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The Intersex Community and the Americans with Disabilities Act Note

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Note

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Members of the intersex community have largely been absent from the civil rights legal discourse and do not constitute a protected class. Consequently, such individuals often face varying levels of discrimination such as stereotyping, medicalizing, pathologizing, and societal misunderstandings. With the passage of the ADA Amendments Act of 2008, Congress significantly expanded the statute. Under the amendments, more people qualify as individuals with disabilities protected by federal disability law, prompting the question of how federal disability law may be a source of protection for intersex individuals. This Note explores the recently amended Americans with Disabilities Act [ADA] and addresses whether intersex individuals can be considered qualified individuals with a disability under the ADA. Examining the components of the statute as well as the recent amendments, this Note also discusses whether federal disability law may be an optimal avenue for advancing the sociopolitical rights and public perceptions of the intersex community. This Note presents arguments supporting and opposing the application of the ADA to protect intersex individuals in such areas as housing, employment, and public accommodation. It also examines the merits of applying the ADA to intersex individuals through an examination of analogous arguments made with respect to state disability laws used to advance transgender rights. Ultimately, this Note explores how the ADA may be the only possible source of protection for an often hidden and forgotten community in immediate need of these protections.

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THE INTERSEX COMMUNITY AND THE AMERICANS WITH DISABILITIES ACT

YAMUNA MENON*

I. INTRODUCTION

When questions concerning the intersex community and associated conditions[1] arose in worldwide media with the story of nineteen-year-old South African middle-distance sprinter Caster Semenya in the fall of 2009,[2] they brought to the forefront issues relating to the legal status of intersex individuals and the sociopolitical rights of persons with ambiguous genitalia in the United States.[3] In a recent Miami conference of international sports officials discussing the merits of sex verification testing[4] in international athletic competition,[5] officials confirmed that questions relating to gender ambiguous athletes should be handled as a "medical" issue[6] and they sought to propose alternatives to the testing scheme to prevent their primary concern of gender fraud.[7] The conference also raised concerns around the use of appropriate terminology to frame the public discourse: officials proposed the use of "disorders of sex[ual] development" ("DSD")[8] over "intersex."

The medicalization[9] of intersex issues and the more recent references

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[1] *See What Is Intersex?*, INTERSEX SOC'Y OF N. AM., http://www.isna.org/faq/what_is_intersex (last visited Jan. 10, 2011) (defining intersex as a mixed biological composition of male and female). While the homepage for the organization indicates its defunct status, the website provides current and frequently cited information about the intersex community. *See* INTERSEX SOC'Y OF N. AM., http://www.isna.org (last visited Jan. 10, 2011) [hereinafter INTERSEX SOC'Y].

[2] *Caster Semenya Biography*, INT'L ASS'N OF ATHLETICS FED'NS, http://www.iaaf.org/athletes/biographies/letter=0/athcode=242560/index.html (last visited Jan. 10, 2011).

[3] This Note will use "intersex" and "individual with ambiguous genitalia" interchangeably.

[4] Meg Handley, *The IOC Grapples with Olympic Sex Testing*, TIME (Feb. 11, 2010), http://www.time.com/time/specials/packages/article/0,28804,1963484_1963490_1963333,00.html.

[5] Ian O'Reilly, *Gender Testing in Sport: A Case for Treatment?*, BBC NEWS (Feb. 15, 2010), http://news.bbc.co.uk/2/hi/8511176.stm.

[6] *See id.* (describing the Medical Commissioner's comment that athletes with DSD be "further investigated and treated"). This will also later be referred to as the "medicalization" of intersex issues.

[7] *See id.* (describing gender fraud as "a man masquerading as a woman").

[8] Handley, *supra* note 4.

[9] "Medicalization" within the context of disability law refers to medical professionals' desires to handle issues around a particular community as that of a medical issue rather than a sociopolitical or cultural issue. *See* Sharon M. McGowan, *Working with Clients To Develop Compatible Visions of What It Means To "Win" a Case: Reflections on* Schroer v. Billington, 45 HARV. C.R.-C.L. L. REV. 205, 220 (2010).

to intersex persons as individuals with DSD suggest that members of the intersex community[10] may be qualified individuals with disabilities under the Americans with Disabilities Act ("ADA").[11] While the ADA explicitly proscribes transgender legal disability protections, a critical statutory ambiguity may lend itself to a broader interpretation encompassing intersex disability protections.[12] As the current American legal system does not provide any protected legal status to intersex persons,[13] one option may be to find such protections under current disability law.[14] Some scholars already advocate the application of state disability law to advance transgender legal protections,[15] and examining this proposal may be a useful model when initiating the discourse on intersex disability protections. Consequently, a critical question is whether the same legal analysis is transferable to intersex disability rights. The more pressing question, however, may be whether the use of federal disability law is the optimal legal strategy for enhancing the rights of the intersex community in the United States.

Previous examinations have promoted the use of transgender rights under state disability law.[16] Other discourse has explained how the ADA's exclusions of homosexuality, bisexuality, transgenderism, and transsexuality may reflect a moral code followed by some segments of society.[17] This Note will explore the pursuit of protections for intersex individuals under the ADA. It will examine how applying the ADA as a civil rights statute within this context may be beneficial or detrimental to elevating the sociopolitical status and human rights of intersex persons in society. This Note will also present how the use of the ADA to protect the intersex community may become a double-edged sword, as the use of the ADA may bring needed protections but at the cost of a new set of social stigmas and perceptions. This Note asserts that, despite such a drawback and until another viable option exists and society supports the expansion of intersex rights, the intersex community's only option may be the ADA.

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[10] *See* AM. PSYCHIATRIC ASS'N, DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS TEXT REVISION 582 (4th ed. 2000) (including the category of intersex and specific conditions, but without providing a definition).

[11] Americans with Disabilities Act Amendments Act ("ADAAA"), P.A. 110-325 (2008) (codified at 42 U.S.C. § 12,101 (2006 & Supp. 2009)). Any reference hereinafter to the ADA refers to the version as amended by the ADAAA.

[12] Ann C. McGinley, *Erasing Boundaries: Masculinities, Sexual Minorities, and Employment Discrimination*, 43 U. MICH. J.L. REFORM 713, 768 (2010) ("While the ADA expressly excludes transgender persons from the definition of disability, it makes no exclusion for intersex individuals.").

[13] 42 U.S.C. § 12,102 (2006 & Supp. 2009).

[14] The same may be true of state disability law, but will not be discussed as this is outside the scope of this Note.

[15] *See* Jennifer L. Levi & Bennett H. Klein, *Pursuing Protection for Transgender People Through Disability Laws*, *in* TRANSGENDER RIGHTS 74, 75 (Paisley Currah et al. eds., 2006).

[16] *See* McGowan, *supra* note 9, at 219–21.

[17] Adrienne L. Hiegel, *Sexual Exclusions: The Americans with Disabilities Act as a Moral Code*, 94 COLUM. L. REV. 1451, 1490–91 (1994).

Part II defines the societal *gender* and *sex* distinction and shows how this becomes part of the larger discussion of intersex inclusion in the disabled community. It also defines the intersex community and societal understandings of intersex identities and bodies. Part III examines the intersex community and details the current legal landscape pertaining to intersex persons in the United States. Part IV discusses the ADA in the context of recent changes to the Act enacted in January 2009. Part V reviews the ADA from the perspective of intersex protections and charts the statutory provisions under which intersex persons may be able to find protections. Part VI frames the potential benefits and disadvantages of using the ADA to advance the civil and human rights of intersex persons. Finally, Part VII proposes possible solutions to protect the intersex community and demonstrates the ways in which the law should accomplish such protection. It also examines the ADA's function as a fundamental political and civil rights tool for a community in deep need of understanding, recognition, humane treatment, and equal rights.

II. THE GENDER DICHOTOMOUS CONSTRUCT AND THE INTERSEX CONDITION

A. *The Gender Dichotomous Construct and Binary System*

Distinguishing between sex and gender is critical to understanding how intersex bodies are culturally and socially understood.[18] While some argue that there is no distinction between sex and gender,[19] "sex" is generally understood as biologically determined.[20] Typically, an individual's sex constitutes the body's chromosomal, hormonal, and reproductive makeup, with a heavy reliance on "what one finds between the legs."[21] While not the most sophisticated definition, people can rely on its simplicity—and have done so—to determine sex as male or female. Notably, the chromosomal analysis did not always define sex and gender distinctions; a

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[18] The U.S. legal system traditionally defines "sex" as strictly male and female for suspect classification under the Equal Protection Clause of the Fourteenth Amendment. The Supreme Court has also addressed the immutability of sex. *See* Frontiero v. Richardson, 411 U.S. 677, 686 (1973) (stating that "sex, like race and national origin, is an immutable characteristic determined solely by the accident of birth").

[19] *See, e.g.*, Dylan Vade, *Expanding Gender and Expanding the Law: Toward a Social and Legal Conceptualization of Gender That Is More Inclusive of Transgender People*, 11 MICH. J. GENDER & L. 253, 262–63 (2005) (denying the existence of a distinction between sex and gender).

