Basic Concepts, Commentary and Opportunities for Addressing Healthcare Inequality of Women with Disabilities

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INTRODUCTION
This article will explore the barriers, legal issues or policy tensions resulting from the interaction of or the relationship between gender and healthcare from the perspective of people with disabilities. Women with disabilities will constitute the focus of this article as they experience discrimination based on disability as well as discrimination based on gender. Notably, this author has a goal that this particular article provides a tangible and helpful tool for public officials on improving healthcare access and quality.

The prevalence of disability, and an exploration of the different prisms through which society understands disability as a construct, will be discussed. The article will subsequently juxtapose disability in the context of international human rights law and policy with the outstanding barriers experienced by disabled women in accessing healthcare services. At the conclusion of the article, the author will incorporate a set of recommendations for civil societies as they seek to design and implement compliance strategies consistent with the mandates of the Convention on the Rights of Persons with Disabilities.

II. PREVALENCE OF DISABILITY: A SIGNIFICANT, BUT MOVING TARGET
Persons with disabilities constitute the world’s largest minority population. More than a billion people, or about 15% of the world’s population, are estimated to live with some form of disability. In addition, it is estimated that twenty percent of the poorest people in the global community have a disability; they are often recognized as the most disadvantaged by their own communities. Furthermore, it is estimated that citizens of nations with a life expectancy above seventy years of age will spend an average of eight years as a disabled person. Concisely, the author will note some statistics about the region of the Americas.

In the region of the Americas, the Pan American Health Organization has estimated that 1 in 10 persons have some form of disability. As of 2010, there are approximately fifty-six million citizens with disabilities in the United States, or about nineteen percent of the population. Data illuminates that women with disabilities, the focus of this article, constitute a significant proportion of overall persons with disabilities.

Globally, women and girls who have some form of physical disability, mental disability, or some combination of disabilities thereof, equal in the range of three hundred million individuals. Women constitute three-fourths of people with disabilities in low- and middle-income countries. According to the World Health Organization, about 450 million people have a mental health disability. Mental health disabilities, including depression, disproportionately...
affect women and girls.\textsuperscript{16} While providing more information on the number of disabled persons, either by kind of disability or by region, is perhaps beyond the scope of this article; the key point is that people with disabilities, significantly comprised of women and girls,\textsuperscript{17} constitute the largest minority group within the global community.\textsuperscript{18}

The number of disabled people is on the rise. The expansion in the number of the disabled is due to increased longevity and an aging population; but it is also due to violence and armed conflicts.\textsuperscript{19} By 2025, the number of aged 60 or over is expected to double, reaching a staggering 1.2 billion persons.\textsuperscript{20} Throughout the world, the fastest growing segment of national populations is that of persons eighty-five years or older;\textsuperscript{21} and many of those persons are women because of their longevity.\textsuperscript{22} Women particularly sustain the brunt of conflict, becoming disabled at disproportionate rates to men.\textsuperscript{23} Moreover, it should be noted that poverty has a substantial impact on the number of the disabled; this is particularly true with regard to women who are disproportionately affected by poverty.\textsuperscript{24} As such, civil societies should recognize that disability will increase in the global community — not vanish.

III. WHAT DOES THE DEFINITION, DISABILITY, MEAN?

A disabled woman could have a myriad of opportunities for equal living, learning, and earning if her disability is understood as an aspect of diversity; therefore, receiving adequate accommodations.\textsuperscript{25} A disabled woman will be circumscribed in her opportunities if she is viewed as diseased and needing a cure. However, a disabled woman may have myriad opportunities for equal living, learning, and earning if the consequences of her disability are understood as a part of diversity, and the extent to which her disability imposes barriers, they should be accommodated.\textsuperscript{26} Consequently, a discussion of the medical versus social models of disability will occur at this point of the article.\textsuperscript{27}

At the working group, one of the discussants commented that the “working paper” did not address, in an adequate way, the interplay of the models of disabilities, namely the medical model versus the social model of disability. Alas. While there is a moment to explore the models, there is neither the time nor the purview to focus this article on the models of disability. The author has the hope that the concise discussion as well as a comparison among an issue that arose in furnishing healthcare services to a woman with an intellectual disability and a hypothetical example will demonstrate the difference among the models of disability.

The medical model is often noted as a factor in the lack of an accessible society for the disabled, including, but not limited to healthcare system.\textsuperscript{28} Society analyzes the disability of individuals in the medical model from a biomedical framework, defining disability through pathology and any resulting exclusions as “inherent in the individual” rather than the result of the interaction between impairments and physical barriers, programmatic barriers, or other barriers.\textsuperscript{29} The medical model has a fundamental presumption under-girding its focus on the inability of ability to be abilities of the disabled; namely the disabled cannot constitute contributing members of society until cured.\textsuperscript{30} “Even in the context of an international human rights system of treaties and monitoring bodies, disability has not always been understood as a rights issue, but viewed instead [consistent with the medical model] as a pathology of exceptional individuals.”\textsuperscript{31} In the medical model, people with disabilities are ill; as such, they may be excused from meeting normal social obligations. In addition, disabled people are malingerers if they do not submit to the treatments of medical providers and seek a cure.\textsuperscript{32} Thus, the medical model has\textsuperscript{33}, resulted in discrimination, and marginalization.\textsuperscript{34} An alternative to the medical model of disability is the social model of disability.

All citizens, including the disabled, should have affirmative human rights in today’s society. The social model of disability supports this notion, focusing on the need of society to accept the human diversity of people with disabilities and to accommodate their disabilities.\textsuperscript{35} As such, where physical or other barriers; or where discriminatory attitudes prevent the full inclusion of the disabled, they should be removed.\textsuperscript{36} Under this social model, or rights model, a person with disabilities, like all other persons, should receive any such supports and services necessary to exercising a full range of human rights.\textsuperscript{37} Slowly, if
steadily, society is, because of legal instruments like the Convention, in transition from the medical to the social model of disability.38

Given this background, comparing an example of an issue that arose in furnishing healthcare services to a woman with a disability and a hypothetical example of an issue much debate in the deaf or hard of hearing community might be helpful.39 An example of the medical model of disability may be found in a case of a woman with an intellectual disability and her eligibility for a life-saving transplant. The surgeons at a renowned education hospital balked at placing the woman with an intellectual disability on the waiting list for a transplant, believing she could not meet the post-transplant regimen.40 If a social model reigns supreme, then the obligation is on society to create and foster accommodations that equalize the status of disabled persons with the able-bodied. Technology, such as programs allowing a person with a hearing impairment to receive test results (communicated via a voicemail) into text is the kind of social model influenced advancement.41 Of particular interest to the discussion about the models of disability and how the disabled themselves are seeking to understand disability, there has been a debate in the deaf community about cochlear implants. There is, however, a segment, or even just individual deaf and hard of hearing persons, who accept the implants if sensible on a case-by-case basis. The author has attempted, given time constraints, to explain the two prevailing models of disability.

The convention has its affirmative obligations grounded in a shift from the medical to the social model of disability.42 Arguably, the broad range of affirmative mandates required of states parties in the Convention has the effect of demonstrating its social model nature. The Convention, a human rights instrument with a social development dimension,43 will arguably promote the human rights of people with disabilities.44 This article will next discuss the international framework respecting the human right to healthcare.

IV. INTERSECTION OF HEALTHCARE, INTERNATIONAL HUMAN RIGHTS, AND DISABILITY

A set of issues, not always, but increasingly recognized as a human rights issue, is that of disability. There is, consequently, a human rights infrastructure that requires brief discussion. As such, the author will briefly explore that infrastructure, seeking to note that, while robust, it did not always adequately address the issues and concerns of the disabled.

