestation of genetic mutations is the penetrance of the gene, which “refers to the probability that disease will appear when a disease-related genotype is present.” Chris Winkelman, *Genomics: What Every Critical Care Nurse Needs to Know About the Genetic Contribution to Critical Illness*, CRITICAL CARE NURSE, June 2004, at 34, 37. This means that:

A trait with incomplete penetrance is characterized by a specific genotype but a varied phenotype; that is, persons with the same genetic anomaly (abnormal genotype) do not have the same abnormal signs, symptoms, and complex disease. An example of a trait with incomplete penetrance is the polydactyl trait. The same genotype might “penetrate” as an extra finger, a small tag, or not at all.

Id.

¹⁰ See RUSSELL, *supra* note 2, at 148.

¹¹ See *Hereditary Cancer Syndromes*, MD ANDERSON CANCER CTR., <http://www.mdanderson.org/patient-and-cancer-information/cancer-information/cancer-topics/prevention-and-screening/hereditary-cancer-syndromes/index.html> (last visited Mar. 26, 2013). For example, many cancers develop as a result of DNA mutations that put the individual inheriting the mutation at a higher risk for developing the cancer in his or her lifetime. Galton & Ferns, *supra* note 1, at 224. Since the 1980s, over twenty genes coding for proteins involved in plasma lipid transport, a cellular activity that is compromised in individuals with many cardiovascular diseases, have been identified and located on the human genome. *Id.* at 223. A genetic defect in the LDL receptor has been correlated with a predisposition for early and sudden myocardial infarction. *Id.* at 225. Lastly, the genetics for diseases like Alzheimer’s disease and diabetes mellitus are partially characterized, and the hope is that they will be fully characterized in the near future. *Id.* at 223–24.

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even by a combination of genetic and environmental factors.¹² Many single mutation diseases like Tay-Sachs disease¹³ and Marfan syndrome are fairly well understood by physicians and researchers, but those diseases that are thought to be the result of multiple mutations are more of a mystery.¹⁴ For instance, scientists have hypothesized that diseases like asthma and heart disease are caused by multiple gene mutations when combined with environmental factors,¹⁵ but scientists are not sure exactly how the mutations and other factors work together to lead to disease.¹⁶

Stem cells have become increasingly important to the study of genetics. Human embryonic stem cells are derived from fertilized human embryos that have not yet implanted in the uterus.¹⁷ The

¹² G. WALLIS, THE BIOCHEMICAL SOCIETY, THE GENETIC BASIS OF HUMAN DISEASE 1 (1999), available at http://www.biochemistry.org/Portals/0/Education/Docs/BASC10_full.pdf.

¹³ A.D.A.M. Medical Encyclopedia: *Tay-Sachs Disease*, PUBMED HEALTH, <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002390/> (last updated Nov. 2, 2012). Tay-Sachs disease affects the nervous system and occurs when the body cannot produce hexosaminidase A due to a mutation on chromosome 15. *Id.* Hexosaminidase A helps break down ganglioside, a substance that is found in nerve cells. *Id.* Because the body lacks the ability to break down gangliosides, the nervous system is severely affected—an individual with Tay-Sachs can become deaf, suffer seizures, and exhibit slow growth. *Id.* Tay-Sachs progresses very rapidly, leading to the death of an affected individual at age four or five. *Id.*

¹⁴ A.D.A.M. Medical Encyclopedia: *Marfan Syndrome*, PUBMED HEALTH, <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001455/> (last updated Apr. 30, 2012). Marfan syndrome affects connective tissue that runs through the skeletal system, the cardiovascular system, the eyes, and the skin. *Id.* Individuals with Marfan syndrome have a mutation in their fibrillin-1 gene, which is a gene that encodes for the production of enzymes that are critical to the functioning of connective tissue. *Id.* Individuals with Marfan syndrome also experience overgrowth in the long bones of their body and weakened connective tissues, which can lead to aneurysms and heart problems. *Id.*

¹⁵ *Frequently Asked Questions About Genetic Disorders*, supra note 1; see Eva Lorenz, Comment, *Predictive Testing in the Workplace—Could the German Model Serve as a Blueprint for Uniform Legislation in the United States?*, 7 N.C. J.L. & TECH 487, 491 (2006).

¹⁶ See Lorenz, supra note 15, at 492.

¹⁷ Yu & Thomson, supra note 3.

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stem cells have a number of unique characteristics that make them useful in the laboratory. First, the cells are undifferentiated, which means that the cells have not developed into a specialized adult cell.¹⁸ Second, the cells are pluripotent.¹⁹ A pluripotent cell can be induced to transform into any of the cell types found in the human body.²⁰ Finally, human embryonic stem cells are self-replenishing, which means that the cells will continue to give rise to more cells as long as they are maintained in certain laboratory conditions.²¹ Human embryonic stem cell research is important to the study of human development, the characterization of genetic disease and disability, and the treatment of the disease and disability.²² For example, human embryonic stem cells have helped scientists determine the function of particular genes through the subsequent creation of in vitro models of genetic disease by differentiating the stem cells into hard to obtain cells and for research.²³

One technique used in conjunction with stem cell research is homologous recombination, a technique useful because it allows scientists to alter or delete specific target genes within the stem cells.²⁴ By doing so, homologous recombination allows scientists to study those genes in any cell type the stem cells can differentiate into, which allows a determination of the gene's function in that context.²⁵ This procedure not only allows scientists to determine the function of a gene but also, once the "proper" modification is found, gives scientists the ability to turn a human embryonic stem cell into a model of human genetic disease.²⁶

Because human embryonic stem cells are undifferentiated and virtually limitless in supply, the cells can be used in research to test

¹⁸ *Id.*

¹⁹ *Id.*

²⁰ *Id.*

²¹ *Id.*

²² *Id.*

²³ *See id.*

²⁴ *Id.*

²⁵ *Id.*

²⁶ *Id.*

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new drugs.²⁷ Many types of drugs can only be tested in animal models because human cell lines are inaccessible or do not exist.²⁸ However, animal models differ from human models in important ways, so toxic drugs that appear safe in animal testing have passed into clinical trials, sometimes resulting in death.²⁹ Human embryonic stem cells could provide the target system needed to test and increase the safety and efficacy of drugs before they enter clinical trials.³⁰

B. *The Popular and Legislative Battle over Human Embryonic Stem Cell Research*

The controversy surrounding human embryonic stem cell research began well before the inception of *Sherley*, taking form in the federal government and in popular culture.³¹ The controversy in the government over stem cell research indicates that the decision in *Sherley* may have an effect on the disabled population that cannot be ignored. Examining the popular controversy provides the rationale, in part, for why the suit was brought.³²

²⁷ *Id.*

²⁸ *Id.*

²⁹ *Id.*

³⁰ *Id.*

³¹ See, e.g., Philip J. Hilts, *Congress Urged to Lift Ban on Fetal-Tissue Research*, N.Y. TIMES, (May 27, 1992), <http://www.nytimes.com/1992/05/27/us/congress-urged-to-lift-ban-on-fetal-tissue-research.html?ref=stemcells> (“The Reagan Administration official who first banned Federal financing of research involving fetal tissue said today that he now believed that the ban was a mistake, and he urged the Bush Administration and Congress to end it.”).