[20] Laura Hermer, *Paradigms Revised: Intersex Children, Bioethics & the Law*, 11 ANNALS HEALTH L. 195, 200 (2002); *see also* Jill Pilgrim et al., *Far from the Finish Line: Transsexualism and Athletic Competition*, 13 FORDHAM INTELL. PROP. MEDIA & ENT. L.J. 495, 497–99 (defining sex and gender as distinct concepts). *But see* WOMEN AND SPORTS IN THE UNITED STATES: A DOCUMENTARY READER 101 (Jean O'Reilly & Susan K. Cahn eds., 2007) ("Many scientists claim that there is no such thing as a clear-cut definition that separates biological females from males, arguing that sex is socially determined, much as gender is . . . .").

[21] Hermer, *supra* note 20, at 200.

visual body inspection was the traditional test for sex.[22] Chromosomal analysis is currently used to determine sex, despite the fact that people can have a different chromosomal makeup than traditionally associated with their sex, while visually exhibiting their gender.[23]

The societal understanding of gender, on the other hand, generally does not refer to biological or chromosomal composition,[24] but to the cultural or societal attitudes toward the characteristics of the male and female sex.[25] People exhibiting characteristics associated with men are considered to be "masculine," whereas those who exhibit characteristics associated with women are considered "feminine."[26] Normative standards support the notion that men are virile, strong, assertive, macho, and rational, while women are understood as weak, passive, quiescent, and emotional.[27]

B. *Impact on the Intersex Community*

The traditional definitions of gender and sex yield a strict binary system[28] in Western culture upon which society relies to categorize various components of life: for example, forms of identification, schools, prisons, sports teams, employment, child custody, and bathrooms. Biologist Dr. Anne Fausto-Sterling's provocative essay, *The Five Sexes*, highlights the complexities of the binary system:

> Western culture is deeply committed to the idea that there are only two sexes. Even language refuses other possibilities; thus to write about [an intersex individual] I have had to invent conventions—*s/he* and *his/her*—to denote someone who is clearly neither male nor female or who is perhaps both sexes at once. Legally, too, every adult is either man or woman, and the difference, of course, is not trivial.[29]

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[22] *Id.*

[23] For example, a person may have the physical gender presentation as a man (i.e., wear male clothing and have facial hair), but have a female chromosomal makeup, or a person may be physically male and may not be questioned for competition, but may have the karyotype of a female.

[24] Hermer, *supra* note 20, at 200. This understanding becomes more complex within the context of the United States legal system, however, as federal and Supreme Court cases use the terms "sex" and "gender" interchangeably. *See, e.g.*, Price Waterhouse v. Hopkins, 490 U.S. 228, 235 (1989) (conflating sex and gender and demonstrating the problem of Title VII's "sex" discrimination language while often contextualizing sex discrimination claims using gender norms and stereotypes).

[25] Julie A. Greenberg, *Defining Male and Female: Intersexuality and the Collision Between Law and Biology*, 41 ARIZ. L. REV. 265, 274–75 (1999).

[26] *Id.* at 274.

[27] *Id.* at 274 n.41.

[28] This Note will use the terms "binary," "gender binary," "gender binary construct," and "dichotomous construct" interchangeably.

[29] Anne Fausto-Sterling, *The Fives Sexes: Why Male and Female Are Not Enough*, SCIENCES, Mar.–Apr. 1993, at 20, 20.

Thus, while some consider sex and gender to be distinct, others conflate the terms. This can confuse societal and legal understandings of the intersex community. For example, U.S. law provides legal statuses only for men and women under the gender binary,[30] whereas many members of the intersex community fall somewhere in between the rigid categories. As humans can be born with chromosomal, hormonal, and genital combinations of the male *and* female sexes, "fitting" individuals within the male-female dichotomous construct, as well as within the legal system, becomes particularly difficult.[31]

III. THE INTERSEX COMMUNITY AND INTERSEX LEGAL STATUS

A. *Intersex Conditions*

While the prevalence of intersex individuals within the general population is difficult to ascertain for a variety of reasons,[32] an estimated one in two thousand people exhibits some form of an intersex condition.[33] Dr. Fausto-Sterling estimates that the rate is closer to two percent,[34] while another estimate is about four percent.[35] Some of the numerical disparities can be attributed to forms of reporting, particularly as some intersex individuals are unaware of their condition and do not self-identify.[36] Additionally, as there is much disagreement on the definition of "intersex," different definitions are used in varying contexts, giving rise to various statistics.[37]

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[30] *See* MORGAN HOLMES, INTERSEX: A PERILOUS DIFFERENCE 66 (2008) (stating that "for all practical, legal, and social purposes there *are* in fact only two sexes").

[31] Fausto-Sterling, *supra* note 29, at 21. There are a number of scholars who reject the binary system, one of whom has proposed an alternative. *See id.* (introducing five sexes in which three categories of intersex are included).

[32] This is partly due to the refusal to come forward as intersex, ignorance regarding one's own condition, and the medical community's previous tendencies to hide the condition. Previous scholars have subsequently described the difficulties in finding accurate numbers. *See* Greenberg, *supra* note 25, at 268 n.9 (noting that "the exact frequency of intersexuality" can be difficult to determine as some conditions are not apparent at birth and most people are reluctant to come forward with such information); Patricia L. Martin, *Moving Toward an International Standard in Informed Consent: The Impact of Intersexuality and the Internet on the Standard of Care*, 9 DUKE J. GENDER L. & POL'Y 135, 142–43 (2002) (describing the potential futility of using statistical analysis to determine an individual's sex or gender).

[33] ARLENE LEV, TRANSGENDER EMERGENCE: THERAPEUTIC GUIDELINES FOR WORKING WITH GENDER-VARIANT PEOPLE AND THEIR FAMILIES 353 (2004); Annette Brömdal, Intersex—A Challenge for Human Rights and Citizenship Rights 21 (Spring 2006) (unpublished Master's Thesis, Södertörn University College) (copy on file with *Connecticut Law Review*); *Frequently Asked Questions*, ADVOCATES FOR INFORMED CHOICE, http://www.aiclegal.org/faq/ (last visited Jan. 10, 2011); *see also* Sharon E. Preves, *Out of the O.R. and Into the Streets: Exploring the Impact of Intersex Media Activism*, 12 CARDOZO J.L. & GENDER 247, 247 (2005) (noting that "approximately one or two in every 2000 infants" is born intersex).

[34] ANNE FAUSTO-STERLING, SEXING THE BODY 51–53 (2000).

[35] Greenberg, *supra* note 25, at 268.

[36] INTERSEX SOC'Y, *supra* note 1.

[37] *See How Common Is Intersex?*, INTERSEX SOC'Y OF N. AM., http://www.isna.org/faq/frequency

The Intersex Society of North America ("ISNA") defines intersex as follows:

> "Intersex" is a general term used for a variety of conditions in which a person is born with a reproductive or sexual anatomy that doesn't seem to fit the typical definitions of female or male. For example, a person might be born appearing to be female on the outside, but having mostly male-typical anatomy on the inside. Or a person may be born with genitals that seem to be in-between the usual male and female types . . . .
>
> Though we speak of intersex as an inborn condition, intersex anatomy doesn't always show up at birth. Sometimes a person isn't found to have intersex anatomy until she or he reaches the age of puberty, or finds himself an infertile adult, or dies of old age and is autopsied. Some people live and die with intersex anatomy without anyone (including themselves) ever knowing.[38]

"Intersex" refers to the "physical and/or chromosomal" set of conditions in which the features that are socially understood as either male or female "are combined in a single body."[39] Some factors that are considered include:

> chromosomal sex, gonadal sex, fetal hormonal sex (prenatal hormones produced by the gonads), internal morphologic sex (internal genitalia, i.e., ovaries, uterus, testes), external morphological sex (external genitalia, i.e., penis, clitoris, vulva), hypothalamic sex (i.e., sexual differentiations in brain development and structure), sex of assignment and rearing, [and] pubertal hormonal sex.[40]

With respect to language and word choice, "intersex" was not always the term used to describe the community. There have been a number of terminological changes over time, particularly as societal attitudes shifted and the medical community's perspective further developed. Beginning with "hermaphrodite," the language moved to "intersex,"[41] and some

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(last visited Jan. 10, 2011) (charting the types of conditions and average frequency per condition).

[38] *What Is Intersex?*, INTERSEX SOC'Y OF N. AM., http://www.aiclegal.org/faq/what_is_intersex (last visited Jan. 10, 2011).

[39] HOLMES, *supra* note 30, at 32.

[40] McGowan, *supra* note 9, at 234. Another phrase used to refer to an individual's psychological sex is "gender identity." *Id*.