The Millennium Development Goals, adopted in 2000, request signatories to address poverty, and by interconnection, maternal and child health.45 In 2010, at the sixty-fifth session of the General Assembly of the United Nations, the members adopted the third of a series of Resolutions on Global Health and Foreign Policy, which among others, acknowledged the emerging world recognition that universal access to healthcare promotes and protects the right of each person to the highest obtainable level of health.46 Point 13 of the Resolution acknowledges, “The need to further address the issue of governance for global health as health is increasingly being challenged by new realities of an interdependent world.”47 Moreover, Points 3, 16, and 18 recognize the leadership of the World Health Organization as the primary agency of the United Nations in international health policy and urge members to link health as an aspect of their overall foreign policy.48 While the Millennium Development Goals have an important role in global health governance, especially with regard to the health of women, they do not have disability-specific targets, metrics, or criteria.49 Namely, there is a human rights infrastructure affecting the quality of life and equality of opportunity of women, including women with disabilities.50

The Preamble to the Constitution of the World Health Organization provides that health is a fundamental freedom of all persons, equaling “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”51 Additionally, The Universal Declaration on Human Rights, drafted in the same timeframe as the Constitution of the World Health Organization, provides for women, including what could be argued to be women with disabilities, to be free from all forms of discrimination, based on gender, in accessing their right to healthcare.52 In addition
to these hortatory documents, there are a range of international instruments that nations have ratified, affirmatively obligating their governments to certain legal and policy measures.

Article 12 of the International Covenant on Economic, Social, and Cultural Rights provides that each person, including individuals with disabilities, has the right to the highest level of obtainable physical and mental health.\textsuperscript{53} The Committee on Economic, Social and Cultural Rights in its General Comment 5 analyzes the obligations of States with respect to equal rights for men and women with disabilities before the law.\textsuperscript{54} Additional international instruments protecting women and their children are the Convention on the Elimination of Discrimination against Women and the Convention on the Rights of the Child.\textsuperscript{55} In 1998, The United Nations adopted the Universal Declaration on the Human Genome and on Human Rights.\textsuperscript{56} In the Americas, there is a regional focused human rights infrastructure.\textsuperscript{57}

The Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities (1999) aims to prevent and eliminate all forms of discrimination against persons with mental or physical disabilities.\textsuperscript{58} Member States, who are within the purview of the Pan American Health Organization, are supposed to “advocate,” “promote,” “protect,” and “safeguard” the human rights of certain groups in situations of vulnerability, especially in the context of services provided by their health agencies. Specifically, the relationship between the exercise of human rights and the enjoyment of health of people with physical and mental disabilities should be a priority to Member States. Finally, it is important to recall Resolution CSP26.R19 on the Extension of Social Protection in Health that establishes the mandate to extend social protection (through appropriate funding) in health.\textsuperscript{59} In addition, there are a range of soft legal instruments or policies that seek to safeguard the rights of the disabled.\textsuperscript{60}

Examples of soft laws are a range of lofty Resolutions and policies passed by the General Assembly at the United Nations, including the Declaration on the Rights of Mentally Retarded Persons [sic Intellectually Disabled Persons]\textsuperscript{61} and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.\textsuperscript{62} These soft laws or policies do not focus attention on disability-specific issues or address disability in a comprehensive way.\textsuperscript{63} Despite the existence of a human rights infrastructure, disability issues required their own attention.

The Convention constitutes the first human rights treaty of the second millennium, comprising what may be a great leap forward for the rights of the disabled in civil society. The Convention is unique among international instruments in that it is applicable to and enforceable on the basis of disability.\textsuperscript{64} In the next part of this article, the author will concisely discuss the Convention and its Protocol.\textsuperscript{65}

V. THE CONVENTION AND OPTIONAL PROTOCOL

Adopted on December 13, 2006, and entered into force on May 3, 2008, the text of the Convention is comprised of 25 preamble paragraphs and 50 Articles.\textsuperscript{66} As of the time the author researched and wrote this article for the conference that occurred in March, 2012, 108 states parties ratified the Convention and 63 states parties ratified the Optional Protocol.\textsuperscript{67} Likewise, 153 signatories and 90 signatories were in existence as of the time of the conference.\textsuperscript{70}

The Convention provides a range of affirmative obligations on states parties, ensuring the equal enjoyment of human rights by women or girls with disabilities.\textsuperscript{71} For example, Article 25 of the Convention provides a requirement that healthcare services be accessible.\textsuperscript{72} The Convention has a critical role in contributing not only to health and human rights law and their interconnection but also to the democratization of such law and policy for the world’s largest minority population.\textsuperscript{73} This article will focus on sundry provisions of the Convention that have a connection to the access of women with disabilities in experiencing the highest obtainable level of health.\textsuperscript{74}

A. Women with Disabilities: Articles of the Convention

In Article 3, General Principles, the Convention provides that state parties will recognize the equality of men and women.\textsuperscript{75} The Convention has specific reference to women with disabilities in Article 6, entitled Women with Disabilities; Article 16, entitled Freedom from Exploitation, Violence, and Abuse; and, Article 28, entitled Adequate Standard
of Living and Social Protection.\textsuperscript{76} Article 6 of the Convention urges that state parties should undertake proactive and on-going measures ensuring the equal enjoyment by women or girls with disabilities of human rights.\textsuperscript{77} Additionally, Article 6 of the Convention provides, “States parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of...human rights and fundamental freedoms.”\textsuperscript{78} Building on these general principles, many Articles of the Convention have robust text, addressing the full range of rights women enjoy as actors in civil society, including, but not limited to, the human right of healthcare.

B. Awareness Raising — Gender and Disability Stereotyping: Article 8

Article 8 of the Convention provides that states parties will undertake affirmative measures “to combat stereotypes, prejudices, and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life” throughout society, including especially at the level of the family.\textsuperscript{79} Article 8 of the Convention provides that measures to this end include, among others, public awareness campaigns promoting greater social acceptance of persons with disabilities, including with respect to their contributions to the workforce. Encouraging positive media images of persons with disabilities is an important measure referenced in this Article.\textsuperscript{80} In short, awareness raising measures as well as visibility of disabled leaders themselves constitutes critical measures in the advancement of affirmative rights.\textsuperscript{81}

C. Equal Recognition before the Law — Legal Capacity: Article 12; and Access to Justice, Article 13

A couple of provisions of the Convention have a notable impact on how people with disabilities interact with the legal system, including with respect to protecting their very right to be part of the community. Because people with disabilities have historically been relegated to the shadows on the guise of limiting decision-making and legal capacity, Articles of the Convention, such as Article 12, guaranteeing access to processes by which the disabled might dispute such limitations, are critical. Articles 12 and 13 respectively requiring community integration and access to the justice system are critical to people with disabilities in protecting their “civil health.”\textsuperscript{82}

Articles 12 and 25 are related in ensuring healthcare protections of people with disabilities.\textsuperscript{83} Arguably, Article 25 (Health) has the effect of reinforcing the principles in Article 12 related to the freedom to make decisions about one’s health care. Article 12 of the Convention is representative of “a paradigm shift” from substituted decision-making to supported decision-making.\textsuperscript{84}

Equal access to the justice system constitutes a felicitous development, ensuring that women and girls with disabilities will be in the position to enjoy their human rights.\textsuperscript{85} With Article 13 fortifying Article 12, a strong tool is put in place. According to Article 13 of the Convention,\textsuperscript{86} people with disabilities have an equal right to effective access to the justice system, whether as an employee, as a party, as a prisoner, or as a victim.\textsuperscript{87} This is to be achieved through the provision of reasonable accommodations.\textsuperscript{88} By having an accessible justice system, which recognizes the needs of the disabled, such as for accommodations or for alternative approaches to historical ways of dealing with the disabled in society, namely institutionalization,\textsuperscript{89} the disabled may have an enhanced role as to fundamental decisions, as best as they are able, about their care, about their community activities, about their supports, and about their living arrangements.