³² The plaintiffs in *Sherley*, Dr. James Sherley and Dr. Theresa Deisher, both oppose the destruction of human embryos, and by extension, human embryonic stem cell research. See Gardiner Harris, *The Two Plaintiffs at Center of the Ban on Stem Cell Use*, N.Y. TIMES (Aug. 24, 2010), http://www.nytimes.com/2010/08/25/health/policy/25scientists.html?_r=0. Dr. Sherley “likened the destruction of human embryos to racial discrimination,” coining the term “embryoism,” which “mean[s] discriminating against human embryos, just like there is discrimination against people of different culture and races.” *Id.* Dr. Deisher is the co-founder of the Ave Maria Biotechnology Company, which creates technologies that can be utilized by scientists using adult stem cells for research. See *id.*

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Congress added the Dickey-Wicker Amendment as a rider to the Administrative Procedure Act in 1996.³³ The Amendment is one of the first pieces of legislation that aims to control the use of human embryos in research, and precludes the use of federal funding for:

- (1) the creation of a human embryo or embryos for research purposes;
- or (2) research in which a human embryo or embryos are destroyed, discarded, or knowingly subjected to risk of injury or death greater than that allowed for research on fetuses in utero under 45 CFR 46.204(b) and section 498(b) of the Public Health Service Act (42 U.S.C. 289(g)(b)).³⁴

Although the language seems to prohibit the use of human embryos in the establishment of human embryonic stem cell lines, the General Counsel of the Department of Health and Human Services (“HHS”) released a statement to the director of the National Institute of Health (“NIH”) stating that the Amendment did not prohibit the use of federal funding for human embryonic stem cell research.³⁵ Following the guidance of HHS, the NIH published guidelines in 2000 that did not prohibit the use of human embryos for human embryonic stem cell research.³⁶

Human embryonic stem cell research has provided fuel for controversy in the legislature, and a cursory examination of the most recent presidential administrations indicates that the executive branch is equally unable to resolve the issue. For example, in 2001, President George W. Bush publicly announced to the country his opposition to human embryonic stem cell

³³ Consolidated Appropriations Act of 2010, Pub. L. No. 111-117, § 509, 123 Stat. 3034, 3280–81 (2009).

³⁴ *Id.*

³⁵ Memorandum from Harriet S. Rabb, Gen. Counsel of the Dep’t of Health & Human Servs., to Harold Varmus, Dir. of the Nat’l Insts. of Health, on Federal Funding of Research Involving Human Pluripotent Stem Cells (Jan. 15, 1999), available at <http://news.sciencemag.org/scienceinsider/Implementing%20New%20Federal%20hESC%20Research%20Policy.pdf>.

³⁶ Brief for Appellees at 16, *Sherley v. Sebelius*, 610 F.3d 69 (D.C. Cir. 2010) (No. 10-5287).

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research.³⁷ In light of his political and moral views, President Bush stated that he would limit federal funding of human embryonic stem cell research—only those cell lines in existence at the date of his announcement would be eligible for federal funding.³⁸ Federal funding would be barred from application to research using all those cell lines coming into existence after his address.³⁹ On June 20, 2007, President Bush issued Executive Order 13,435, which continued to ban federal funding for human embryonic stem cell research.⁴⁰

When President Barack Obama took residence in the Oval Office, he quickly reversed Bush's limitations on federal funding for human embryonic stem cell research when he issued Executive Order 13,505 on March 9, 2009.⁴¹ The order allowed the Secretary of HHS and the Director of NIH to continue to conduct human embryonic stem cell research.⁴² As such, the HHS and the NIH were required to issue new guidelines and safeguards for human embryonic stem cell research.⁴³

Human embryonic stem cell research has proven to be controversial to law makers, and it has also been a source of significant controversy in the popular culture.⁴⁴ Proponents of

³⁷ Press Release, President George W. Bush, President Discusses Stem Cell Research (Aug. 9, 2001), *available at* <http://georgewbush-whitehouse.archives.gov/news/releases/2001/08/20010809-2.html>.

³⁸ *Id.*

³⁹ *Id.*

⁴⁰ See Exec. Order No. 13,435, 3 C.F.R. 222 (2008); *see also* Bush, *supra* note 37 (ordering funding priority to research clarifying alternative methods of isolation and testing of human embryonic stem cells like umbilical cord placentas).

⁴¹ See Exec. Order No. 13,505, 3 C.F.R. 229 (2010). President Obama stated that “[t]he purpose of this order is to remove . . . limitations on scientific inquiry, to expand NIH support for the exploration of human stem cell research, and in so doing to enhance the contribution of America’s scientists to important new discoveries and new therapies for the benefit of humankind.” *Id.*

⁴² *Id.*

⁴³ *Id.*

⁴⁴ See, e.g., *Grant for Fetal-Tissue Study Is First Since Ban Was Lifted*, N.Y. TIMES (Jan. 5, 1994), <http://www.nytimes.com/1994/01/05/us/grant-for-fetal-tissue-study-is-first-since-ban-was-lifted.html?ref=stemcells> (stating that the

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human embryonic stem cell research point to the enormous potential of the tool in developing new therapies to treat human disability and disease.⁴⁵ However, because the creation of human embryonic stem cell lines requires the destruction of a fertilized human embryo, opponents of the research take the stance that the use of human embryonic stem cell research shows disrespect for the value of human life.⁴⁶ Although many different opinions exist, there are generally four camps. Each camp defines personhood, the instance in which an embryo becomes a human, at different times.⁴⁷

For example, one camp believes that the human embryo is a human being, or at least a potential human being, from the moment it is fertilized.⁴⁸ The proponents of this definition of personhood state that it is difficult to determine exactly when a fertilized embryo becomes a human being because the process is continuous.⁴⁹ Thus, an embryo should be afforded the same respect as any human being.⁵⁰ Those opposing this definition of early personhood state that certain interests must be weighed.⁵¹ Although an early embryo has the potential to lead to human life, it

Federal government approved funding for a fetal tissue research study after funding had been banned for five years); Nicholas Wade, *Ruling in Favor of Stem Cell Research Draws Fire of 70 Lawmakers*, N.Y. TIMES (Feb. 17, 1999) <http://www.nytimes.com/1999/02/17/us/ruling-in-favor-of-stem-cell-research-draws-fire-of-70-lawmakers.html?ref=stemcells> (stating that members of the House of Representatives asked the Secretary of Health and Human Services to “rescind a ruling that Federal money may finance research on human embryonic stem cells”).

⁴⁵ Amy Jo Thomas, *Proponents Plea for Stem Cell Research*, ABC NEWS, <http://abcnews.go.com/Health/story?id=117967&page=1#.UUs9ozmzdUQ> (last visited Mar. 26, 2013).

⁴⁶ See Bush, *supra* note 37.

⁴⁷ See *Embryonic Stem Cell Research: An Ethical Dilemma*, EUROSTEMCELL, <http://www.eurostemcell.org/factsheet/embryonic-stem-cell-research-ethical-dilemma> (last updated Mar. 23, 2011).