[41] *See, e.g.*, Fausto-Sterling, *supra* note 29, at 31 n.* (noting that members of the present-day intersex movement "eschew" the use of the term "hermaphrodite" and prefer "intersex").

researchers indicate that there may be future changes.[42] "Hermaphrodite" originates from the Greek mythological story of Hermaphroditus, the androgynous offspring of Aphrodite and Hermes.[43] The term was first used to describe members of the intersex community between A.D. 23 and 79.[44] During the late nineteenth and early twentieth centuries, studies of intersex conditions rose in parts of England.[45] Over time, "hermaphrodite" became negatively associated with "chicks with dicks pornography, circus sideshows, and spectacles."[46] To avoid the negative connotations associated with "hermaphrodite,"[47] people shifted to "intersex" and its synonym, "genital ambiguity."[48] Some advocate labeling intersex conditions as "DSD" or "VSD," standing for "disorders of sex[ual] development," "differences of sex development,"[49] or "variation of sex[ual] development."[50] This latter shift may lend itself to looking at intersex conditions in a way that engages federal disability protections.[51]

Dr. Alice Domurat Dreger offers three primary categories to describe the current medical intersex discourse: male pseudohermaphroditism, female pseudohermaphroditism, and true pseudohermaphroditism.[52] Under these categories, if an "ambiguous" individual has testicular tissue only, the person is a male pseudohermaphrodite; if ovarian tissue only, a female pseudohermaphrodite; and if one or more ovotestis,[53] a true hermaphrodite.[54] Some of the most common types of intersex conditions include complete androgen insensitivity syndrome ("CAIS"), partial androgen insensitivity syndrome ("PAIS"), congenital adrenal hyperplasia ("CAH"), Klinefelter Syndrome, and Turner Syndrome.[55]

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[42] *See* Brömdal, *supra* note 33, at 54–55 (noting that some advocate for a change in terminology for the intersex community).

[43] *See* GERALD N. CALLAHAN, BETWEEN XX AND XY: INTERSEXUALITY AND THE MYTH OF TWO SEXES 25–27 (2009) (detailing the Greek mythological story of Hermaphroditus and the subsequent use of "hermaphrodite").

[44] *Id.* at 27.

[45] *See* ALICE DOMURAT DREGER, HERMAPHRODITES AND THE MEDICAL INVENTION OF SEX 21–30 (1998) (referring to the period as the "Age of Gonads" and describing the medical studies and analyses during the Victorian era in England and France).

[46] HOLMES, *supra* note 30, at 32.

[47] *Id.*; LEV, *supra* note 33, at 355 (describing the intersex community's reluctance to use the word).

[48] HOLMES, *supra* note 30, at 32.

[49] *Frequently Asked Questions*, ADVOCATES FOR INFORMED CHOICE, http://www.aiclegal.org/faq/ (last visited Jan. 10, 2011).

[50] Brömdal, *supra* note 33, at 54–55.

[51] *See infra* Part V (applying the ADA to find federal disability protections for the intersex community).

[52] DREGER, *supra* note 45, at 36.

[53] *See id.* (referring to "ovotestis" as "an organ with both ovarian and testicular attributes").

[54] *Id.* As true pseudohermaphroditism is considered "extremely rare," and as this section is intended to provide a basic survey of intersex conditions, only the more common intersex conditions will be discussed here. *See id.* at 37 (explaining true pseudohermaphroditism as a rare and less understood intersex condition).

[55] LEV, *supra* note 33, at 387–88. While this is not a comprehensive list, and does not purport to

CAIS and PAIS are genetic syndromes "in which the internal reproductive organs differ from the person's chromosomal sex due to an X chromosome defect."[56] The fetus develops testes but is unable to respond to androgens and the genitals differentiate into the female rather than the male pattern.[57] In PAIS, for instance, the androgen "insensitivity is not complete and the external genitalia can appear typically male, typically female," or somewhere in between.[58] The cells have receptors that do not respond properly, causing an irregularity in the development of the genitals.[59] The AIS[60] individual has typically female external sex organs and will develop typically female secondary sex characteristics, but will have "undescended . . . testes instead of ovaries, an absent uterus and cervix, and a vagina that is usually short or absent."[61] Women with AIS can have immature nipples and genitals that have not fully developed, and an absence of underarm and pubic hair, facial oil, or acne.[62] AIS individuals diagnosed during infancy often have surgery performed to remove the undescended testes.[63]

Congenital adrenal hyperplasia ("CAH") "is a disorder that affects the adrenal glands," which are the glands on top of the kidneys that make various hormones and add them to the blood stream.[64] With CAH, "[t]he adrenal glands produce hormones, including sex hormones and cortisol and aldosterone."[65] A person who has CAH does not make sufficient cortisol and aldosterone, and makes too much androgen.[66] In effect, "there is a broken genetic 'recipe' for making cortisone in the adrenal glands."[67] "Because the recipe is broken, the adrenal glands . . . may make an unusually high level of other hormones that are 'virilizing'":[68] "they can

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be, it does include the majority of conditions. Klinefelter Syndrome and Turner Syndrome are examples of instances in which "ambiguous" genitalia can result from other conditions besides the three aforementioned categories. *See* DREGER, *supra* note 45, at 39. Some sources refer to "Turner's Syndrome" (as noted by Lev), while others refer to the condition as "Turner Syndrome." This Note will maintain the latter, which is consistent with medical sources, such as the National Institutes of Health. *See Turner Syndrome*, NAT'L INSTS. OF HEALTH: EUNICE KENNEDY SHRIVER NAT'L INST. OF CHILD HEALTH AND HUMAN DEV., http://turners.nichd.nih.gov/ (last visited Jan. 10, 2011).

[56] LEV, *supra* note 33, at 387.

[57] *Id*.

[58] *Id.*

[59] *Id.*

[60] References to the "AIS" individual apply to individuals with CAIS and PAIS.

[61] LEV, *supra* note 33, at 387.

[62] *Id.* at 387–88.

[63] *Id.*

[64] *Congenital Adrenal Hyperplasia: What It Is and How It's Treated*, FAMILYDOCTOR.ORG, http://familydoctor.org/online/famdocen/home/children/parents/special/birth/362.printerview.html (last visited Jan. 10, 2011).

[65] *Id.*

[66] *Id.*

[67] *Congenital Adrenal Hyperplasia (CAH)*, INTERSEX SOC'Y OF N. AM., http://www.isna.org/faq/conditions/cah (last visited Jan. 10, 2011).

[68] *Id.*

make XX embryos have larger than average clitorises."[69] Additionally, "an anomaly of the adrenal function causes the synthesis and excretion of an androgen precursor, initiating virilization of a [sic] XX person in-utero."[70] As "the virilization originates metabolically, masculinizing effects continue after birth."[71] CAH can cause the development of "characteristics like dense body hair, a receding hairline, deep voice, [and] prominent muscles."[72] CAH individuals diagnosed during infancy may have surgery performed to remove undescended testes, inhibiting the development of male hormones.[73]

Klinefelter Syndrome is a condition in which an individual with male external features has an extra X chromosome, creating an XXY karyotype and a pattern outside of the typical XX female chromosomal makeup and the XY male chromosomal makeup.[74] While the physical effects range widely, testosterone production is generally limited for those with Klinefelter Syndrome.[75] They do not virilize as strongly as men without the condition,[76] and doctors often prescribe testosterone treatment throughout their lives.[77] Klinefelter Syndrome "can affect different stages of physical, language and social development."[78] Infertility is the most common symptom.[79] Because individuals with Klinefelter often do not produce as much of the male hormone testosterone as those without the condition, teenagers with Klinefelter Syndrome may have less facial and body hair, may be less muscular than other boys, and may have trouble using language to express themselves.[80]

Turner Syndrome is a chromosomal condition that occurs in female births and is caused by a missing or incomplete X chromosome.[81] People

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[69] *Id.*

[70] *Id.*

[71] *Id.*

[72] *Id.*

[73] *See Ambiguous Genitalia*, UNIV. OF MICH. DEP'T OF SURGERY, *available at* http://surgery.med.umich.edu/pediatric/clinical/physician_content/a-m/ambiguous_genitalia.shtml (last visited Jan. 10, 2011) ("If no other surgery is planned, removal of the testes should be done just before puberty to prevent male development during puberty.").

[74] *See Karyotyping*, MEDLINEPLUS, http://www.nlm.nih.gov/medlineplus/ency/article/003935.htm (last visited Jan. 10, 2011) (describing karyotyping as "a test to examine chromosomes in a sample of cells, which can help identify genetic problems as the cause of a disorder or disease" and noting that the common chromosomal makeup for men is XY and for women is XX).

[75] LEV, *supra* note 33, at 388.

[76] *Id.*

[77] *Id.* at 388–89.

[78] *Klinefelter Syndrome*, MEDLINEPLUS, http://www.nlm.nih.gov/medlineplus/klinefelterssyndrome.html (last visited Jan. 10, 2011).