D. Respect for Home and the Family — The Right to Marry and Found a Family: Article 23

Article 23 of the Convention provides that, “States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others.”\textsuperscript{90} In addition, Article 23 recognizes that states parties will respect the family planning decision-making and reproductive choices of people with disabilities.\textsuperscript{91}
E. Freedom from exploitation, violence, and abuse: Article 16

Article 16 of the Convention provides that, “States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.” Furthermore, Article 16 of the Convention provides that States Parties will seek to promulgate, enact, and implement gender-focused legislation, regulations, and policies. On a sublegal level, they are to disseminate information, provide services, and ensure supports to prevent, to foster reporting, and to enhance prosecution of gender-based violence. Article 16 of the Convention also mandates that state parties will, through all appropriate measures, ensure the recovery, rehabilitation, and social reintegration of persons with disabilities through an environment that incorporates and includes gender and age specific needs.

F. Protecting the Integrity of the Person: Article 17

Article 17 provides that “[e]very person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.” As one Article discussed: “In the original drafts of this Article, specific mention was made of forced institutionalization and involuntary treatment but these were omitted in the final version due to differences in opinion as to the scope of this right. Arguably, Article 17, when read with the prohibition against torture or cruel, inhuman, and degrading treatment or punishment in Article 15, provides the basis for understanding forced psychiatric interventions as a violation of human rights.”

G. Health: Article 25

Article 25 of the Convention provides, consistent with the human rights framework for health, that, “States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.” Article 25 of the Convention requires that, “States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.” States parties are to undertake affirmative measures to ensure equal access to health, including, but not limited to, providing equal access to sexual and reproductive health information and programs. Article 25 specifies that States Parties must require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent.

In short, this Article of the Convention recognizes the importance of sublegal or sub-judicial approaches to improving the access and quality of healthcare services to the disabled, through many processes, including the proactive training of healthcare providers.

H. Information Access: Articles of the Convention

In international law, the right to healthcare has the effect of encompassing information access that protects against harm, disease complications, and preventable mortality. “[t]he right to health specifically requires that information be accessible to all.” Yet, in the new millennium, when technology is transforming everyday life, modes of communication and information acquisition and dissemination, including, but not limited to, the Internet, are an added barrier to the disabled having equal opportunities for living, learning, and earning. The Convention has the effect of addressing access to information, including through technology and alternative formats.

Accessibility is discussed in Article 9 of the Convention. In addition, Article 21 addresses freedom of expression and opinion and access to information. Education is discussed in Article 24 of the Convention. When interpreted comprehensively, these Articles provide a remarkable right of access to information and technology. Arguably, these Articles may serve as an important impetus for positive advancements in the equality of disabled persons.
I. Community Inclusion and Integration — Accessibility, Article 9; Adequate Standard of Living and Social Protection, Article 28; Article 19

According to the working group, there is a continued need to insist on the right to community inclusion. Article 9 of the Convention is important in that it language imposes affirmative accessibility mandates. Mandates regarding early-on universal design, and where existing, the removal of physical barriers and communications barriers are present in the Article. Article 28 of the Convention, which provides that “States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right....”107 States parties are to undertake, among others affirmative measures ensuring that women and girls with disabilities, including older adults, have equal access to social protection and poverty reduction programs.108 Article 19 of the Convention is important in that it language addresses the right of persons with disabilities to reside in the community, rather than, as has been the historical practice, in institutions excluded from the public.109 Under this Article, supports and services must be furnished first in the furtherance of having people with disabilities in the community; and institutionalization is a last resort.110 Taken together, these Articles provide for a strong legal framework to integrate and include the disabled.

J. Adequate Standard of Living and Social Protection: Article 28

Article 28 of the Convention provides that “States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right....”111 States parties are, to among others, undertake affirmative measures ensuring that women and girls with disabilities, including older adults, have equal access to social protection and poverty reduction programs.112

K. Enforcement

In short, the Convention and its Optional Protocol provide arguably “robust mechanisms to promote national compliance with and implementation of the obligations” set forth in the instruments.113 While this article cannot hope to serve as a catalog of the many provisions of the Convention and its Optional Protocol, it is worth noting that these instruments are unique among international human rights instruments in that they have specific and strong provisions and language regarding national level monitoring.114 Articles 31 through 40 provide the monitoring and reporting mechanisms of the instruments imposing affirmative obligations on states parties to actively comply with and implement the affirmative obligations and to involve people with disabilities in such process.115 The Convention has a state reporting mechanism, and reports are submitted to a Committee on the Rights of Persons with Disabilities at the United Nations.116 While not enforceable and often confidential, the Optional Protocol to the Convention provides for additional mechanisms to focus attention on human rights violations of state parties and to encourage state parties to address violations. Namely, it provides for the transmittal of communications and the convening of investigatory inquiries regarding egregious violations.117

The foregoing discussion may be a good source for public officials to consult in seeking to address healthcare inequality. There is a range of barriers encountered by disabled women and girls in accessing healthcare services. The article will subsequently address the kind of barriers confronted by women in enjoying their rights and in obtaining the highest level of healthcare. In the analysis part of the article, the author will then seek to incorporate the recommendations of the working group in terms of how the affirmative mandates of the Convention might be applied to redress the barriers.

VI. BARRIERS ENCOUNTERED BY WOMEN WITH DISABILITIES IN ACCESSING HEALTHCARE SERVICES AND SOCIAL SUPPORTS

The deprivation of rights to one classification of individuals weakens the human rights of all.118 There is a “special situation” of women or girls with disabilities who are disadvantaged not only because of gender, but also because of disability.119
Levels of social position, as well as disadvantage, are divergent among women and men.120 “While women with disabilities have much in common with men with disabilities, women with disabilities have to face multiple discrimination in many cases, so that they are often more disadvantaged than men with disabilities in many circumstances.”121 Women with disabilities are likely to be unemployed or underemployed, are likely to be poor, and are likely to be excluded from equal access to an array of services, supports, and systems provided by civil society.122 An array of issues disproportionately and uniquely affects women with disabilities as opposed to men with disabilities.123 A women’s health organization in Australia eloquently wrote in a policy paper about the rights status of women with disabilities in Australia that: “The denial and infringement of women with disabilities right to health can be seen in an array of human rights violations: they experience violence at higher rates than their non-disabled sisters, experience less control over what happens to their bodies, have less access to vital health care services, such as cervical and breast cancer screening and, face discrimination, societal prejudice and stigma when it comes to determining their reproductive right.”124 A brief discussion of the barriers encountered by women with disabilities within the healthcare and related social systems will ensue.125

A. Introductory Review of Prejudice, and its Stigmatizing Effect on the Body and Reproductive Choices

A full range of sexual feelings, desires, needs and problems are experienced by all people with disabilities.126 Perhaps this is a mind blower to society; people with disabilities are sexually active, reporting as equal sexual desire as the non-disabled.127 People with disabilities, especially women with disabilities, do encounter, however, an array of issues in accessing and enjoying sexual and reproductive health services and opportunities.128 Contained below is the briefest of discussions on disability and sexuality.