⁴⁸ *Id.*

⁴⁹ *Id.*

⁵⁰ *Id.*

⁵¹ See *id.*

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does not possess any of the characteristics that are popularly associated with human beings, so unique characteristics of the embryo might be used to help those already developed persons live longer, healthier lives.⁵²

Another camp believes that a human embryo is a person at fourteen days after fertilization and contends that the human embryo should be protected from destruction at this time.⁵³ Those arguing in favor of this definition believe that after fourteen days the human embryo is stable and will begin to develop senses.⁵⁴ The opponents of this definition of personhood articulate many of the same arguments as those who oppose the view that a human embryo is a person at the moment it is fertilized, adding that it is arbitrary to define an embryo as a person just because it has begun to develop a nervous system.⁵⁵

A third camp defines personhood by placing the human embryo on a developmental continuum.⁵⁶ This camp believes that the human embryo deserves some protection at the moment it is fertilized, but as the embryo develops, it should be afforded more protection when it begins to take on those qualities that characterize humans.⁵⁷ This definition of personhood leaves room for the use of human embryonic stem cell research as it recognizes that a majority of all fertilized human embryos never actually develop into a human life.⁵⁸ Because of this, some human embryos can be used for stem cell research.⁵⁹ Those opposing this definition of personhood believe that it is too unclear—a human embryo should not be destroyed if there is uncertainty as to whether it is a human being.⁶⁰

⁵² *See id.*

⁵³ *Id.*

⁵⁴ *Id.*

⁵⁵ *See id.*

⁵⁶ *See id.*

⁵⁷ *Id.*

⁵⁸ *See id.*

⁵⁹ *Id.*

⁶⁰ *Id.*

The fourth camp argues that personhood begins when the fertilized human embryo can survive independently.⁶¹ This view of personhood is of the opinion that human embryos are property and should be given the respect that any other property should receive.⁶² Those arguing against this definition of personhood believe that even if a human embryo is not considered a person, the potential of the human embryo to develop into a person is prevented.⁶³

III. SHERLEY V. SEBELIUS

The U.S. District Court for the District of Columbia first heard *Sherley v. Sebelius* in October 2009.⁶⁴ The plaintiffs, Dr. James Sherley and Dr. Theresa Deisher were joined in the lawsuit by other organizations condemning the destruction of human embryos.⁶⁵ The plaintiffs claimed that HHS, the NIH, and the Director of the NIH had created guidelines that violated the Dickey-Wicker Amendment by illegally allowing federal funding to be used for research using human embryonic stem cells.⁶⁶ The plaintiffs sought to enjoin defendants from applying federal funding guidelines to human embryonic stem cell research.⁶⁷ However, the court dismissed the suit in October 2009, holding that the plaintiffs did not have standing.⁶⁸ The case was never heard on the merits.⁶⁹

⁶¹ *Id.*

⁶² *Id.*

⁶³ *See id.*

⁶⁴ *See Sherley v. Sebelius*, 686 F. Supp. 2d 1 (D.D.C. 2009).

⁶⁵ *See Sherley*, 686 F. Supp. 2d at 3. Some of the other organizations that were initial plaintiffs in the lawsuit were Nightlight Christian Adoptions, an agency that assists in the adoption of embryos; various Nightlight Christian Adoptions clients; the Christian Medical Association; and all human embryos fertilized via *in vitro* fertilization but not needed for reproduction. *Id.*

⁶⁶ *Id.*

⁶⁷ *Id.*

⁶⁸ *Id.* at 7.

⁶⁹ *See id.* at 7 (holding that “the court finds that plaintiffs lack standing and will grant defendants’ Motion . . . to Dismiss”).

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The plaintiffs appealed to the U.S. Court of Appeals for the District of Columbia Circuit in June 2010.⁷⁰ There, the court found that Dr. Sherley and Dr. Deisher had standing and remanded the issue of the preliminary injunction to the district court.⁷¹ Upon remand, the district court upheld the preliminary injunction, and the NIH was forced to halt the application of federal funds to human embryonic stem cell research.⁷²

In April 2011, the Court of Appeals for the D.C. Circuit heard the appeal from the district court's 2010 decision.⁷³ The court reversed the injunction granted by the district court and gave deference to the NIH's 2009 guidelines.⁷⁴ The court then remanded the case to the district court, which granted summary judgment in favor of the NIH.⁷⁵ The district court followed the D.C. Circuit's decision by giving deference to the NIH guidelines.⁷⁶

Dr. Sherley and Dr. Deisher appealed again in *Sherley*,⁷⁷ and the Court of Appeals for the D.C. Circuit upheld the grant of summary judgment in favor of the NIH.⁷⁸ The three-judge panel wrote three different opinions but unanimously upheld the grant of summary judgment.⁷⁹ Judge Sentelle, the chief judge on the panel, wrote most strongly in favor of the NIH, rejecting the plaintiffs' arguments on the merits and stating that the panel was bound to the holding by the law-of-the-case doctrine.⁸⁰ Judge Henderson

⁷⁰ See *Sherley v. Sebelius*, 610 F.3d 69 (D.C. Cir. 2010).

⁷¹ *Id.* at 75.

⁷² See *Sherley v. Sebelius*, 704 F. Supp. 2d 63, 66 (D.D.C. 2010).

⁷³ See *Sherley v. Sebelius*, 644 F.3d 388 (D.C. Cir. 2011).

⁷⁴ *Id.* at 389–90.

⁷⁵ *Sherley v. Sebelius*, 776 F. Supp. 2d 1, 24–25 (D.D.C. 2011).

⁷⁶ See *id.* at 12.

⁷⁷ *Sherley v. Sebelius*, 689 F.3d 776 (D.C. Cir. 2012).

⁷⁸ *Id.* at 785.

⁷⁹ See *id.* The plaintiffs filed a petition for certiorari at the Supreme Court on October 10, 2012, but the petition was denied on January 7, 2013. *Sherley v. Sebelius*, 133 S. Ct. 847 (2013).

⁸⁰ *Sherley*, 689 F.3d at 780. The law-of-the-case doctrine requires that a reviewing court must apply the same law to a case that the trial court applied.

concurring, stating she also believes that the law-of-the-case doctrine requires that summary judgment be granted for the NIH, but that if not for the doctrine, she would have voted against the NIH.⁸¹ Judge Brown also concurred, stating that while she agreed with Judge Henderson in that *Chevron* was inapplicable to the case, the outcome of the case would be the same even if it were subject to de novo review because Congress has consistently interpreted the Dickey-Wicker Amendment as being inapplicable to human embryonic stem cell research.⁸²

IV. POSSIBLE PROBLEMS: IMPACT ON THE DISABLED POPULATION

In *Sherley*, Dr. Sherley and Dr. Deisher brought suit against the NIH partly because their personal views on the destruction of human embryonic stem cells led them to oppose the technique.⁸³ The NIH resisted because they believe that human embryonic stem cell research could provide huge benefits for society.⁸⁴ Although the disabled population would benefit from the advancement of science and the development of new treatments, the D.C. Circuit's decision in *Sherley* may have a uniquely negative effect on the disabled population. By permitting federal funding to be used for human embryonic stem cell research, the NIH may be able to advance rapidly in its ability to characterize genetic abnormalities in an individual's genome. This could create an expanded definition of the disabled individual in that any individual having a

Id. at 780–81. In this case, the district court applied *Chevron* in its initial hearing, so the D.C. Circuit had to continue to apply *Chevron*. *Id.* at 781.

⁸¹ *Id.* at 786 (Henderson, J., concurring). Judge Henderson wrote a dissent in *Sherley II*, stating that *Chevron* should not have been applied to the case, and that the 2009 NIH guidelines violate the plain meaning of the Dickey-Wicker Amendment. *Sherley v. Sebelius*, 644 F.3d 388, 399–406 (D.C. Cir. 2011) (Henderson, J., dissenting).