[79] *Id.*

[80] *Id.*

[81] *Turner Syndrome*, MEDLINEPLUS, http://www.nlm.nih.gov/medlineplus/turnersyndrome.html (last visited Jan. 10, 2011). A forty-five XO karyotype means that a chromosome is missing, as the typical number is forty-six. *See How Many Chromosomes Do People Have?*, GENETICS HOME REFERENCE, http://ghr.nlm.nih.gov/handbook/basics/howmanychromosomes (last visited Jan. 10, 2011).

with the syndrome exhibit female external features, but do not develop secondary sex characteristics unless hormone therapy is provided during puberty.[82] Girls who have it are short, their ovaries do not work properly, and most are infertile.[83] Individuals with Turner Syndrome "are at risk for health difficulties such as high blood pressure, kidney problems, diabetes, cataracts, osteoporosis and thyroid problems."[84] "Other physical features typical of Turner Syndrome are [a] short, 'webbed' neck with folds of skin from the tops of the shoulders to the sides of the neck, [l]ow hairline in the back, [l]ow-set ears, and [s]wollen hands and feet."[85] Individuals with Turner Syndrome often need some level of estrogen treatment.[86]

B. *Intersex Legal Status*

The most prominent case outside of the United States involving an intersex individual's rights was decided in the Colombian Constitutional Court in 1999.[87] The Colombian court held that "intersexed minors may constitute a minority group entitled to special protection against prejudice and its [resulting] consequences."[88] The court also suggested that where parental attitudes show prejudice, a court may deny support for parental consent to surgically "normali[ze]" the child.[89]

Within the United States, the legal system still does not provide any protected legal status to intersex persons. The closest that the American system has come to addressing intersex issues arose within a procedural due process case involving an intersex prisoner.[90] In *Estate of DiMarco v. Wyoming Department of Corrections*, Miki Ann DiMarco, after violating the terms of her probation resulting from a check fraud conviction, was sentenced to prison.[91] State prison officials consigned DiMarco—who "lived her life as a woman even though she was anatomically male"—to administrative segregation for fourteen months in a high security prison[92]

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[82] *Id.*
[83] *Id.*
[84] *Id.*
[85] *Id.*
[86] *See Learning About Turner Syndrome*, NAT'L HUMAN GENOME RESEARCH INST., http://www.genome.gov/19519119 (last visited Jan. 10, 2011) (citing estrogen treatment as a form of treatment for those with Turner Syndrome).
[87] *See* Morgan Holmes, *Deciding Fate or Protecting a Developing Autonomy? Intersex Children and the Columbian Constitutional Court*, *in* TRANSGENDER RIGHTS, *supra* note 15, at 102, 102–03 (describing the case and its impact on intersex rights in Columbia); Jo Bird, *Outside the Law: Intersex, Medicine and the Discourse of Rights*, 12 CARDOZO J.L. & GENDER 65, 66–67 (2005) (noting that the Colombian Court is "the only court in the world to recognize that the treatment of intersex [individuals] can amount to a [human] rights violation"); Brömdal, *supra* note 33, at 11 (describing the case as the first intersex case in the world).
[88] Holmes, *supra* note 87, at 102.
[89] *Id.*
[90] Estate of DiMarco v. Wyo. Dep't of Corr., 473 F.3d 1334, 1334 (10th Cir. 2007).
[91] *Id.* at 1336–37.
[92] *See id.* at 1337 ("At intake, DiMarco was housed in Pod 3, the most restrictive and isolated

without providing a hearing to challenge their decision.[93] Prison officials segregated DiMarco because "the officials believed that she presented a safety risk," and because "they concluded she should not be placed with the general female prison population."[94] On appeal, DiMarco raised the issue of whether Wyoming had a constitutional duty to provide an opportunity to challenge the placement and conditions of confinement under the Fourteenth Amendment's Due Process Clause.[95] The Court of Appeals for the Tenth Circuit held that the state prison officials did not violate the Due Process Clause in their decision to confine DiMarco, as she did not have a protected liberty interest in her placement and conditions of confinement.[96] Despite her intersex status being a seemingly vital aspect of the decision to confine DiMarco, the case did not specifically address DiMarco's rights as an intersex individual, leaving the intersex community uncertain about its legal status in the United States.

IV. THE AMERICANS WITH DISABILITIES ACT

The Americans with Disabilities Act, passed by Congress in 1990, is wide-ranging federal civil rights legislation created and designed to protect individuals with physical and mental disabilities against discrimination.[97] It applies primarily to "employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services."[98] Under the ADA, "disability" refers to an individual who has "a physical or mental impairment" that "substantially limits" one or more "major life activities," who has a "record of" such an impairment, or who is "regarded as" or perceived as having such an impairment.[99]

In the years between the implementation of the 1990 version of the ADA and its current amended form, the courts interpreted the ADA in ways that prompted Congress to reform the Act. Beginning in 1999, the U.S. Supreme Court limited the construction and interpretation of the ADA in three major cases[100]—*Sutton v. United Air Lines, Inc.*,[101] *Murphy v. United Parcel Service, Inc*.,[102]and *Albertson's, Inc. v. Kirkingburg*.[103] In

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housing pod used for inmates confined to administrative or protective custody.").

[93] *Id.*; *see also* Cheryl Chase, *Federal Judge Finds Wyoming Prison Violated Constitutional Rights of Intersexual Prisoner*, CHERYL CHASE'S BLOG (June 22, 2004, 8:03 AM), http://www.isna.org/dimarco (summarizing the *DiMarco* case).

[94] *DiMarco*, 473 F.3d at 1336.

[95] *Id.* at 1336–37.

[96] *Id.*

[97] 42 U.S.C. §§ 12,101–12,102 (2006 & Supp. 2009).

[98] *Id.* § 12,101(a)(3).

[99] *Id.* § 12,102(2).

[100] RUTH COLKER, THE LAW OF DISABILITY DISCRIMINATION 29 (7th ed. 2009).

[101] 527 U.S. 471, 475 (1999).

[102] 527 U.S. 516, 518–19 (1999).

each of the cases, the Court concluded that the plaintiffs were not qualified individuals with disabilities either because the determination of whether they were "substantially limited" should have been made after accounting for mitigating measures like medication, assistive technology, accommodations, or personal modifications,[104] or because the failure to obtain one specific job without being precluded from other positions did not constitute having an impairment that substantially limited the major life activity of working.[105] The Court held that the Sutton twins—who claimed they were qualified as disabled because of poor vision—were not disabled, as their vision could be corrected to 20/20 with glasses;[106] that Murphy was not disabled with hypertension, as he could perform major life activities with medication;[107] and that Kirkingburg was not disabled, as his brain had accommodated his ability to see only through one eye.[108]

The narrowing of the interpretation of the ADA continued in 2002 with *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams*.[109] In *Toyota*, the Court held that the ADA's language of "substantially" and "major" should be strictly interpreted to create a demanding standard, and that to be substantially limited in performing a major life activity under the ADA, "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."[110]

By 2006, Congress initiated action to respond to the Supreme Court's limiting of the ADA's reach, seeking to reinvigorate the Act and ensure that the ADA would be broadly construed. The Americans with Disabilities Restoration Act was introduced and was eventually referred to two committees, but did not advance further.[111] Finally, in 2008, the ADAAA was passed by the House of Representatives in a 402–17 vote, and passed by voice vote in the Senate, clearing it for unanimous House

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[103] 527 U.S. 555 (1999).

[104] *See Albertson's*, 527 U.S. at 565–66 ("While the Act 'addresses substantial limitations on major life activities, not utter inabilities,' it concerns itself only with limitations that are in fact substantial." (quoting Bragdon v. Abbott, 524 U.S. 624, 641 (1998))); *Murphy*, 527 U.S. at 521 ("[T]he question granted was limited to whether, under the ADA, the determination of whether an individual's impairment 'substantially limits' one or more major life activities should be made without consideration of mitigating measures.").

[105] *See Sutton*, 527 U.S. at 482 ("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."); *id.* at 510 (Stevens, J., dissenting) ("[I]t is especially ironic to deny protection for persons with substantially limiting impairments that, when corrected, render them fully able and employable.").

[106] *Id.* at 493–94 (majority opinion).

[107] *See Murphy*, 527 U.S. at 519, 521 ("[W]hen medicated, [Murphy's] high blood pressure does not substantially limit him in any major life activity.").

[108] *Albertson's*, 527 U.S. at 566.

[109] 534 U.S. 184 (2002).

[110] *Id.* at 185.

[111] COLKER, *supra* note 100, at 30.

consent and subsequent signing by President George W. Bush on September 25, 2008, for an enactment date of January 1, 2009.[112] Congress explicitly overturned *Sutton* and *Toyota Motor* and clarified its original intention that the ADA was meant to protect a broadly defined group of individuals. The House and Senate votes indicate the overwhelming support for the ADAAA.

As the amendments went into effect on January 1, 2009, the ADA saw a number of substantial changes, including a more expansive definition of "disability." For example, "major life activit[y]" now includes "caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working."[113] The category of "[m]ajor bodily function[s]," which also falls under "major life activity," includes "functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine, and reproductive functions."[114] The ADA also states that a person may not be barred from legal action even if the disability is perceived rather than actual; for example, an individual would still meet the third "regarded as" prong of the statutory definition of "disability" even if that person did not actually have the disability but was only regarded as having such a disability.[115]

While the amended form of the ADA was enacted more than two years ago and some courts have interpreted the newer version, its full effects have yet to be seen.