Civil society often stigmatizes the body of women with disabilities, thereby decreasing positive body images.129 “The long and shameful history of stigmatization of sexuality, reproduction, and parenting by people with disabilities is well known.”130 As the following attitudes, notions, or belief systems demonstrate, the bodies of women with disabilities are stigmatized.

Only independently functioning women can handle sexual relationships. Disabled women who are single are celibate. Youth and beauty are essential to sexuality.131 Even if they are in the position for sex, disabled women should be grateful for sexual relationships. Given this illustrative manifest of attitudes about the disabled and their sexuality, that the disabled encounter problems finding potential pro-disability partners should be no source of shock.132 Disability has an impact on a relationship just like any other aspect of human difference. Unlike other types of differences, the attitude of greater society of disability as pathology may prevent a relationship from beginning, or may create conflict within a relationship.133 Once those barriers are overcome, then questions of sexual arousal and gratification may arise.134 This article will discuss the issue of sexual intercourse, then shifting to a focus on procreation and child rearing.

The presence of a disability does not preclude sexual activity. However, sexual intercourse may necessitate adaptation to accommodate limited movement, fatigue, pain sensitivity, lack of sensation, or other disability-related factors.135 Women with disabilities need to be just as careful as able-bodied women in preventing sexually transmitted diseases or in informing their decisions about family planning, including birth control.136 The story below describes disability and sexuality.

A woman with a spinal injury named Angela Rockford stated that, “Sexy is not about sensation.” She recounted the impact of her disability on sexuality, expressing that, “It took time to recognize that what I was feeling during sex was less about physical sensation and more of a mental build-up. It’s mind over matter, but there’s definitely a release. It was completely frustrating at first, but I think part of the healing process was learning the ways my body works differently after my accident.”137 Should she find her way to the bedroom or other room, she may encounter additional barriers should she and her partner desire to procreate.
The reproductive choices of disabled women are typically discounted.\textsuperscript{138} “Whether a woman is born with a disability or acquires it later in life, the message she gets from the medical system and society is that she is ineligible for normal societal female roles as lover, wife, or mother.”\textsuperscript{139} A well-entrenched notion holds that women with disabilities are not entitled to or should not be allowed to procreate.\textsuperscript{140} Pregnancy is an intimate decision for women regardless of disability.\textsuperscript{141} “Women with disabilities, however, often are not allowed to make such choices independently.”\textsuperscript{142} People often believe that disabled women cannot be mothers and that all disabled women are heterosexual.\textsuperscript{143}

People with disabilities encounter an array of issues with their reproductive health.\textsuperscript{144} Women and girls with disabilities are perceived as ill, and as such many believe it is in the best interest of the disabled women not to procreate.\textsuperscript{145} Specifically, women and girls with disabilities are sterilized, violating their human rights.\textsuperscript{146} One would hope that the type of attitude expressed in the famous domestic case of Buck v. Bell where Associate Supreme Court Justice Oliver Wendell Holmes stated that three generations of imbeciles are enough would be antiquated. Yet, that notion is held by some civil society actors and women with disabilities are still the victims of sterilization. If a disabled woman surmounts these attitudes, then she may encounter physical or programmatic barriers in accessing her healthcare.

**B. Access to Health Services: Physical and Communications Access**

Women with disabilities are the subjects of unequal healthcare services, such as gynecological examinations. Specifically, Women with disabilities often encounter physical, attitudinal, and policy barriers in seeking to meet their health care needs.\textsuperscript{147} Even when a Provider, meaning a party who furnishes healthcare services, is not outright discriminatory, their benign neglect or treatment decisions can have the effect of discrimination.\textsuperscript{148} A mixture of physical as well as communications barriers will be concisely set forth herein.

Unequal access, in a physical sense, is a serious detriment to the overall health and welfare of women with disabilities. Physical barriers may include inaccessible entrances to healthcare facilities as well as inaccessible medical diagnostic equipment, such as weight scales.\textsuperscript{149} Women with disabilities cannot access diagnostic medical equipment, such as mammography machines.\textsuperscript{150} In addition to physical or programmatic barriers, the inability or unwillingness of Providers to accommodate sensory impairments may pose barriers.\textsuperscript{151} The disabled may encounter inaccessible websites when they seek to interact with insurance companies, healthcare service providers, or even the government.\textsuperscript{152} “In addition to barriers of physical access, disabled people are often marginalized because they are unable to access information or other material.”\textsuperscript{153} In terms of requiring accommodations, such as specialized formatting or design specifications, people with sensory disabilities are notably disadvantaged by these inaccessible platforms.\textsuperscript{154} As Michael A. Schwartz states, “[u]p to two million deaf people in the United States use sign language to communicate, but when they need to see a doctor, they find that many medical offices and hospitals are ‘aurally inaccessible,’ that is, they lack appropriate auxiliary aids for deaf patients.”\textsuperscript{155} The complexity of information may also create accessibility problems for people with intellectual disabilities\textsuperscript{156} Thus, the failure of a Provider to provide auxiliary aids or services necessary to ensure that a woman with a disability is not segregated or otherwise excluded is a violation of the American with Disabilities Act\textsuperscript{157} and arguably also a human rights violation.

Advancements in healthcare technology should provide valuable information to the procreative decision-making of people with disabilities. If a social model of disability shapes the conversation about disability rights, then advancements in healthcare technology should allow for the treatment of conditions of the fetus that may lead to disabilities or at least enable parents to plan for accommodating such disability. The wondrous developments in healthcare technology have the effect of increasingly allowing humans to peer earlier and earlier into the beginnings of life. If parents have the ability to peer into the early stages of life of their child, obtaining information about the possibility of a disability by a pro-disability medical Provider; such parents will be in the position to maximize this information-sharing to plan for and implement community-based
supports and services. However, bias, prejudice, and discrimination are pervasive.

People with disabilities have notable health disparities. Women with disabilities suffer higher rates of disease and injury, including, but not limited to their sexual and reproductive health. As evidence of overall health disparities, sexual and reproductive health will be mentioned, once again.

Receiving that annual set of routine examinations, such as a Pap test and breast examination is not always that simple for a disabled woman. “Falsely assuming that women with disabilities are asexual leads health care providers to withhold needed information and services.” Women without disabilities receive mammograms eleven percent more frequently than women with physical disabilities. Breast examination are important not only for all women, but in circumstances where a woman’s disability limits her ability to self-monitor her gynecological health. Various studies show that women with disabilities suffer higher rates of cancers, including gynecologic cancers because they are not receiving important screenings. Given the bias, discrimination, and stereotypes pervasive in the Provider community regarding the asexuality of women with disabilities, sexually transmitted diseases in women with disabilities are less likely to be reported or even detected. In addition to their sexual and reproductive health, women with disabilities have notable health disparities as to other health issues, such as maintaining a healthy cardiovascular system and in preventing cardiovascular disease.

Heart disease constitutes a leading killer in the United States, particularly impacting women. Women with disabilities are less likely to receive screenings for cardiovascular disease. As such, it is not difficult to understand that women with disabilities also encounter barriers in ensuring their overall heart health. The couple of stories provided below will attempt to furnish the seriousness of the discrimination experienced by the disabled.

Annual examinations, such as pap tests, are the important part of a health regimen. Yet, many women with disabilities have barriers in accessing these important, and even life-saving examinations.