⁸² *Sherley*, 689 F.3d at 787 (Brown, J., concurring).

⁸³ See *supra* note 32 and accompanying text.

⁸⁴ Brief for Appellants at 6, *Sherley v. Sebelius*, 610 F.3d 69 (D.C. Cir. 2010) (No. 10-5287), 2010 U.S. D.C. Cir. Briefs LEXIS 44, at *47.

genetic mutation could be classified as disabled, even if the corresponding disease has not physically manifested.

The 2008 amendments to the Americans with Disabilities Act (“ADA”) make the development of the expanded definition of the disabled individual more probable.⁸⁵ The ADA puts forth three definitions of disability, with the first definition encompassing most individuals who are ultimately categorized as disabled under the law.⁸⁶ Under the ADA, the basic definition of a disability has been, and remains, “a physical or mental impairment that substantially limits one or more major life activities”⁸⁷ The Americans with Disabilities Act Amendment Act (“ADAAA”) broadened the definition of the disabled individual under the ADA such that those individuals who are impaired at a systemic or cellular level are covered.⁸⁸

As stated, each human being’s DNA has a large number of mutations, yet many people are unaffected by these mutations.⁸⁹ However, scientists have been able to identify a large number of genetic mutations that predispose individuals to certain conditions

⁸⁵ See Laurie A. Vasichek, *Genetic Discrimination in the Workplace: Lessons from the Past and Concerns for the Future*, 3 ST. LOUIS U. J. HEALTH L. & POL’Y 13, 28 (2009). Vasichek states:

[A job] applicant or employee today could argue that if he or she were discriminated against based on a genetic condition that the employer perceived the person as having an impairment. For example, a woman discharged for having a mutation on the BRCA1 or BRCA2 gene could argue that the employer perceived her as having a disorder that substantially affects a body system, and therefore, the employer regarded her as having a disability.

Id.

⁸⁶ See 42 U.S.C. § 12102(1) (Supp. III 2009).

⁸⁷ *Id.* § 12102(1)(A). The Act also defines a disability as an individual having “(B) a record of such an impairment; or (C) being regarded as having such an impairment.” *Id.* § 12102(1).

⁸⁸ Pub. L. No. 110-325, § 3(2)(B), 122 Stat. 3553, 3555 (2008) (codified at 42 U.S.C. § 12102(1)(3)(B) (Supp. II 2008)). The Act states that a major bodily function “includ[es,] but [is] not limited to, functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions.” *Id.*

⁸⁹ See *supra* note 9 and accompanying text.

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like cancer, diabetes, and cardiovascular problems.⁹⁰ Tools like homologous recombination that function by using human embryonic stem cells allow scientists to characterize such genetic mutations more precisely than older techniques and procedures that do not utilize the unique characteristics of human embryonic stem cells.⁹¹ Because the decision in *Sherley* will allow the NIH to use federal funding for human embryonic stem cell research, scientists may be able to rapidly characterize the genetic mutations that predispose humans to debilitating health conditions.⁹² Healthcare providers might allow individuals to be screened for these genetic mutations, and it is possible that those who possess unexpressed genetic mutations will be considered disabled simply because their DNA is abnormal in some way.⁹³

Courts applying the ADAAA have found that certain cancers, when active, are conditions covered by the ADA; furthermore, even when the cancers are in remission, they are covered by the ADA.⁹⁴ Courts have also found that the HIV-positive status of an

⁹⁰ See *supra* note 11 and accompanying text.

⁹¹ See Yu & Thomson, *supra* note 3.

⁹² See *id.*

⁹³ See Vasichek, *supra* note 85, at 28.

⁹⁴ See *Norton v. Assisted Living Concepts, Inc.*, 786 F. Supp. 2d 1173, 1185 (E.D. Tex. 2011); see also *Hoffman v. Carefirst of Fort Wayne, Inc.*, 737 F. Supp. 2d 976, 985 (N.D. Ind. 2010). The court stated:

[T]he court finds that renal cancer, when active, constitutes a “physical impairment” under the statute. Further, the court states that renal cancer, when active “substantially” limits the “major life activity” of “normal cell growth.” Therefore, that [Claimant] may have been in remission when he returned to work . . . is of no consequence. . . . [Claimant’s] renal cancer qualifies as a disability even if the only “major life activity” it “substantially limited” was “normal cell growth.”

Norton, 786 F. Supp. 2d at 1185 (citations omitted). The *Hoffman* court stated:

This Court is bound by the clear language of the ADAAA. Because it clearly provides that “an impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active,” and . . . Stage III Renal Cancer, when active, constitutes a disability, this Court must find that [Claimant] was “disabled” under the ADAAA. In other words, under the ADAAA, because [Claimant]

individual is enough for the individual to be protected under the ADA, despite the fact that the disease has not progressed to full-blown AIDS.⁹⁵ Because conditions like cancer and HIV are the result of mutations in an individual's genetic machinery, it seems that the changes to the ADA, as manifested in the ADAAA, have forced courts to acknowledge that some genetic mutations are disabling, even if the genetic mutations do not have physical effects on the individual. The step from categorizing some genetic mutations as disabling to categorizing all genetic mutations as disabling is not a large one.⁹⁶

Along with the possibility that an expanded pool of individuals will be considered disabled comes a possibility that increased discrimination will result.⁹⁷ Genetic abnormalities in DNA predisposing an individual to disabling health conditions, even if not physically manifested, could be construed as actual physical disabilities. Increased discrimination could result across the board, but discrimination in employment could be of particular concern.

had cancer in remission . . . [Claimant] does not need to show that he was substantially limited in a major life activity at the actual time of the alleged adverse employment action.

Hoffman, 737 F. Supp. 2d at 985.

⁹⁵ See *Horgan v. Simmons*, 704 F. Supp. 2d 814, 819 (N.D. Ill. 2010). The *Horgan* court adopts the same reasoning as the *Hoffman* court. See *id.* However, the *Horgan* court adds that certain impairments will be considered *per se* disabilities; that is, the impairments will “consistently meet the definition of disability.” *Id.* Also, the “individualized assessment of the limitations on a person can be conducted quickly and easily, and will consistently result in a determination that the person is substantially limited in a major life activity.” *Id.* (quoting Regulations to Implement the Equal Employment Provisions of the Americans with Disabilities Act, as Amended, 74 Fed. Reg. 48,431 (proposed Sept. 23, 2009) (to be codified at 29 C.F.R. pt. 1630)).

⁹⁶ See *Vasichek*, *supra* note 85, at 28. If one claimant's claim that his genetic mutation constituted a disability was found to be sufficient to state a claim, then it is possible that many other claimants will be permitted to make logically similar claims.

⁹⁷ See *Vasichek*, *supra* note 85, at 26–28. See also *infra* pp. 18–19 (explaining that the characterization of the sickle cell anemia trait led to discrimination).

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Indeed, an analogous event occurred in our country's past. The sickle cell anemia trait was the basis of discrimination in the middle of the twentieth century.⁹⁸ Soon after, Congress passed the National Sickle Cell Anemia Control Act in 1972, which contained the false statement that two million Americans suffered from the disease.⁹⁹ In truth, two million Americans carried the trait for the disease but were unaffected by it.¹⁰⁰ As a result of the false information written into the National Sickle Cell Anemia Control Act, the American Air Force Academy ("the Academy") prohibited the entry of those carrying the sickle cell anemia trait into the Academy.¹⁰¹ Commercial airlines soon adopted a similar policy, allowing sickle cell carriers to perform only tasks that kept them on the ground.¹⁰² These policies affected primarily African Americans, as the sickle cell trait can be found in the African American population at a higher frequency than in many other races.¹⁰³ Unfortunately, the policies resulted in decreased employment opportunities for African American individuals.¹⁰⁴

The clarification of the sickle cell trait was a huge victory for science and undoubtedly led to the development of methods for treatment¹⁰⁵ and diagnoses,¹⁰⁶ which ultimately benefitted society.