V. THE ADA AND THE INTERSEX COMMUNITY

A. *The ADA*

Despite the recent changes to the ADA, one section that remained unaltered included an exclusion of certain categories of individuals from receiving federal disability protection. Under 42 U.S.C. § 12,211, "disability" does not include homosexuality, bisexuality, transvestism, transsexualism, pedophilia, exhibitionism, voyeurism, "gender identity disorders not resulting from physical impairments, or other sexual behavior disorders."[116] This section specifically prohibits individuals from filing for disability discrimination protection if they identify as gay, lesbian, bisexual, or transgender.

Notably, the language does not include explicit references to the

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[112] *Id.* at 31.
[113] ADA Amendments Act of 2008 § 4(a), 42 U.S.C. § 12,102(2)(A) (Supp. II 2007–2009).
[114] *Id.* § 12,102(2)(B).
[115] *Id.* § 12,102(3)(A).
[116] *Id.* § 12,211(a), (b)(1).

intersex community, or to persons with disorders of sexual development, intersexual or hermaphroditic features, or sex or genital ambiguities. While this Note argues otherwise, the prohibitive language that may preclude intersex protections is possibly the "gender identity disorders not resulting from physical impairments" portion, which is explored in the following section.

B. *The Intersex Individual as a Person with a Disability*

1. *The Intersex Condition as a Physical Impairment*

While there is no case law interpreting the "gender identity disorders not resulting from physical impairments" provision under the ADA, the language suggests that Congress intended to address transgender individuals, leaving a statutory gap for intersex individuals. Additionally, there is no legislative history or other documentation demonstrating that Congress considered the intersex community in creating this provision.

A "physical impairment," as defined by the ADA, is "any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological; musculoskeletal; special sense organs; respiratory, including speech organs; cardiovascular; reproductive, digestive, genito-urinary; hemic and lymphatic; skin; and endocrine."[117] Given the recent amendments and Congressional intent to broaden the scope and coverage of the ADA, "impairment" may now also refer to a different chromosomal, hormonal, endocrinological, or other physical differences preventing an individual from being categorized as female or male, per the societal understandings of those terms. Additionally, under the ADAAA, a person may be considered to have an impairment if the person has partially developed or underdeveloped sex organs preventing them from operating with normative levels of sexual, reproductive, and biological functioning.

While some courts have interpreted this specific provision with regard to sexual orientation or transgender orientations and identities, courts have not interpreted it in light of intersex conditions. Moreover, when courts acknowledge that an individual may have a disability under the provision, the analysis has tended to end promptly thereafter, as the plaintiff usually cannot demonstrate how the impairment substantially limited one or more major life activities, as required by the Act.[118]

Notwithstanding these apparent drawbacks in sexual orientation or

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[117] 45 C.F.R. § 84.3(j)(2)(i)(A) (2009).

[118] *See, e.g.*, Kastl v. Maricopa Cnty. Cmty. Coll. Dist., No. CIV 02-1531-PHX-SRB, 2004 U.S. Dist. LEXIS 29825, at *17–18 (D. Ariz. June 2, 2004) ("Plaintiff neglects to explain how Defendant's refusal to accommodate her or retain her as an employee bars her from other similar work, and the Court fails to see how a single employer's reaction to a physical impairment could alter the nature or severity of the impairment itself.").

transgender cases, and depending on the type of condition,[119] intersex persons may find statutory protections despite the "gender identity disorders not resulting from physical impairments" language. Certain intersex conditions, for example, have endocrinological components, such as changing hormone levels, particularly testosterone or "male" hormone levels. This means that for an intersex individual, gender identity results *from* a physical impairment, and is therefore not excluded from protection under the statute.[120] Additionally, physical disfigurement can result from what often occurs to intersex individuals in their personal experiences prior to adulthood—infant or minor non-consensual genital "corrective" or gender-assignment surgery.[121] During these surgeries, doctors perform what they believe to be "necessary" procedures with respect to assigning the individual a male or female gender.[122] In the case that these surgeries are improperly conducted, the results can include disfigurement and a variety of resulting medical complications that can impact the person physically, emotionally, mentally, socially, and psychologically.[123]

For example, issues of the intersex community and medical complications arose out of a case involving non-intersex male twins, Bruce and Brian Reimer, also known as the now-infamous 1965 Dr. John Money experiment.[124] Bruce lost his penis in an accidental burning during a routine electrocautery procedure.[125] Dr. Money recommended that Bruce be raised as a female due to his lost penis.[126] His parents agreed and raised Bruce as "Brenda."[127] For more than thirty years the medical community considered the experiment to be a "success," and Dr. Money's assertion that gender was completely socially controllable seemed incontrovertible.[128] The discourse took a very different turn, however, when biologists Milton Diamond and Keith Sigmundson revealed that "Brenda" was displeased with her gender identity and presentation and

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[119] See *supra* Part III.A for a description of the types of intersex conditions.

[120] *See* 45 C.F.R. § 84.3(j)(2)(i)(A) (2009) (defining "impairment" as "any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting" the endocrine system, among other systems).

[121] *See What's ISNA's Position on Surgery?*, INTERSEX SOC'Y OF N. AM., http://www.isna.org/faq/surgery (last visited Jan. 10, 2011) (arguing that elective surgeries performed on patients who do not give informed consent to such surgeries subject these individuals to unnecessary harm and risk).

[122] *See What Do Doctors Do Now When They Encounter a Patient with Intersex?,* INTERSEX SOC'Y OF N. AM., http://www.isna.org/faq/standard_of_care (last visited Jan. 10, 2011) (reporting that most medical centers practice a "concealment-centered model of care" where doctors perform "'normalizing' (medically unnecessary) genital surgeries").

[123] Furthermore, it seems that, despite their "aware[ness] of the controversy surrounding intersex treatment, [doctors] are still taking the basic approach of 'cut now, maybe ask about quality of life later.'" *Id.*

[124] Preves, *supra* note 33, at 273.

[125] *Id.*

[126] *Id.*

[127] *Id.*

[128] *Id.* at 273–74 (stating that "gender is socially malleable, at least in early childhood").

underwent surgery to become male.[129]

As a result of surgeries such as the one performed in Dr. Money's experiment,[130] intersex individuals could face a variety of complications because of anatomical loss, including neurological, musculoskeletal, special-sense organ, respiratory, cardiovascular, reproductive, digestive, genito-urinary, hemic, lymphatic, skin, or endocrine problems.[131] Such complications could allow intersex individuals to find statutory protections under the ADA due to the nature of the condition and the associated "physical impairment." Consequently, intersex individuals may be able to satisfy the definition of disability, despite the specific exclusions of transgenderism, homosexuality, and bisexuality. Even assuming that an intersex person can overcome the exclusions to the definition of disability and can show that the person has a physical impairment, one must still satisfy the three prongs of the ADA to warrant protection.[132]

2. *Prongs of the ADA*

With the amended version of the ADA, an intersex individual may find legal protection under the Act by satisfying at least one of its prongs.

a. "Substantially Limits" Prong

Under this prong, the individual must have "[a] physical or mental impairment that *substantially limits one or more . . . major life activities*."[133] In the case of an intersex individual, for example, the absence of a provision excluding them is not sufficient to find ADA protection; the person must be able to show that the stated physical impairment substantially limits one or more major life activities.

For some intersex conditions that require medical treatment for daily human functioning, the condition itself may substantially limit one or more major life activities. For a person with CAIS or PAIS whose sexual development is negatively affected before birth or during puberty, for example, the individual may find that his or her condition is covered under "major bodily function,"[134] which is now included as a major life activity

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[129] *Id.* at 274.

[130] Notably, while the technology is significantly more advanced than it was at the time of Dr. Money's experiment, medical professionals still consider certain intersex surgeries to be complex procedures. *See* Nancy Ehrenreich & Mark Barr, *Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of "Cultural Practices,"* 40 HARV. C.R.-C.L. L. REV. 71, 106 (2005) ("The initial surgery performed on an intersex child can be quite complex").

[131] *See generally* Thorn E. Lobe et al., 22 J. PEDIATRIC SURGERY, 651–52 (1987) (describing the rate of frequency and nature of complications for intersex surgeries).

[132] The individual must have "[a] physical or mental impairment that substantially limits one or more . . . major life activities," must have "a record of such an impairment," or must "be regarded [or perceived] as having such an impairment." ADA Amendments Act of 2008 § 4(a), 42 U.S.C. §§ 12,102(1), (3) (Supp. II 2007–2009).

[133] Americans with Disabilities Act of 1990, 42 U.S.C. § 12,102(2)(A) (2006) (emphasis added).

[134] ADA Amendments Act of 2008, 42 U.S.C. § 12,102(2)(B).

by the amended ADA.[135] Because Congress expanded the definition of disability, and because the provision specifically states that "major bodily function" may include, *but is not limited to*, the enumerated functions,[136] sexual development and functioning would likely qualify as a major bodily function. Moreover, an individual with CAIS or PAIS may have additional problems associated with reproductive functioning,[137] particularly as they have trouble responding to sex hormones, thus stunting sex and reproductive development and functioning. It may also implicate cell growth, as the hormonal makeup of a person with CAIS or PAIS may cause difficulty in cell development,[138] thus falling under the "major bodily function" provision.