Just as one example, a 69 year-old woman experienced a stroke, which paralyzed her right arm and leg. Before the on-set of her disability, she always received regular physical examinations. Given her limitations and the inaccessibility of medical Providers, she wondered how she would access a physical examination, such as climbing onto an exam table for a breast exam. The author will briefly discuss how animals sometimes play into health disparities.

When a handler of a highly specialized bred and trained guide dog navigates into an array of medical Providers, such as a physician office or a hospital, she often receives a similar rebuff. All too often, a Provider will disgorge the shibboleth “no dogs allowed.” For example, the reception staff refused a woman with a guide dog to visit her son who was to be examined. Naturally, the front office staff, specifically the office manager, rebuffed the request for access of the guide dog because of the lack of a written policy on interacting with people with disabilities. The office manager claimed to the police that denying access was for the safety and comfort of the woman and of her dog.

The experience of a Canadian woman, a well-accomplished computer program designer, who is blind and who resides in Ottawa, describes the invidious discrimination still in civil society. Donna, an accessibility consultant, could not apply for a position utilizing an on-line jobs site because it was not structured to work with a screen-reader.

In the experience of this author as a Civil Rights Commissioner, the argument of the Canadian government embroiled in the litigation is, not unlike governments and others in the United States, where some believe that full access to the Internet is a “special right.” The Canadian government argued that the website is discretionary and that Donna could access the same information through alternative means, such as via telephone.

C. Institutionalization

Institutionalization still has, and has historically had, a detrimental impact on the integration and inclusion of the disabled. People who are institutionalized reside in some form of communal housing with various medical supports and
services. In these areas, they are the subjects of strict regimentation, where they are unlikely to have strong self-determination, and where they are unlikely to be full participants in their own healthcare.\textsuperscript{185} The institutionalization of people with all forms of disabilities is an unfortunate mechanism of promoting the stigma in that ostensibly allows civic society to hide people with disabilities out of sight, leading to the diminished social capital, as well as poor health and welfare.\textsuperscript{186} Notably, people with all forms of disabilities are usually the subjects of deplorable living conditions.\textsuperscript{187} Institutionalization has been specifically shown to lead to abuse and neglect.\textsuperscript{188} Thus, institutionalization has the effect of weakening the health status of people with disabilities.

D. Violence and Abuse

1. Gender and Disability—Intimate partner Physical Violence Abuse and Violence by a Partner or Family

A woman with a disability named Tracy, an Executive Director of an Independent Living Center in Ontario, Canada, sustained domestic violence by her abusive and non-disabled husband.\textsuperscript{189} According to Tracy, she played “Ms. Executive Director by day” and her husband beat her at night.\textsuperscript{190} The domestic violence would cycle through the typical progression of outbreaks and then fawned harmony, worsening when the couple moved to South Africa for the husband’s employment.\textsuperscript{191} At the eventual criminal trial of the husband, the husband’s defense attorney attempted to justify the abusive relationship, based on Tracy’s disability.\textsuperscript{192}

An interview between Human Rights Watch and a Ugandan woman with a hearing impairment in 2010 found the disturbing prevalence of disability as a justification for domestic violence.\textsuperscript{193} “I was hated because I was deaf, even by my parents. My mother used to beat me so much.” The interviewee expressed that, because of her disability, “There was a time when another relative pierced me [points to a scar on her leg].”\textsuperscript{194}

2. Abuse and Violence by Personal Attendants & Care providers

People with disabilities, who are particularly from the mobility impaired community, may rely on third persons for additional support in performing daily living tasks, such as bathing. As might be imagined, interacting with and even relying on a third party for personal and intimate tasks may lead to vulnerability and even harm. This article will dispense with a longer discussion, providing an example as evidence without the need for further explanation.

Just as one example, a gentleman named Jefferson, a 51 year old insurance adjuster, has cerebral palsy. The severity of his disability required Jefferson to have a personal attendant. His former home health care aide persisted with unwelcome sexual advances, forcing Jefferson to terminate the employment of the person.\textsuperscript{195}

3. Criminal Acts, E.g. Sexual Offenses

In Zimbabwe, a young girl with a disability attended a residential academy.\textsuperscript{196} Her instructor committed rape.\textsuperscript{197} “I could not report the matter to any one, as I did not know whom to trust anymore because the school matron had let him rape me.”\textsuperscript{198}

In 2004, a Canadian woman with a mental health or intellectual disability expressed to her teacher that she and her stepfather played a “‘hugging’ game.”\textsuperscript{199} The stepfather of the disabled woman would touch her genitals and buttocks.\textsuperscript{200} In 2005, the disabled woman described the game to police, and when her sexual assault case went to trial, the defendant initially received an acquittal based on the disability of the woman.\textsuperscript{201}

These stories provide a basic understanding that gender-based violence, including, domestic violence, is all too common, occurring throughout the life cycle.\textsuperscript{202} “Domestic violence against women with disabilities is disturbingly prevalent.”\textsuperscript{203} Women with disabilities have been estimated to be twice as likely to constitute the victims of intimate partner abuse as women without disabilities.\textsuperscript{204} Gender-based violence may occur in myriad forms, and it may include, but not be limited to, sex-selective abortion or selective abortion, battery during pregnancy, physical and psychological violence within intimate relationships, and genital mutilation.\textsuperscript{205} Abusers may uniquely target the specific disability of the woman.\textsuperscript{206}

Violence may, whether perpetrated by a spouse, a family member, or a personal care attendant, have several forms, such as physical violence, or
even killing a pet. For instance, an abuser might intentionally harm an assistance dog of a woman with a disability or disable her assistive devices. Again, violence against people with disabilities may be psychological or emotional in nature. There may be glares in a crowded establishment that a sighted spouse would be married to a blind spouse and his furry partner. Sometimes disabled persons, including those who are emerging leaders in disability rights are exposed to criticism for marrying a non-disabled person, regardless of how supportive and disability friendly the non-disabled spouse may be. Alternatively, people with disabilities are, in the view of some, justified as the victims of violence because they are not whole people. Because of these factors, women with disabilities are likely to constitute the victims of violence, and because they are historically excluded from equal access to information and services, they are unlikely to recover. Additionally, women with disabilities are often excluded from domestic violence prevention information and programs, post-violence habitation, and rehabilitation.

E. End-of-life Issues

“I hate the men who would prolong their lives by foods and drinks and charms of magic art perverting nature’s course to keep off death … when they no longer serve the land to quit this life, and clear the way for youth.” As the population in each nation ages, public policymakers will continuously confront end-of-life issues. The higher acuity of services posed by older adults at the end-of-life and its influence on healthcare rationing is among the range of issues they must confront in formulating public policy.

The disability rights community argues that rationing will only result in the modern day gatekeepers of The Tree of Knowledge — where a physician selects who is deemed to be worthy of life. Masked as procedures, services, and therapies intended to alleviate suffering and humanely hasten death, such healthcare, scientific, and technological developments, such as Physician Assisted Death, have been argued to be expressions of the dream of the eugenicist realized at the end-of-life. Providers are likely to engage in rationing, i.e. selecting, based on prejudice about life with a disability, healthier individuals over the disabled. In other words, Providers ostensibly utilize their storied status to differentiate between the strong and the weak, with the disabled receiving the negative brunt of science and technology. Arguably, practices such as Physician Assisted Death rarely constitute a free decision of the disabled, especially the intellectually disabled. As such, people with disabilities of any age, who have a terminal condition, may morph into unintended victims of health care rationing due to larger prejudices of society. Thus, people with and without disabilities should be cautious, but should not, at the same time, reflexively condemn options.