⁹⁸ RUSSELL, *supra* note 2, at 77.

⁹⁹ Galton & Ferns, *supra* note 1, at 230.

¹⁰⁰ *Id.*

¹⁰¹ *Id.*

¹⁰² *Id.*

¹⁰³ See U.S. Dep't of Energy, *Genetic Disease Profile: Sickle Cell Anemia*, HUM. GENOME PROJECT INFO., http://www.ornl.gov/sci/techresources/Human_Genome/posters/chromosome/sca.shtml (last updated May 5, 2005).

¹⁰⁴ James E. Bowman, *Anthropology: From Bones to the Human Genome*, ANNALS AM. ACAD. POL. & SOC. SCI., Mar. 2000, at 140, 144.

¹⁰⁵ See, e.g., Samuel Charache et al., *The Effect of Hydroxyurea on the Frequency of Painful Crises in Sickle Cell Anemia*, 332 NEW ENG. J. MED. 1317, 1321 (1995) ("Hydroxyurea is the first clinically acceptable drug shown to prevent painful crises in adults with sickle cell anemia . . ."); *A Brief History of Sickle Cell Disease*, HARVARD UNIV. INFO. CENTER FOR SICKLE CELL AND THALASSEMIC DISORDERS, http://sickle.bwh.harvard.edu/scd_history.html (last updated Apr. 10, 2002) (giving examples of many advancements that have been made in the treatment of sickle cell anemia since the gene's clarification).

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However, discovery of the sickle cell trait also came at a cost—numerous individuals were incorrectly labeled as disabled, and subsequently disenfranchised, on the basis of a genetic abnormality.¹⁰⁷

The decision in *Sherley* could have a similar result. An employer might mistakenly perceive an individual with a genetic abnormality that has no physical manifestations as disabled or at risk for becoming disabled, and the employer may refuse to hire the individual. Although the ADA was passed to prevent discrimination in employment, and the Genetic Information Nondiscrimination Act (“GINA”) was passed to prevent discrimination based on the genetic information of an individual,¹⁰⁸ the laws could fall short if the decision in *Sherley* leads to an expanded definition of the disabled individual.¹⁰⁹

¹⁰⁶ See *How Is Sickle Cell Anemia Diagnosed?*, NAT’L HEART, LUNG, AND BLOOD INST., <http://www.nhlbi.nih.gov/health/health-topics/topics/sca/diagnosis.html> (last updated Sept. 28, 2012) (stating that a “simple blood test” can show whether a newborn infant has sickle cell disease).

¹⁰⁷ Galton & Ferns, *supra* note 1, at 230.

¹⁰⁸ See Jessica L. Roberts, *Article: Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act*, 63 VAND. L. REV. 439, 441 (2010). GINA was passed after results of the Human Genome Project were released. *Id.* at 442. Scientists hoped that by clarifying the human genome, they would be able to better understand diseases like diabetes, heart disease, bipolar disorder, and other genetically linked health conditions. *Id.* at 442–43. For the purposes of this Recent Development, an individual covered by an expansive definition of disabled that may result after the decision in *Sherley* will be referred to as a “post-*Sherley* disabled individual” or “an individual falling into the post-*Sherley* definition of disabled.”

¹⁰⁹ See Vasichek, *supra* note 85, at 31–33. Vasichek states:

An entity covered by GINA does not violate the legislation if it obtains the genetic information inadvertently, if it obtains the information when an employee requests leave in accordance with the Family Medical Leave Act, if it obtains genetic information through public or commercial sources, or if it obtains genetic information through voluntary wellness programs provided by the employer.

Id. The exemptions in the statute, although narrow, could expose a post-*Sherley* individual to discrimination. Interview with Amy Flanary-Smith, Professor, Campbell Univ. Sch. of Law, in Raleigh, N.C. (Nov. 23, 2012).

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The ADA¹¹⁰ and GINA¹¹¹ should provide some protection against employment discrimination to those individuals falling into the expanded definition of disabled after *Sherley*, but, as will be shown, the legislation does not provide complete protection. This Part examines the scope of the coverage of Title I of the ADA and Titles I and II of GINA.

A. *Title I of the ADA*

The ADA is a body of civil rights legislation that Congress passed in order to eliminate disability-based discrimination.¹¹² Under Title I of the ADA, an individual is considered disabled, and will qualify for protection under the statute, if he meets one of three definitions as set out by the statute:

- A. a physical or mental impairment that substantially limits one or more major life activities of such individual;
- B. a record of such an impairment; or
- C. being regarded as having such an impairment¹¹³

Indeed, the Supreme Court has addressed the definition on multiple occasions throughout the last several decades.¹¹⁴

¹¹⁰ See Vasichcek, *supra* note 85, at 37 (“With the ADAAA, there is a colorable argument if someone is discriminated against because of the presence of a genetic condition, even if that condition is presenting only slightly, that the employer regarded the individual as having an impairment, thereby invoking ADA’s coverage.”).

¹¹¹ See *id.* at 28, 36 (stating that GINA prohibits the acquisition of genetic information by certain means and also prohibits an entity from discriminating based upon genetic information that it has obtained).

¹¹² 154 CONG. REC. S8344 (daily ed. Sept. 11, 2008) (statement of Sen. Tom Harkin).

¹¹³ 42 U.S.C. § 12102(1) (Supp. III 2009).

¹¹⁴ The Supreme Court has addressed the meaning of “substantially limits” in many cases over the last thirty years. See, e.g., *Toyota Motor Mfg., Ky., Inc. v. Williams*, 534 U.S. 184, 198 (2002) (holding that “to be substantially limited in performing manual tasks, an individual must have an impairment that prevents or severely restricts the individual from doing activities that are of central importance to most people’s daily lives”); *Sutton v. United Air Lines, Inc.*, 527 U.S. 471, 482 (1999) (“A ‘disability’ exists only where an impairment ‘substantially limits’ a major life activity, not where it ‘might,’ ‘could,’ or ‘would’ be substantially limiting if mitigating measures were not taken.”); Sch.

Because Title I of the ADA protects disabled individuals from discrimination in employment situations, a post-*Sherley* disabled individual facing discrimination in the workplace may attempt to seek protection under the third prong of the ADA—his employer may treat the individual’s genetic predisposition for disease or disability as an actual disability, which may result in discrimination.¹¹⁵ On its face, a post-*Sherley* disabled individual seems to qualify as disabled by falling into the third definition. However, the legislative history of the ADAAA indicates that Congress did not intend to protect those considered disabled due to abnormalities in their genetic makeup.¹¹⁶

Jurisprudence on the third prong, referred to as the “regarded as” prong, of Title I has changed dramatically over the years. In *Sutton v. United Air Lines*,¹¹⁷ a landmark case, the Supreme Court narrowed the application of the third prong.¹¹⁸ The Court held that in order to be considered disabled, an individual’s disability must be considered in its mitigated state.¹¹⁹ The Court’s holding meant that an individual did not have a disability under the ADA if his physical or mental impairment was corrected by treatment or other

Bd. of Nassau Cnty. v. Arline, 480 U.S. 273, 280 n.5 (1987) (stating that a physical or mental impairment is not considered a disability under the Rehabilitation Act, the predecessor to the ADA, unless the impairment is of such severity “that it results in a substantial limitation of one or more major life activities”).