For someone with CAH whose adrenal glands do not function properly, the disorder may impair the bodily function of normal cell growth, as well as endocrine and reproductive functioning. The most readily available provision is likely the endocrine provision, as the CAH individual's inability to properly produce cortisone and aldosterone most directly affects the endocrine system.[139] Moreover, CAH persons may need their undescended testes to be surgically removed to avoid testicular cancer.[140] Should this occur, the intersex condition substantially limits a major life activity. While a mitigating factor could be surgery and subsequent removal, this is not always the case, and the condition remains one that substantially limits one or more major life activities.

For an individual with either Klinefelter or Turner Syndrome, one of the major problems involves the production of either testosterone or estrogen, which can cause problems with respect to reproductive and sexual functioning (regardless of his or her gender identity or gender expression). Also, because the condition may affect language and social development,[141] a person with Klinefelter Syndrome may find their neurological and brain functioning impaired. Finally, as one of the most common problems in intersex conditions is infertility, and as the reproductive system is covered under the "major bodily function," an

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[135] *See infra* Part V.B.

[136] *See infra* Part V.B.

[137] The United States Supreme Court has held that reproduction qualifies as a major life activity under the pre-amended ADA. Bragdon v. Abbott, 524 U.S. 624 (1998).

[138] *See* INTERSEX SOC'Y, *supra* note 1 (noting the cell's failure to respond to testosterone and inhibiting such development).

[139] See *supra* notes 64–73 and accompanying text for a discussion of CAH and its effects.

[140] *See* HEALTHLINE, *Congenital Adrenal Hyperplasia: Complications*, http://www.healthline.com/channel/congenital-adrenal-hyperplasia_complications (last visited Jan. 10, 2011) (noting that one of the potential conditions of CAH is a testicular lump, which may cause cancer).

[141] *See Klinefelter Syndrome*, HORMONE FOUNDATION, *available at* http://www.hormone.org/upload/Klinefelter-Bilingual-WEB.pdf (last visited Jan. 10, 2011) (noting such signs and symptoms as speech and language problems, delayed speech, problems with learning and reading, social interaction problems, and mood and behavioral problems).

individual with Klinefelter or Turner Syndrome may also find coverage under the reproductive function provision.

All of the aforementioned conditions could also affect the expanded list of major life activities, which includes "caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working."[142] Intersex persons may have difficulty caring for themselves with regard to their gender and sex ambiguity; this may include basic bodily functioning and continual and persistent pain in the genital area, even outside of the context of surgical intervention.

Moreover, an intersex individual's mental, emotional, and psychological experiences could qualify as a mental disability under the ADA, resulting from the complexities associated with gender presentation, gender identity, and gender expression. Particularly in the case of an intersex person who discovers their condition later in life, this could also result in alternative mental conditions, such as depression, anxiety, and a continued discomfort with one's biological sex, gender presentation, or fear that they are not squarely "male" or "female" for purposes of socio-political distinctions and markers.[143]

It appears that, based on the medical complications and issues arising from intersex conditions, the first prong is the most straightforward to apply to intersex persons, and may be the best prong for them to pursue rights under the ADA. Even assuming that an individual could not find protections under this prong, however, the next two prongs may be satisfied.

b. "Record" Prong

An individual can be a qualified person with a disability under the ADA if they can show a record of impairment.[144] For an intersex individual, if they can show a record of past medical treatment for an intersex condition, they may be able to find protections under this prong. It is unclear whether there would be disagreement as to whether an intersex individual is always intersex, or whether sex-assignment surgery effectively assigns the male or female gender and sex to an individual and removes the intersex status. This is a vexing question with regard to this prong, as the "record of impairment" prong can protect an individual who previously had an impairment, but who may not currently be considered disabled.

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[142] ADA Amendments Act of 2008 § 4(a), 42 U.S.C. § 12,102(2)(A) (Supp. II 2007–2009).

[143] *See* AMER. PSYCHOLOGICAL ASS'N, *Answers to Your Questions About Individuals with Intersex Conditions*, http://www.apa.org/topics/sexuality/intersex.pdf (last visited Jan. 10, 2011) ("Persons with intersex conditions and their families may also experience feelings of shame, isolation, anger, or depression.").

[144] Americans with Disabilities Act of 1990, 42 U.S.C. § 12,102(2)(B) (2006).

A number of intersex persons, however, may find that this prong falls short of protecting them while others may not realize that they may be subject to ADA protection, as they may not realize their intersex status.[145] As the Intersex Society of North America aptly notes, it is possible for an individual to live most, if not one's entire life, without awareness of an intersex condition, depending on the severity and appearance of the condition, among other factors.[146] Should this be the situation, providing a "record of impairment" becomes particularly problematic, if not impossible.

c. "Regarded As" Prong

Finally, an intersex individual may be "regarded as" as having a substantially limiting impairment.[147] Congress added the "regarded as" prong to the definition of handicap in 1974 in order to address disability discrimination resulting from stereotypical attitudes and ignorance about disabilities.[148] The legislative history reflects that the "regarded as" prong is particularly important in addressing the emotional complexities associated with being an individual with a disability. It was intended to prohibit discrimination against persons with impairments that invoke fear and discomfort in others and against those who have no impairment but are only "regarded as" having one.[149] The U.S. Supreme Court noted the importance of enacting protections against discrimination based on "prejudiced attitudes or the ignorance of others."[150] Moreover, an impairment that is cosmetic in nature "might not diminish a person's physical or mental capabilities, but could nevertheless substantially limit that person's ability to work as a result of the negative reactions of others to the impairment."[151]

For the intersex community, being identified as intersex can result in tremendous stigma and can engender fear and discomfort in others. The notion that an individual can have a mixed sex or gender composition is exceptionally unnerving to many, and the idea that an individual could be an "it"[152] evokes varying levels of societal confusion and unrest.

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[145] *See What Is Intersex?*, INTERSEX SOC'Y OF N. AM., http://www.isna.org/faq/what_is_intersex (last visited Jan. 10, 2011) [hereinafter INTERSEX SOC'Y, *Intersex*] (stating that "[s]ome people live and die with intersex anatomy without anyone (including themselves) ever knowing"); *see also supra* note 36 and accompanying text.

[146] *See* INTERSEX SOC'Y, *Intersex*, *supra* note 145 (noting that intersex anatomy does not necessarily show up at birth, and that some people are not discovered to be intersex until their bodies undergo autopsy after death).

[147] Americans with Disabilities Act of 1990, 42 U.S.C. § 12,102(2)(C).

[148] Levi & Klein, *supra* note 15, at 88.

[149] *Id.* at 88–89.

[150] Sch. Bd. of Nassau Cnty. v. Arline, 480 U.S. 273, 284 (1987).

[151] *Id.* at 283.

[152] *See supra* Part IV, for a description of the types of discrimination faced by the intersex community. As a result of not fitting squarely into the "male" or "female" categories (which itself can

Importantly, this prong may be more effective than the others in that the prong shifts the focus from the individual with the impairment to the reactions—the mental state—of others to that person. This shift can be a critical one for an intersex person, who can then be protected from irrational discrimination based on an adverse reaction to the condition. This distinguishing feature of the ADA is what makes it a unique federal non-discrimination statute. Under this analysis, an intersex person may be able to successfully find disability protection under the ADA.

For a community without any legal status in the United States, the ADA could be come a way for the intersex community to pursue rights and legal protections without lobbying for a change in legislation. The reality, however, is that the notion of the intersex community becoming a protected class is one that seems quite distant. While the Obama administration has recently recognized transgender individuals as a protected class under federal hate crimes law,[153] it may be a long time before the intersex community—a typically more stigmatized, less understood group—constitutes a protected class outside of the context of the ADA.

VI. THE ADA AS A FORUM IN WHICH TO ADVANCE INTERSEX RIGHTS

The previous section examined the ways in which the intersex community may be able to find protections under the ADA. Whether this is in the best way to pursue rights for the intersex community remains a critical question.

A. *The Drawbacks of Using the ADA To Advance Intersex Rights*

In their study on the use of state disability law to advance the rights of the transgender community, Jennifer Levi and Bennett Klein, Senior Staff Attorneys[154] at the Boston-based Gay and Lesbian Advocates and Defenders ("GLAD"),[155] acknowledged that some transgender people worry that using disability law to secure legal protections for transgender people will perpetuate social myths and stereotypes that transgender people

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be arbitrarily decided), an intersex person may find that they are not referred to with personal pronouns or treated in a humane manner, but rather are objectified as a medical subject.

[153] *See* Matthew Shepard and James Byrd, Jr. Hate Crimes Prevention Act, Pub. L. No. 111-84, §§ 4701–03, 4707(a), 2009 U.S.C.C.A.N. (123 Stat.) 2190, 2835–36, 2838–39 (to be codified at 18 U.S.C. §§ 1, 249; 28 U.S.C. § 994; and 42 U.S.C. §§ 3716 to 3716a) (adding "gender identity" as a protected class under the Act).

[154] At the time of their publication, Klein and Levi were Senior Staff Attorneys with GLAD. Klein is currently the Senior Attorney and AIDS Law Project Director, and Levi is the Transgender Rights Project Director. *See* GAY AND LESBIAN ADVOCATES AND DEFENDERS, http://www.glad.org/ (last visited Jan. 10, 2011).