Developments in healthcare, science, and technology can, if not counterbalanced by bioethical and legal safeguards, outstrip the spiritual power of each human, leading to a nightmare-like society. In profit driven healthcare systems, to be specific, minority populations for which there are noted disparities are likely to receive the negative impact of healthcare rationing or scientific and technological developments, or both. “There is a long and regrettable history of scientific discrimination against people with disabilities….” Conversely, when there is properly diagnosed terminal condition it is imprudent to dismiss the ability of any individual with or without disabilities to participate in end-of-life planning, decision-making, and choices, even if that means ending life.

VII. CONCLUSION

The global community is presently poised at an epoch in history in which tangible improvements in the rights status of people with disabilities can be achieved. Innovations in healthcare service delivery, or science and technology, such as personalized medicine, various forms of genetic screening and testing, and concierge medicine, have the potential of providing benefits to or diminishing the rights of people with disabilities. No one in civil society should be arguably disadvantaged by barriers that prevent them from accessing services available to without limitations. Should healthcare science and technology outstrip human spirituality, uniqueness, and individuality, then individuals with or without disabilities will denigrate to the level of the widget. Thus, an important centurion against the sinister forces
of civic society that have been historically expressed through a range of means, including healthcare, science, and technology, is the law. The Convention on the Rights of Persons with Disabilities is an important component of that legal framework.

This article, initially utilized at a conference in March, 2012, attempted to describe some of the barriers and also an international human rights development that might catalyze its redress, the Convention.228 “In an age of pervasive eugenics, where the inherent dignity of every human being and the objectivity of ethics is [sometimes legitimately] doubted,”229 the experience of people with disabilities within the healthcare system results in frustration at best and discrimination at worst.230 Notable barriers related to health as well as social supports and services, such as equally accessing physical brick-and-mortar facilities, compounds their exclusion.231 232 As this article has attempted to show, there is arguably a gap between the law and its day-to-day implementation, development, and compliance.233 While a need for affirmative panoply proactively formulated and actively enforced is certainly important, often the law is the mere work product of a legislator if acculturation to the standards, norms, and morals it should reflect, is flagging.234 “Factors that can influence attitudes in relation to belief or behavior toward disabled people [sic] are a fundamental issue, as the improvement of attitudes toward this group in society must remain high on the agenda of social policy if disabled people are to be full members of society.”235 As such, conferences, such as the parties herein hosted, constitute an innovative tool or approach for bringing diverse individuals together to discuss and perhaps formulate solutions to vexing public policy challenges. This article would be remiss without mentioning the United States and its role with regard to the Convention.

The Convention discussed in this article will only apply to the United States if its Senate ratifies the instruments.236 In summer, 2012, the Foreign Affairs Committee of the United States Senate favorably reported ratification of the instruments.237 The authors do understand that the Senate Majority Leader, as of the time of editing this article, Harry Reed of Nevada, has indicated he will bring the issue to the floor should there be the votes.238 If the United States ratifies the Convention, then the Convention and the monitoring mechanisms attached to the Convention will ensure the United States is accountable.239 Disability is in part a result of societal normative frameworks,240 historically subjecting such persons to an inadequate social status. Society should, in accordance with the social model of disability, aim toward eliminating the practices that create health disparities.241 There is, building on the law, a need for an array of mechanisms and approaches to acculturating Providers to the rights of this minority population.

1 L.L.M. with Certificates in Administrative and Healthcare Law, American University, Washington College of Law, May 2011; J.D. Cleveland-Marshall College of Law, May 2000; and B.A. Wright State University, June 1997. As a disabled person, and as a Civil Rights Commissioner in Maryland, the author has a strong interest in resolving the inaccessibility of the healthcare system. The author is also the Co-founder, Vice President, and Corporate Secretary of the Mid-Atlantic Lyceum. Views expressed in this article do not represent the views of any organization with which the author is employed, engaged, or associated — now and in the past. Specifically, this article does not represent the views, opinions, or policies of the United States Department of Health and Human Services. The author acted on his own time, and did not act as an agent, representative, or spokesperson in writing this article. Simply, these are the sole opinions of the author. This article would not be possible without the assistance of notable leaders with disabilities who have gone before this instant author and who also helped in some manner to advance this article towards its publication. For instance, thanks are owing to Janet E. Lord, Esq. and Stephanie Ortoleva, Esq. Moreover, any note of thanks would be inadequate if not targeted at the favorite of all women of this author, his wife, Laura N. Norman, L.C.S.W.-C. She is to this author in terms of affection and appreciation like that of First Lady Abigail Adams to President John Adams. This author is grateful for her understanding of the many hours each of his projects demands on their time together.

2 In the Republic, Plato recounted the words of his instructor, Socrates; words that still have relevant meaning in an age of iPhones. The didactic conversation contained in that opus stated, “You know also that the beginning is the most important part of any work, especially in the case of a young and tender thing; for that is the time at which the character is being formed…” See the Republic. http://classics.mit.edu/Plato/republic.3.i.html (last visited July 30, 2012). This instruction, while discussing arguably children and their roles as future philosopher kings, also has relevance to any endeavor, including the current publication. Id.

Where applicable, this opus may discuss affirmative measures that Maryland could undertake; however, its applicability is obviously not limited to Maryland. Measures discussed in this opus could be undertaken, and are encouraged to be undertaken, by any local, or province, or state jurisdiction; or nation; or compact of nations. The instant author constitutes an emerging public official in Maryland. Serving on the Maryland Commission on Civil Rights, the instant author hopes that Maryland will undertake affirmative legal, legislative and policy measures to improve healthcare access of the disabled. One such approach this author supports is a multiple stakeholder engagement process. See, e.g., Debra T. Berube & Gary C. Norman, Improving Healthcare Accessibility for People with Disabilities: A Call to Maryland’s Leaders, 45 Mo. B. J. 12 (Mar.-Apr. 2012).

The reader should be advised that this article may utilize people with disabilities or “disabled” as a modifier. As a person with a disability, the author utilizes any such word with the best of intentions, namely from a pro human and civil rights bent. That being stated, the author realizes that some individuals may have sensitivity or even hypersensitivity about word usage.

This author initially drafted this article as a “working paper” for a conference on global health, gender and human rights hosted by American University, Washington College of Law in conjunction with the Pan American Health Organization. At the conference, attendees divided into working groups, developed recommendations, and reported on those recommendations at the closing session.


11 In other words, one out of every five Americans has a disability. At least half of this overall demographic reported having severe or targeted disabilities, such as blindness. See U.S. CENSUS BUREAU, U.S. DEPARTMENT OF COMMERCE, P70-131 AMERICANS WITH DISABILITIES: 2010, at 4 (2012).


13 See Women in Development, supra note 7.

14 Id.


17 Compare Orteola, supra note 12, at 90, with Gender and Women’s Mental Health, supra note 16.

18 See World Facts and Statistics on Disabilities and Disability Issues, supra note 8.

19 See Orteola, supra note 12, at 89, 93.


22 See Orteola, supra note 12, at 93.

23 See World Facts and Statistics on Disabilities and Disability Issues, supra note 8.

24 A consistent point of discussion with the staff at the Washington College of Law and the Pan American Health Organization in drafting this article, and at the conference, including within the working group, was that the author should attempt to address the models of disability. As the goal for this particular article is, and was always a basic introduction of the topic of gender and global health and their interconnection with disability, any such discussion has to be circumpect in nature. For a broader discussion of this issue, at least in terms of two models, compare Gary C. Norman, Reexamining Models of Disability and Applying Rationality, Morality, and Ethics to Support Disability Rights in the Context of Genetics, ASS. U. HEALTH L. & POL’Y. BR. 20-34 (Spring 2010), with Jared D. Cantor, Note, Defining Disabled: Exporting the ADA to Europe and the Social Model of Disability, 24 CONN. INT’L. L. 399, 401 (2009).