¹¹⁵ See 42 U.S.C. § 12102(1); 42 U.S.C. 12112 § 12112 (2006 & Supp. III 2009).

¹¹⁶ Interview with Amy Flanary-Smith, *supra* note 109. See generally 154 CONG. REC. S8342-56 (daily ed. Sept. 11, 2008) (giving examples of impairments intended to be covered by the ADAAA, but not mentioning “genetics,” “DNA,” or “gene”).

¹¹⁷ 527 U.S. 471 (1999).

¹¹⁸ *Id.* at 475–76. In the case, two very near-sighted individuals applied to be pilots for a large commercial airline but were rejected *because* they did not meet the airline’s minimum requirements for uncorrected vision. *Id.* The Supreme Court found that because the claimants’ vision could be corrected by contact lenses or eyeglasses, they did not meet the definition of disability under the “regarded as” prong of the ADA. *Id.* at 476.

¹¹⁹ *Id.* at 487.

measures such that the impairment did not “substantially limit” any major life activity.¹²⁰ After *Sutton*, the claimant then had to prove that his impairment met a very high level of functional limitation.¹²¹ Thus, an amputee whose prosthetic allowed him to function with no substantial limitation,¹²² or an individual whose very poor hearing was corrected by a hearing aid, would not be considered disabled under the ADA and, therefore, would not receive any of the anti-discriminatory protections provided by the law.¹²³

However, Congress passed the ADAAA in 2008 in order to attempt to cure the Court’s narrowing of the “regarded as” prong and restore the broad protection that the ADA was meant to provide to disabled individuals.¹²⁴ The ADAAA required that an individual’s disability be examined in its unmitigated state.¹²⁵ A genetic mutation predisposing an individual to develop a particular disease, if not corrected, could be considered a disability.¹²⁶ A straightforward reading of the ADAAA indicates that the “regarded as” prong of Title I of the ADA might protect a post-*Sherley* disabled individual,¹²⁷ but, as will be shown, the legislative history of the ADAAA indicates otherwise. Because the ADAAA is a young statute, courts with high authority have not had occasion

¹²⁰ *Id.* at 483 (“To be sure, a person whose physical or mental impairment is corrected by mitigating measures still has an impairment, but if the impairment is corrected it does not ‘substantially limi[t]’ a major life activity.”).

¹²¹ See 154 CONG. REC. S8345 (daily ed. Sept. 11, 2008) (statement of Sen. Tom Harkin).

¹²² *Sutton*, 527 U.S. at 497 (Stevens, J., dissenting) (“With the aid of prostheses, coupled with courageous determination and physical therapy, many of these hardy individuals can perform all of their major life activities just as efficiently as an average couch potato.”).

¹²³ *Id.* at 498.

¹²⁴ See 154 CONG. REC. S8342 (daily ed. Sept. 11, 2008) (statement of Sen. Tom Harkin).

¹²⁵ See *id.* at S8345.

¹²⁶ See Vasichcek, *supra* note 85, at 37 (stating that an individual could argue, under the ADAAA, that he suffered discrimination due the presence of a genetic condition).

¹²⁷ See *id.*

to apply it extensively;¹²⁸ therefore, an examination of the legislative history is a good indicator of the ways in which the ADAAA could be practically applied.

Pointing to the *Sutton* line of cases, the Congressional Record indicates that the Supreme Court “impos[ed] a stricter standard for determining disability” that led lower courts to determine that many individuals did not meet the ADA’s definition of disabled.¹²⁹ Because of the strict standard, the definition of disability was narrowed, and those individuals with debilitating impairments “such as amputation, intellectual disabilities, epilepsy, multiple sclerosis, diabetes, muscular dystrophy, and cancer” were not protected by the ADA.¹³⁰ Because Congress felt that the Supreme Court had created a very strict legal standard “in which individuals must demonstrate an inappropriately high degree of functional limitation” to receive coverage under the ADA, the ADAAA’s purpose was to lower the degree of functional limitation that was required by the *Sutton* line of cases.¹³¹ Further, the ADAAA is intended to modify jurisprudence of the “regarded as” prong of the ADA such that individuals will not be subject to any kind of functional test and must only show that they were the subject of discrimination because of an “actual or perceived” impairment.¹³²

When the ADAAA’s legislative history is considered as a whole, the Congressional Record indicates that it was not the intent of the legislature to cover the post-*Sherley* disabled individual in passing the ADAAA. The category “genetic abnormalities” does

¹²⁸ Interview with Amy Flanary-Smith, *supra* note 109. Many recent cases raising issues under the ADAAA have resulted in statements of procedural, not substantive, law by the courts. *See, e.g.*, *Feldman v. Law Enforcement Assocs. Corp.*, 779 F. Supp. 2d 472, 483 (E.D.N.C. 2011); *Lawson v. Plantation Gen. Hosp., L.P.*, 704 F. Supp. 2d 1254, (S.D. Fla. 2010); *Dave v. Lanier*, 681 F. Supp. 2d 68, 72 (D.D.C. 2010) (finding that the ADAAA does not apply retroactively).

¹²⁹ 154 CONG. REC. S8345 (daily ed. Sept. 11, 2008) (statement of Sen. Tom Harkin).

¹³⁰ *Id.*

¹³¹ *Id.*

¹³² 154 CONG. REC. S8344 (daily ed. Sept. 11, 2008) (statements of Sen. Tom Harkin).

not appear on the list of impairments to which Congress states the ADAAA was intended to restore protection.¹³³ The list of impairments is likely not exhaustive, but, notably, only functional impairments are named.¹³⁴ This may indicate that Congress intended to restore coverage of the ADA to conditions that have at least some functional manifestation.¹³⁵ A post-*Sherley* disabled individual, by definition, will have no functional impairment unless and until his mutation manifests into a disease or disability, so it may be contrary to congressional intent to allow for a post-*Sherley* disabled individual to receive protection under the ADA.

Additionally, the legislative intent does not support protection of the post-*Sherley* disabled individual under “regarded as” prong of Title I of the ADA. As stated, a post-*Sherley* disabled individual will not suffer from any kind of functional impairment because his genetic mutation has not physically manifested itself.¹³⁶ It is not possible for a post-*Sherley* disabled individual to show that he was mistakenly perceived to have a physical impairment because he will, necessarily, have no physical impairment based on his genetic mutation.

B. *GINA*

In order to prevent acts of discrimination as a result of advancements in science, GINA was passed after the Human Genome Project was completed during a time in which researchers and scientists were hopeful that they would be able to find treatments for ailments with genetic origins.¹³⁷ Unlike most anti-

¹³³ *Id.* at S8345.

¹³⁴ *See id.* (stating that “amputation, intellectual disabilities, epilepsy, multiple sclerosis, diabetes, muscular dystrophy, and cancer” are impairments that the ADAAA is intended to cover).

¹³⁵ Interview with Amy Flanary-Smith, *supra* note 109.