[155] *Id.*

are sick, abnormal, or inferior due to their disability status.[156] They further note that the stigma associated with disability is often misunderstood or unfounded.[157]

Additionally, Ruth Colker provides a detailed explanation for the sources of discrimination relating to disability rights that may impact the intersex community in pursuing rights under the ADA.[158] Colker describes discomfort, stereotyping, and stigmatization as some of the major feelings and sentiments that individuals with disabilities experience.[159] An additional important category is one resulting from the addition of intersex to the disabled category—one of misunderstanding regarding the labeling of an intersex person as "disabled" for purposes of the ADA.

1. *Discomfort*

Colker notes that people often feel discomfort in their interactions with people with disabilities, and that such sentiments occur especially among people who lack the experience to know what limitations result from handicaps and what is considered appropriate to say or how to act in response.[160] Such discomfort may also arise from fear of patronizing a disabled individual intentionally or from the person's visible vulnerability to disease, disability, and injury.[161]

Arguably the level of discomfort that may arise from knowing that someone is intersex can be quite different for different people. While many in society are extremely uncomfortable with the notion that an individual may be neither male nor female, the discomfort arises not from the disability, but from the idea that a human being may have a mixed chromosomal and biological composition that may move them outside of the gender female-male dichotomous construct. This can emanate in a variety of contexts similar to the different forms of disability discrimination: employment, transportation, education, and public accommodations.[162]

In the context of employment, the discrimination may come from misunderstandings about how to categorize the individual's gender while also being confused as to how, or if, the individual may be physically or mentally disabled. Should co-workers or supervisors become aware of a person's intersex status, discomfort may arise within a variety of contexts. The context in which it appears most likely, however, is that of public accommodation. For instance, as with the experiences of transgender

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[156] Levi & Klein, *supra* note 15, at 74.
[157] *Id.*
[158] COLKER, *supra* note 100, at 4–6.
[159] *Id.*
[160] *Id.* at 4.
[161] *Id.*
[162] *Id.* ("Whatever the cause, handicapped people encounter the reaction of aversion every day.").

workers, the use of gender-specific restroom facilities can be quite problematic for intersex workers.[163] The worker's decision to use a certain restroom can bring significant discomfort to coworkers if the worker uses that facility against the wishes of others.

Another experience that both disabled and intersex individuals may face is that of aversion or avoidance.[164] Like disabled individuals, a number of gender- and sex-ambiguous persons have faced significant discrimination in areas of public accommodation, transportation, and other such areas.[165] The sense of being avoided is one that deeply impacts both communities and can sharply define their respective experiences.

2. *Stereotyping*

Colker notes that disabled individuals may face various forms of stereotyping, particularly with regard to conjuring up certain images or connotations of the disabled community,[166] despite the broad variance of disabilities themselves and subsequent manifestations. Within the context of intersex individuals—people who have previously been called *hermaphrodite*—terminology strongly denotes the societal perceptions that the community has faced over time. Due to stereotyping and negative understandings, the community has moved to the use of DSD.[167] The term *hermaphrodite*, and its Greek mythological origins, has damaged and stereotyped the community.[168] Similarly, if the stereotypes and attendant burdens of the disabled community are transferred to the intersex community, the effects could move the intersex community away from its goals rather than toward them.

Interestingly, terminology also plays a significant role with respect to the disabled community. For example, other words used to describe the disabled community have previously included "handicapped," "crippled," or "the disabled," which some consider outdated and inappropriate today.[169] The disabled community has faced its own set of societal and

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[163] *See* Diana Elkind, *The Constitutional Implications of Bathroom Access Based on Gender Identity: An Examination of Recent Developments Paving the Way for the Next Frontier of Equal Protection*, 9 U. PA. J. CONST. L. 895, 896 (2007) ("Bathroom access is one of the most critical issues faced by the transgender community.").

[164] *See* Alex Long, *State Anti-Discrimination Law as a Model for Amending the Americans with Disabilities Act*, 65 U. PITT. L. REV. 597, 616 (2004) ("Given the public's general fear of mental illness, individuals with mental disabilities are perhaps more likely to face discrimination in the form of stereotyping, fear, and avoidance than are individuals with physical disabilities.").

[165] *See supra* note 159 and accompanying text.

[166] COLKER, *supra* note 100, at 5.

[167] *See* Emi Koyama, Intersex Initiative, Keynote Speech at the University of Vermont Translating Identity Conference: From "Intersex" to "DSD": Toward a Queer Disability Politics of Gender (Feb. 2006), *available at* http://www.intersexinitiative.org/articles/intersextodsd.html (referencing the notion of advancing intersex rights from the perspective of disability rights law).

[168] *Id.*

[169] *See Disability Etiquette: Tips on Interacting With People with Disabilities* UNITED SPINAL ASS'N 6, *available at* http://www.unitedspinal.org/pdf/DisabilityEtiquette.pdf (last visit Jan. 10, 2011)

political shifts in perspectives over time. Levi and Klein suggest that current perceptions of the disabled community are less stigmatizing than older societal perceptions,[170] but that the community still faces negative perceptions.[171] While the same may be true of the intersex community, stereotyping still deeply impacts both communities and could cause a combination that ultimately harms both communities.

3. *Stigmatization*

Colker also notes that the stigmatization of persons with disabilities is rooted in a notion of an "*undesirable* difference."[172] Widely held conceptions that an individual is physically or mentally different in a way that is unnatural or undesirable brings feelings of shame, embarrassment, and a strong sense of stigmatization. The level of stigmatization may also depend on the type or severity of the disability.[173]

4. *Normal/Abnormal Bodily Distinction*

Another problem is societal understandings of what constitutes a "normal" or "abnormal" body. This problem could inflate if the ADA becomes a legal avenue for the intersex community. For example, in the context of a disabled individual, a physical or mental disability is considered socially negative, a harm to the body, or something that is "wrong" with the body.[174] This notion similarly faces the intersex community, since the conception that a person neither squarely fits into *male* or *female* renders them socially abnormal or even sub-human. Should the two be combined, both communities stand to be harmed, as each understanding of that which is abnormal in each of the communities may reinforce and worsen the other.[175]

5. *Community Reluctance*

Another problem arising from the use of the ADA to advance the rights of the intersex community stems from its reluctance to align itself with the plight and issues of the disabled community. An intersex person may be resentful of the need to use federal disability law to advance

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(suggestions specific terminology and etiquette in interacting with persons with disabilities).

[170] *See* Levi & Klein, *supra* note 15, at 79 (noting the recent political, legal, and social shifts to understanding the disadvantaged status of disabled persons as the product of a socially hostile environment as a more advanced understanding of the meaning of "disability").

[171] *Id.* at 74 (referring to the "stigma still associated with the term "disability").

[172] COLKER, *supra* note 100, at 5–6 (internal quotation marks omitted).

[173] *Id.* at 6.

[174] *Id.*

[175] Intersex people are not only considered abnormal due to genital ambiguity, but being labeled as a person with a disability may reinforce the abnormality of being different. Additionally, a person with a disability may feel that it is inappropriate to be labeled in the same category as an intersex individual.

intersex civil rights, just as a disabled individual may find it an "intrusion" for an intersex person, who may appear non-disabled, to use disability law to advance their rights. Regardless of whether the feeling stems from a dissimilarity of interests or a need to protect those who they may feel are "truly" disabled, the fact remains that the use of the ADA could drive the communities into polarizing and potentially destructive directions.

6. *Medicalization*

Another concern with finding intersex protections under the ADA comes from the medicalization of the intersex community in prior discourse, and the concern that utilizing the ADA may dehumanize and objectify the community. For example, in prior research conducted on the intersex community and in prior articles, pictures of intersex individuals demonstrate the objectified and medicalized tone with which medical professionals interacted with intersex individuals.[176] Medical experts, scientists, and those studying intersex individuals and intersex conditions would remove the most humanizing component of the picture—the eyes.[177] The viewer would then lose human connection to the intersex individual.

Should the intersex community align itself with the disabled community, many in the community might fear that this would simply revert the intersex community to the days of those dehumanizing pictures and would push further away from finding protection. This dilemma has left the intersex community unsure as to whether the ADA is a solution, or whether it is better to pursue protections under other areas of law.

7. Asexuality

The notion of asexuality faces both the intersex and disabled communities. Societal perception of intersex individuals, because they may have a mixed biological and chromosomal composition, can lead the public to believe that intersex persons may not have feelings associated with sexuality. A similar notion has also been advanced with respect to the disabled community—that they too do not have feelings associated with sexuality. This may further reinforce such misunderstandings of the

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[176] *See* DREGER, *supra* note 45, at 49 (displaying a picture of a person with an intersex condition with a bag covering her head). While the caption notes that the reason for the anonymity was to protect the young woman's identity, such pictures also remove any human or personal connection the viewer may have with that person.