25 See Elizabeth A. Pendo, Disability, Doctors, Dollars: Distinguishing the Three Faces of Reasonable Accommodation, 35 U.C. DAVIS L. REV. 1175, 1191-94 (2002) (discussing various models of disability, including a focus on the medical versus social models of disability).

26 See generally id., at 1191-94.

27 See Lord et al., supra note 20, at 566.


30 See Pendo, supra note 26, at 1215 (quoting American sociologist Talcott Parsons).

31 See Norman, supra note 25, at 25-26 (discussing the view that the models of disability must be understood in tandem).


33 Samaha at 1257-58, 1268-69.
37 See id. at 9-10.
38 As compared in the examples herein.
39 Armando Vasquez, a physician who served as a facilitator at the working group, commented that the medical and the social models of disability have to be integrated in improving service delivery. He expressed that they both have relevance to shaping the interaction of the disabled with the healthcare system. This author agrees.
40 She eventually received a transplant, becoming the first woman with an intellectual disability to receive a heart and lung transplant. See Mary Crossley, *Becoming Visible: The ADA’s Impact on Healthcare for Persons with Disabilities*, 52 Ala. L. Rev. 51, 65 (2000).
42 Lord et al., *supra* note 20, at 564.
43 Joan Durocher, Esq., General Counsel, National Council on Disability, Lecture at Indiana University School of Law: Convention on Rights of People with Disabilities/ Legal Ramifications And Trends (Mar. 4 2009).
44 Id.
47 Id. ¶13.
48 See id. at 3-5 (suggesting that member states should consider foreign policy and global health in concert and emphasizing the central role of the World Health Organization in health policy formulation).
49 *See Disabled People’s International*, *supra* note 15, at 2 (stating that the Millennium Development Goals do not specifically address mental health disabilities).
50 See generally Vasquez & Vasquez, *supra* note 10 (discussing the intersection of international human rights and healthcare).
52 See Lance Gable, *Reproductive Health as a Human Right, 60 Case W. Res. L. Rev. 957, 977-78 (2009-2010) (noting that the Universal Declaration on Human Rights requires guarantees for individual access to health-related resources and emphasizes the special status of women and motherhood).
53 Vasquez & Vasquez, *supra* note 10, at 3-4.
54 Id. at 8.
57 See Pan American Health Organization, Res. No. CD50-R8 (urging health authorities to utilize human rights treaties and standards to reform health systems, collaborate with actors in the civil society, including the legal system, and train health providers on human rights obligations); Pan American Health Organization, *Health and Human Rights, Doc. CD50/12* (recognizing the unifying conceptual and legal framework enshrined in international and regional human rights instruments).
62 Id.
63 See Stein, *supra* note 60, at 679 (lamenting that “hard” laws do not expressly target disabled individuals and “soft” laws are not legally enforceable).
64 See id. (holding that before the Convention, no human rights instrument combined applicability to and enforceability by disabled persons).
68 Id.
70 Id.
73 See Lord et al., *supra* note 20, at 564.
74 Again, this is the simplest of overviews, focusing on the sole group within the gender classification — women. Subgroups within this classification who have interesting and
perhaps unaddressed issues, but who this article will not discuss for purposes of brevity, in accessing healthcare services are — the Gay, Lesbian, Bi-sexual, and Trans-gendered. The article on this subgroup, also published in this symposium edition, may discuss their specific issues in access to healthcare.

75 G.A. Res. 61/106, supra note 65, at 5.
77 G.A. Res. 61/106, supra note 65, at 7.
78 Id.
79 Id. at 8.
80 Id. at 8.

For instance, consult the forthcoming article of this author discussing an experience at the United States Supreme Court, which will appear in the winter alumni newsletter of Guide Dogs for the Blind.
83 Lord et al., supra note 20, at 573-74.
84 Again, the author wrote this article as initial background on which leaders involved with the conference could comment through a website. This author would thank the many contributions of Professor Robert Dinerstein of the Washington College of Law to this article and to the conference. See Comments of Robert Dinerstein to Gary C. Norman, available at http://new.paho.org/wcl/?page_id=800. This author agrees with the views put forward by the professor as to the shift the Convention represents; it is from substituted to supported decision-making. A helpful tool in this regard is elder mediation. Consult Robert J. Rudy, Esq. Senior Mediation Reaching the Tipping Point, 41 Mo. B. J. 12 (Mar.-Apr. 2008), available at http://www.mlsba.org/departments/commpubl/publications/bar_journ/v41/v41n2.asp.
85 Compare id. at 296 (noting that the International Covenant on Economic, Social and Cultural Rights recognizes the importance of a judicial or administrative remedy, but an effective remedy does not always need to be judicial) with Ortoleva, supra note 82, at 287-88 (arguing that access to justice is a fundamental right).
86 See id. at 291-92 (discussing the language of Article 13 of the Convention).
87 See generally id. (discussing the United Nations Convention on Rights of Persons with Disabilities); id. at 299-312 (highlighting areas in which individuals with disabilities have been denied access to justice).
91 See id. (discussing respect for home and the family).
92 Id. at 10.
93 Id.
94 Id. at 11.
96 See Vasquez & Vasquez, supra note 10, at 5.
97 G.A. Res. 61/106, supra note 65, at 15.
98 Id.
99 Id.
100 Id.
101 See McSherry, supra note 95, at 573-574.
103 Id. at 434.
104 G.A. Res. 61/106, supra note 65, at 8.
105 Id. at 12.
106 Id. at 14.
107 Id. at 17.
108 Id.
109 Id.
110 Id.
111 Id.
112 Id.
113 See Lord, supra note 20, at 569.
114 Id. at 570.
115 Id.
116 Id.
117 Id. at 570-71.
119 Id.
120 See Ortoleva, supra note 12, at 90 (discussing a gender-sensitive approach to politics).
121 Id.
123 Ortoleva, supra note 12, at 92.
125 In no way will this constitute an all-inclusive discussion; it is a starting point for the reader.
Holly Anne Wade, *Discrimination, Sexuality, And People With Significant Disabilities: Issues Of Access And The Right To Sexual Expression In The United States*, 22 No. 4 DISAB. STUDIES QUARTERLY (2002), available at http://www.dsq-sds.org/article/view/369/485 (“At the turn of the century, many individuals with significant disabilities began to realize their dreams and have their rights recognized. During the past two decades, the quality of life for individuals with significant disabilities has improved. As a result of groundbreaking litigation, disability rights legislation, advocacy on the part of persons with disabilities and their family members, people with disabilities can no longer be subjected to institutionalization, involuntary sterilization, over medication, over restraint, aversive interventions, and denial of health and other care (Mitchell, et al., 2000). However, history continues to perpetuate misconceptions about sexuality and disability.”).