¹³⁶ *See* Vasichек, *supra* note 85, at 37 (stating that an individual could argue, under the ADAAA, that he suffered discrimination due the presence of a genetic condition). The “individual” that Vasichек identifies is similar to the post-*Sherley* disabled individual in that Vasichек’s individual presents with the genetic condition only “slightly,” and the post-*Sherley* disabled individual simply possesses the genetic abnormality that codes for the disease. *Id.*

¹³⁷ Roberts, *supra* note 108, at 442.

discrimination legislation, which acts retrospectively, GINA acts prospectively, aiming to prevent discrimination before it occurs.¹³⁸

Titles I and II of GINA are most relevant to the post-*Sherley* disabled individual because they prohibit discrimination based on genetic information. Title I prohibits discrimination by health insurers against individuals seeking coverage, and Title II prohibits discrimination by employers against current or prospective employees.¹³⁹

In theory, a post-*Sherley* disabled individual would be protected by Titles I and II of GINA. Title I prohibits health insurance companies from using an individual's genetic information or his family's genetic information in making determinations on coverage, premiums, or eligibility.¹⁴⁰ So, for example, if a parent discovers that his child carries a gene that makes her more susceptible to developing breast cancer, Title I bars a health insurer from refusing to cover the man because his daughter carries the genetic abnormality.¹⁴¹ Similarly, if the man himself discovers that he carries a gene that makes him more prone to heart attacks at a young age, Title I bars the health insurance from dropping the man from his plan.¹⁴²

In prohibiting health insurers from denying coverage to an individual based on his genetic information, Title I may provide indirect protection to some post-*Sherley* individuals in the

¹³⁸ *Id.* at 457. Title VII of the Civil Rights Act, the Age Discrimination in Employment Act, the Rehabilitation Act, and the ADA were the major legislative protections against discrimination in employment. *Id.* at 440.

¹³⁹ *Id.* at 454. Title III deals less with genetic information discrimination: It states that if any part of GINA is held to be unconstitutional, it can be read out, and the remaining parts of the Act will remain in effect. *Id.*

¹⁴⁰ See Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, §§ 101-106, 122 Stat. 881, 888-905 (2008) (codified at 29 U.S.C. § 1182(b) (Supp. II 2008)).

¹⁴¹ See *id.*; see also *How Does GINA Impact ME?*, COALITION FOR GENETIC FAIRNESS, http://www.geneticfairness.org/ginaresource_impact.html#2 (click "Health Insurance" hyperlink under "Examples of Genetic Discrimination") (last updated Nov. 10, 2008).

¹⁴² See *How Does GINA Impact ME?*, *supra* note 141.

workplace.¹⁴³ The protection would be indirect because Title I actually protects employers who provide healthcare to their employees.¹⁴⁴ These employers would not be subject to higher premiums because of the protections that Title I offers, and they will be able to hire freely without worrying about the costs.¹⁴⁵

However, it is important to note that, although Title I does protect a post-*Sherley* disabled individual in theory, that does not mean that it will provide protection when applied. Many employers, especially those who are owners of small companies, may not understand the legislation, or they may not even know that the legislation exists. Thus, it is conceivable that a post-*Sherley* individual will still be subject to discrimination in employment.

Title II prohibits employers from purposefully acquiring information about an individual's genetic abnormalities to make discriminatory decisions regarding hiring, firing, promotion, conditions of employment, privileges of employment and compensation.¹⁴⁶ The law also aims to limit the manner in which an employer is able to obtain information regarding an individual's genetic abnormalities by barring the employer from requesting, requiring, or purchasing genetic information about a job-seeking individual, a job-holding individual, or a family member of the individual.¹⁴⁷

In theory, Title II would provide direct protection to a post-*Sherley* disabled individual. Here, a hypothetical is instructive. Bill, who works at the Widget Factory, gets his hand caught in a widget maker and suffers an injury. Because he cannot work, Bill stays home for the next month and files a worker's compensation claim. During a visit to the doctor to get treated for his injury, Bill learns that he suffers from a genetic condition that results in a reduction in hand-eye coordination; perhaps it was Bill's genetic condition, not the employer's negligence, which contributed to

¹⁴³ See Genetic Information Nondiscrimination Act § 102.

¹⁴⁴ *Id.*

¹⁴⁵ *Id.*

¹⁴⁶ See *id.* §§ 201–210 (codified at 42 U.S.C. § 2000(e)(3) (2009)).

¹⁴⁷ See *id.*

Bill's injury at the Widget Factory. When Bill returns to work, he discovers that since he filed a worker's compensation claim, his employer is requiring him to take a genetic test that would pick up on his condition in addition to any genetic abnormalities. Bill refuses to take the genetic test. Under Title II, Bill's employer is prohibited from firing him due to the refusal to take the test.¹⁴⁸

Unfortunately, Title II does not prohibit an employer's "incidental acquisition of genetic information."¹⁴⁹ One method of acquiring information in this way is colloquially called "the water cooler problem" and is relatively common in the workplace.¹⁵⁰ The problem occurs when an employee accidentally reveals genetic information to the employer in a casual conversation.¹⁵¹ For instance, the employee might tell the employer that all of the women on her mother's side of the family suffered from breast cancer. Under Title II, if an employer accidentally learns that one of his employees or job candidates has a particular genetic abnormality, the employer need not be blind to the information and may use the information to make employment decisions.¹⁵²

Additionally, Title II provides no protection to the genetic information of individuals inadvertently acquired through an employer's "purchas[e] of commercially available documents" that reveal the medical history of an employee's family.¹⁵³ So, if an employer stumbles upon an obituary of a relative of an employee that reveals that the individual died of complications due to Type I diabetes, then the employer can use the information in making decisions in employment.

Title II of GINA will provide some protection to a post-*Sherley* disabled individual, but the legislation falls short. Although Title II will prohibit employers from asking a post-*Sherley* disabled

¹⁴⁸ *Id.* § 202(b).

¹⁴⁹ Roberts, *supra* note 108, at 456.

¹⁵⁰ *Id.*

¹⁵¹ *Id.*

¹⁵² Genetic Information Nondiscrimination Act §§ 202(b), 203(b), 205(b).

¹⁵³ Genetic Information Nondiscrimination Act §§ 202(b)(4), 203(b)(4), 205(b)(4).

individual for information about his genetic abnormality, the employer could purposefully look for information about the individual in public documents like newspaper obituaries, or the employer could subtly ask around about an individual's genetic health triggering the "water cooler problem." The employer could then make employment decisions based on whatever information he finds. Because the employer's tactic in these sorts of situations would be considered incidental acquisition of genetic information, Title II would not provide complete protection to the post-*Sherley* disabled individual.

V. POSSIBLE RESOLUTION: THE FUTURE OF THE POST-SHERLEY INDIVIDUAL

As indicated, current legislation may not adequately address the unique issues that would face the post-*Sherley* individual in seeking employment.¹⁵⁴ Because the ADA already aims to protect the disabled population, it may be that Congress' best course of action is to modify this legislation so that the post-*Sherley* disabled individual would be protected. Although the post-*Sherley* class of individuals has not yet been developed, the intersex population serves as a ready analogy.¹⁵⁵ If this group can become a class protected by the ADA, then the post-*Sherley* disabled individual will also have a strong argument for becoming a protected class.