[177] *See* Koyama, *supra* note 167 ("Intersex movement discovered 'public stripping' on its own, although their chosen term was 'medical display.' This term includes not only the actual 'public stripping' of naked intersex children in front of the audience, but also the use of photos taken of those children which often show the genitalia only, or with a black rectangle blocking their eyes to make them anonymous. . . . Alice Dreger observed these photos and pointed out that while the black rectangle protects the privacy of the person being photographed, it also dehumanizes her or him, reducing the subject to her or his genitalia. . . . Cheryl Chase said it more emphatically: the only thing that the black rectangle accomplishes is that it keeps the viewer from being stared back.").

communities.

The possible harms in using the ADA to advance intersex rights stem from the intersex community's strong push away from stigmatization, stereotyping, and negative connotations that the disabled community has also tried to transcend over the years. If the ADA is used as a tool to advance the intersex rights movement, the feelings of discomfort around disabled individuals, combined with the uncomfortable feeling associated with individuals with ambiguous genitalia, may cause legal, social, and political setbacks for the intersex community.

B. *The Benefits of Using the ADA To Advance Intersex Rights*

Despite the potential drawbacks of using the ADA to advance intersex rights, its advantages may outweigh its disadvantages. While the question of whether the ADA should be a civil rights forum for the intersex community has been only minimally addressed in academic or legal discourse,[178] one helpful model that may be transferable to this question is the use of state disability law—with language comparable to the ADA—to advance the rights of the transgender community.[179]

Levi and Klein argue that a viable option to advance transgender rights is through state disability law.[180] They argue that state disability laws do not use "disability" in its colloquial or common sense,[181] and that the interpretation that the law only prohibits discrimination against individuals with debilitating impairments is a flawed understanding of disability civil rights law.[182] They argue that "[t]he barriers to equal opportunity that [disabled] individuals face" do not come from the actual disability so much as they originate from "the prejudice, hostility, and misunderstanding of others about their health conditions."[183] Levi and Klein also address the fact that disability non-discrimination law "cover[s] both those who experience some limitations because of a health condition, as well as those who experience discrimination solely because of ignorance, stereotypes, and misperceptions about their health conditions."[184] This is analogous to the "regarded as" prong under the ADA.

Levi and Klein understand the modern view of disability status: "[T]he 'disadvantaged status of persons with disabilities is [viewed as] the product of a hostile (or at least inhospitable) social environment, not simply the

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[178] *But see id.* (broaching the topic of intersex rights from the perspective of disability rights law).

[179] The author acknowledges the differences in state and federal disability law, as well as the differences between the transgender and intersex community.

[180] Levi & Klein, *supra* note 15, at 75.

[181] *Id.* at 74.

[182] *Id.*

[183] *Id.* at 75.

[184] *Id.*

product of bodily defects.'"[185] Their focus is the protection of individuals with disabilities based on social constructions of those individuals, rather than on the actual physical or mental disabilities of the individuals.[186] A corollary component is that "[d]isability laws are intended to cover both persons whose lives are impacted 'naturally' by their physical or mental health conditions, as well as those whose lives are impacted by the social consequences of their having a condition."[187] This approach is consistent with the congressional intent behind the ADA, the current understanding of the "regarded as" prong analysis, and modern disability discourse.

Also, the possible social stigma that may attach to the intersex community should not justify avoiding the establishment of fundamental legal protections for a community in dire need of them.[188] The appropriate response, Levi and Klein claim, is "to address the stigma, not to enhance it by avoiding the law."[189] Avoidance could ultimately harm the community in a way that goes far beyond the possible social constructions of the community.

Another related argument is whether the advancement of the law damages social constructions of the intersex community, or whether concerns over social constructions harm the advancement of the law for the community: Does the law come first, and thus advance the social construction, or does the social construction come first? While history may indicate that there is no clear answer, it may be that the advancement of the law, even if it is through the ADA, shifts the perspective of the intersex community forward rather than bringing *only* the burdens of negative associations of the disabled community.[190]

1. *Availability*

The ADA is the only current option for members of the intersex community. Intersex people cannot find legal protection from any other law, and the ADA may provide rights not previously available to intersex persons. For a community otherwise socially ostracized, grossly misunderstood, and socially shunned, the use of the ADA may actually elevate the status of intersex individuals into a more favorable category than its current social and legal status.

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[185] *Id.* at 79 (alterations in original) (quoting Mary Crossley, *Disability Kaleidoscope*, 74 NOTRE DAME L. REV. 621, 654 (1999)).

[186] *See id.* (recognizing the influence of social constructions of persons with disabilities).

[187] *Id.* at 82–83.

[188] *Id.* at 81.

[189] *Id.* at 82.

[190] *See, e.g.*, Brown v. Bd. of Educ., 347 U.S. 483, 500 (1954) (ordering the desegregation of schools during a time in which the majority of the U.S. population supported segregation); Kerrigan v. Comm'r of Pub. Health, 957 A.2d 407, 482 (Conn. 2008) (holding that the denial of marriage licenses to same-sex couples was unconstitutional during a time in which only four states recognized same-sex marriage).

Nevertheless, not all are persuaded that the intersex community can find protections under the ADA. One author writes:

> [I]t seems highly unlikely that an ADA case based on intersexuality would be successful without the presence of other conditions (such as depression) because in order to count as a relevant disability, a condition must impair a major life activity. . . . I do not know of any intersex conditions which impair major life activities such as these.[191]

To examine the statute in this constructionist form, however, narrows the scope of the ADA in the manner that Congress intended to undo with its recent amendments. While one could argue that the intersex condition is not related to disability or disability law because it does not cause any difficulties or inconveniences on its own, such an interpretation loses sight of the broad interpretation of "disability" intended by the amendments. Even assuming that the analysis in Part V(B)(2) is flawed in understanding and application, "disability is not simply a characteristic of one's body, but the product of social institutions that divide human bodies into normal and abnormal, privileging certain bodies over others."[192] The recently amended ADA supports this notion and remains consistent with legislative intent.

Some could argue that the lack of other legal remedies should not warrant the use of the ADA as a protective tool for the intersex community. This argument assumes that it is optimal to wait for non-discrimination laws or other new legal remedies to pursue intersex civil and human-rights discourse, rather than use the ADA, as being the only available option. Even with this counter-argument, the reality remains that intersex individuals can still qualify as persons with disabilities under the ADA, particularly given the variety of conditions that may leave an individual physically or mentally disabled. Even if other laws existed to protect the intersex community, the ADA, with statutorily defined disabilities that intersex people fit, may be the community's best forum. Intersex activists should not avoid using the ADA in the context of intersex individuals who have disabilities, whether due to damaging surgeries or experiences or from mental and physical conditions resulting from the stress of not squarely fitting into the male or female categories. Such a use would be appropriate and would protect a community in severe need of such protections.

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[191] Ilana Gelfman, *Because of Intersex: Intersexuality, Title VII, and the Reality of Discrimination "Because of . . . [Perceived] Sex*," 34 N.Y.U. REV. L. & SOC. CHANGE 55, 58 n.3 (2010) (citations omitted). Notably, this analysis relies on the 2006 version of the ADA, under which, as Gelfman aptly notes, it would have been difficult to successfully defend the application of the ADA to the intersex community. *Id.*

[192] Koyama, *supra* note 167.

This Note asserts Levi and Klein's compelling argument that potential social stigma should not justify denying critical federal disability protections. The intersex community cannot wait for alternative forms of protection, and social perceptions may change alongside the law as it expands to address the needs of those who face discrimination, those who are underrepresented, and those who may otherwise be left hanging in the balance.

VIII. CONCLUSION

This Note examined whether the intersex community and intersex individuals could be considered "individuals with disabilities" under the ADA, and the extent to which the ADA is the optimal legal option for the intersex community's ability to find legal protections. It examined whether the statutory language would include the community, as well as whether the intersex community could satisfy any of the prongs of the definition of an individual with a disability.

Arguments opposing the use of the ADA or comparable state disability law to protect intersex persons stem from the potential conflation of stigma and negative associations that would attach to both the intersex and the disabled communities and project those associations onto those communities. Moreover, the severe misunderstandings of the disabled and intersex communities could create significant difficulties in moving towards a more inclusive and forward-thinking perspective for both communities. As both face harsh stereotyping, stigmatization, and varying forms of isolation, the conflation could set the respective movements back.

Assuming that intersex individuals can find legal protections under the ADA, arguments that the ADA should be used to advance the rights of the community note that the ultimate issue is one of the social constructions of the intersex individual and not actual physical or mental disabilities. Moreover, that the use of disability law may impact social constructions of the intersex community should not warrant denying the opportunity for federal protection to advance much-needed rights for intersex persons, who do not otherwise have protected legal status in the United States.

Finally, despite the potential drawbacks of the use of the ADA to protect the intersex community—and given the need for rights and protections for an often hidden and less-vocal community—the ADA may be the only option for some time to come. As federal law falls far short of protecting LGBT persons and sexual minorities, the intersex community's ability to find legal protections under any other law in the near future is bleak. While the intersex community struggles to find protections in other areas of the law, the newly amended ADA may be the way in which this marginalized and insular community can move forward on a broader path to finding legal protections, respect, and most importantly, recognition. While shifting the medical and social dialogue is a gradual change in

perceptions and societal understandings, the application of the ADA may be that critical first step for a community long in need of it.