Intersex describes a group of conditions in which an individual has a "discrepancy between the external genitals and the internal genitals."¹⁵⁶ Historically, individuals suffering from this condition were termed "hermaphrodites."¹⁵⁷ One specific intersex condition called "complex or undetermined intersex disorders of sexual development" occurs when an individual has one of several abnormal sex chromosome configurations.¹⁵⁸ Many intersex

¹⁵⁴ See *supra* Part IV.

¹⁵⁵ See *supra* Part IV.

¹⁵⁶ *A.D.A.M. Medical Encyclopedia: Intersex*, PUBMED HEALTH, <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002634/> (last updated Aug. 2, 2011).

¹⁵⁷ See *id.*

¹⁵⁸ *Id.* Some intersex individuals suffering from this condition have only one X chromosome, an XXY configuration, or an XXX configuration. *Id.*

individuals do not have any functional impairment—their only abnormality may be in their appearance.¹⁵⁹ The similarity of the intersex population to the post-*Sherley* disabled individual is clear—both have abnormal genetics but no outwardly visible physical impairment.¹⁶⁰ Employers should be prohibited from discovering the genetic predispositions of both a post-*Sherley* disabled individual and an intersex individual.

Currently, the intersex population is not protected by any of the federal legislation that prohibits discrimination in employment,

¹⁵⁹ See Yamuna Menon, Note, *The Intersex Community and the Americans with Disabilities Act*, 43 CONN. L. REV 1221, 1228 (2011). Individuals with an XXY chromosomal configuration suffer from Klinefelter’s Syndrome. See *id.* at 1231. Only men suffer from Klinefelter’s, and the most common symptom is infertility. *A.D.A.M. Medical Encyclopedia: Klinefelter Syndrome*, PUBMED HEALTH, <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001420> (last updated Nov. 2, 2012). Indeed, most men do not even know that they have the condition until they go to a physician for issues with infertility. *Id.* Men with Klinefelter’s may or may not have cognitive and physical symptoms—the degree of functionality varies between individuals. See *Klinefelter’s Syndrome*, MEDLINEPLUS, <http://www.nlm.nih.gov/medlineplus/klinefelterssyndrome.html> (last updated Mar. 1, 2013). Intersex individuals also may suffer from congenital adrenal hyperplasia (“CAH”), which causes the individual to have abnormal genitalia. *Congenital Adrenal Hyperplasia*, PUBMED HEALTH, <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001448> (last updated May 8, 2012). These individuals may or may not have physical impairments. *Id.* Complete androgen insensitivity syndrome (“CAIS”) may also cause an individual to develop an intersex condition. *A.D.A.M. Medical Encyclopedia: Androgen Insensitivity Syndrome*, PUBMED HEALTH, <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002163> (last updated July 19, 2012). An individual with CAIS has mismatched genitalia, but no cognitive physical dysfunction and no physical dysfunction besides infertility. *Id.* Women suffer from Triple X syndrome, in which they have an extra X chromosome. *Triple X Syndrome*, GENETICS HOME REFERENCE, <http://ghr.nlm.nih.gov/condition/triple-x-syndrome> (last visited Mar. 29, 2013). Interestingly, this condition does not cause the individual to have unusual physical features, and like men suffering from Klinefelter’s, a woman suffering from Triple X may have cognitive and/or physical impairments, but the manifestation of the abnormality varies widely. *Id.*

¹⁶⁰ See *supra* note 159 and accompanying text.

housing, or public accommodations.¹⁶¹ Many municipalities have prohibited discrimination against the intersex population on civil rights grounds, but this protection is inadequate.¹⁶² Transsexuals, homosexuals, bisexuals, and transgender individuals are explicitly excluded from protection by the ADA,¹⁶³ but the intersex community makes no appearance in the ADA at all.¹⁶⁴

The intersex community could argue that it should be protected by the ADA under the “regarded as” prong of Title I.¹⁶⁵ It is possible for an intersex individual to have no significant functional impairment at all, so the community should be protected from employment discrimination based on prejudice or ignorance.¹⁶⁶ Indeed, the “regarded as” prong of Title I of the ADA was meant to prevent discrimination against the disabled based on stereotypes and ignorance.¹⁶⁷ The Supreme Court has stated that the prong is critical in protecting individuals who are capable of performing on the job from discrimination due to “prejudiced attitudes or the ignorance of others.”¹⁶⁸ Even if an intersex individual has no functional impairment, he could easily be the target of discriminatory action based on an employer’s fear or ignorance of intersex conditions.¹⁶⁹ An intersex individual’s genetic abnormality may confer no reduced functionality in the workplace,¹⁷⁰ so he should be protected from discrimination.

¹⁶¹ *What Is the Legal Standing of Intersexuality?*, INTERSEX SOC’Y OF N. AM., <http://www.isna.org/node/128> (last visited Mar. 29, 2013).

¹⁶² *See id.* The same municipalities that protect the intersex population from discrimination also provide that transgender and transsexuals should be protected from discrimination. *See id.*

¹⁶³ 42 U.S.C. § 12211 (2006).

¹⁶⁴ Menon, *supra* note 159, at 1236.

¹⁶⁵ *See id.* at 1241–42.

¹⁶⁶ *See id.* at 1241.

¹⁶⁷ *Id.*

¹⁶⁸ *Id.* (quoting *Sch. Bd. of Nassau Cnty. v. Arline*, 480 U.S. 273, 284 (1987)).

¹⁶⁹ *Id.* at 1243 (“[M]any in society are extremely uncomfortable with the notion that an individual may be neither male nor female This can emanate in a variety of contexts similar to the different forms of disability discrimination: employment, transportation, education, and public accommodations.”).

¹⁷⁰ *See supra* note 159 and accompanying text.

A post-*Sherley* disabled individual could easily benefit if the intersex community wins its fight and receives coverage under the ADA. A post-*Sherley* disabled individual could follow the argument of the intersex community and state that his genetic predisposition for a disease that has not yet manifested makes him no less able to perform employment duties. GINA would then provide protection to the employer by barring a health insurance provider from charging higher premiums based on the post-*Sherley* disabled individual's genetic makeup. However, as discussed above, the legislative intent of the ADA does not seem to cover genetic abnormalities, so extending protection to the intersex community and to the post-*Sherley* individual would probably require legislative or judicial action.¹⁷¹

VI. CONCLUSION

The decision in *Sherley v. Sebelius* is very important to the scientific community. Federally funded human embryonic stem cell research could benefit our society immensely. Researchers may be able to discover treatments for diseases and disabilities that have haunted humans throughout history. However, the decision is not just a victory for the scientific community and a loss for the pro-life community. It is important to consider the effect the decision would have on the current disabled community.

It is true that the decision in *Sherley* does not mandate the result described. If a post-*Sherley* definition of the disabled individual were to result and healthy individuals who simply have a genetic predisposition to particular diseases or disabilities are lumped into a wider definition of disabled, Congress and the courts would be tasked with coming up with solutions to many issues. Current anti-discrimination legislation designed to protect the disabled and legislation designed to protect the genetic information of individuals would not provide sufficient protection to a post-

¹⁷¹ See *supra* Part IV. Since the ADAAA and GINA do not provide complete protection to the post-*Sherley* disabled individual, Congress could amend the laws to extend protection to the individual or it could pass new legislation to do so.

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Sherley disabled individual. Although *Sherley* may pose many difficult questions for Congress and the courts to answer, perhaps the post-*Sherley* disabled individual could find the beginnings of a resolution to the problem of discrimination by joining with the intersex community to seek protection under the ADA.