129 Id.
130 See Pendo, supra note 127, at 16.
132 Hershey, supra note 126, at 388.
133 Id.
134 See id. (describing the barriers to disabled women understanding and feeling comfortable with their sexuality).
135 See id. at 388 (discussing some of the physical barriers disabled women when engaging in sexual activity).
136 See id. at 387 (discussing how disabled women face barriers to accessing education related to sex).
141 See Volz, supra note 138, at 211 (addressing generally the intimate nature of the decision to reproduce).
142 Id.
143 Basson, supra note 131, at 359.
145 Id.
148 Volz, supra note 138, at 211.
149 See Pendo, supra note 127, at 18 (discussing how even after over 15 years after the passage of the Americans with Disabilities Act of 1990, women with mobility impairments face inaccessibility to medical equipment).
150 Id.
151 Id.
152 See generally, Joshua L. Friedman & Gary C. Norman, The Norman/Friedman Principle: Equal Rights to Information and Technology Access, 18 Tex. J. On C.L. & C.R. (forthcoming Winter, 2013) (this is but one example of a source discussing the impact of technology access as regards opening opportunities for equal living, learning, and earning. In this article, the authors discuss technology access, the barriers to such access, and a way moving forward for thinking about the law and its application to technology access.). See also, Thomas R. Burke, *Starting and Managing An On-line Business*, 1 International Law & Practice, §5.1 (Updated July, 2012).
154 Id. at 567 (finding that websites pose the greatest risk of harm).
156 Lawson, supra note 153, at 567.
157 See Crossley, supra note 40, at 60 (discussing the added burden created by providers’ failure to provide auxiliary aids and services).
158 See, e.g., Norman, supra note 25, at 27.
160 See generally, Pendo at 159-60.
161 Id.
162 See Pendo, supra note 127, at 43.
163 Id. at 27.
164 Id.
165 Id. at 28.
166 See id. at 44-45 (discussing how misperceptions of people with disabilities leads to lower rates of detection of STDs).
169 See Pendo, supra note 127, at 20.
See Albert v. Solimon, 721 N.E.2d 17, 17 (1999) (holding that an examination room of a physician’s office is not a public facility and is not required to accommodate service animal).

See Sheely v. MRI Radiology Network, P.A., 505 F.3d 1173, 1178-80 (11th Cir. 2007) (explaining that Sheely was not allowed to accompany her minor son beyond the waiting room because of MRN’s policy that animals were not permitted beyond that point), on remand, Sheely v. MRI Radiology Network, No. 05-61240-CIV, 2008 WL 111305 (S.D. Fla. Jan. 8, 2008).


Ed Eames, Ph.D., What’s That Dog Doing In here? 18:11 ADA COMPLIANCE GUIDE NEWS’L, 10 (Nov. 2007) (“Although the Americans With Disabilities Act was signed into law in 1990, issues related to assistance dogs as service animals still remain a controversial and sometimes litigious area. In my role as IAADP president and as a guide dog partner, I have been involved in cases of access denial involving taxis, restaurants, hotels, hospitals and the workplace.”).

Sheely, supra note 174, at 1178.

Id. at 1179-80.

Id. at 1178-79.


Id.

Id.

See Megan Flynn, Olmstead Plans Revisited: Lessons Learned From The U.N. Convention On The Rights Of Persons With Disabilities, 28 Law & Ineq. 407, 418 (2010) (explaining that “[s]ince there are few statistics or studies on the number of qualified individuals with disabilities awaiting community placement, it is difficult to accurately measure states’ compliance with Olmstead’s integration mandate. Case law, however, demonstrates the states’ failures to develop Olmstead plans that transfer qualified individuals to community placements in a timely manner, thereby contravening the integration mandate. By examining two representative cases, one can see that states often utilize unreasonably paced wait lists and unreasonable caps on Medicaid waiver programs in their Olmstead plans, forcing wait-listed individuals to remain on such lists for indefinite periods of time.”).

See Gail Zoppo, Forced Institutionalization Of People With Disabilities Is Illegal, DiversityInc (Oct. 12, 2010), http://www.diversityinc.com/article/7816/Forced-Institutionalization-of-People-With-Disabilities-Is-Illegal/ (stating that in Olmstead v. L.C. the court “determined that isolating people with disabilities in institutional settings deprives them of the opportunity to participate in their communities, interact with individuals who don’t have disabilities and make daily choices.”).

See generally Virginia Focht-New, Beyond Abuse: Treatment Approaches For People With Disabilities, 17 Issues In Mental Health Nursing 427 (1996) (concluding that “[l]iving with a label has dramatic effects on people, especially people who have been or are institutionalized. They are economically deprived, have little credibility, lack opportunity for self-determination, depend on others to meet their needs, have limited access to resources, and are taught to be compliant”; see also Elina Niitilä & Pekka Martikainen, Institutionalization of Older Adults After the Death of a Spouse, 98:7 AM. J. PUB. HEALTH 1228, 1229 (2008) (stating that “[l]ong-term institutional care was defined as 24-hour care in nursing homes and service homes and as inpatient care in hospitals and health centers lasting more than 90 days or confirmed by a long-term-care decision. Long-term psychiatric care was included. The more-than-90-days criterion was met if a patient had stayed in the same institution or successively in different institutions for that period.”).

Id.

See Debbie Jolly, Research Paper on Community Living and the Support of Independent Living: Costs and Benefits, European Network on Independent Living 1, 5 (2009), http://www.leeds.ac.uk/disability-studies/archiveuk/jolly/Research%20paper%20Community%20living%20and%20the%20support%20cost%20benefits.pdf (explaining that “the cheapest institutions achieve the illusion of economic efficiency only through the severest violation of ‘residents’ human rights by bypassing basic needs. These violations include the lack of adequate nutrition, clothing, heating, basic health needs and clean environments. Sitting on a chair all day or being tied to a bed in such conditions does indeed save money ... Also in instances where countries and localities lack a service infrastructure to provide adequate community support, cost differences on the budget sheet between cheaper institutionalisation and community living will be more pronounced. The human costs of maintaining what can be perceived as the ‘cheap’ options are limitless while the costs of maintaining institutions per se are incalculable in terms of abuse of dignity, human rights and individual choice.”).

Id. at 8.


Id.

Id.

Id.


Id. at 3.


See generally The Right to Reproductive and Sexual Health, United Nations Department of Public Information (1997), http://www.un.org/ecosocdev/geninfotwomen/womrepro.htm (discussing the many ways in which gender violence may occur throughout a woman’s lifespan).


See Jones, supra note 203, at 215 (explaining that “[p]hysical abuse is the most visible manifestation, but domestic violence also includes name-calling, isolating a woman from friends and family, forcing a woman to engage in unwanted or disliked sexual acts, and/or threatening to kill or harm pets.”).

See id. at 227 (stating that “more minor forms of abuse, such as the disabling of a wheelchair, withholding assistance with necessarily life activities, or ‘rough’ transfers from a wheelchair to a bed may be experienced as part of everyday life . . . .”).

See Ellie J. Emanual, Breaking the Power of Discrimination, Impact: Feature Issue on Violence Against Women with Developmental or Other Disabilities (2000), http://eci.umn.edu/products/impact/133/over4.html (stating that “[g]ood discrimination perpetuates violence against women with developmental disabilities, justifying that violence on the basis of their devalued status in society — in some people’s minds, they’re not really ‘women’ and not fully ‘human.’”).

Reid Neil, Disabled Face High Risk of Sex Abuse, Sunday News (New Zealand), Mar. 6, 2011, at 8.


See Jessica Mantel, Setting National Coverage Standards for Health Plans Under Healthcare Reform, 58 UCLA L. Rev. 221, 240 (2010) (arguing that proposals for cutting health care costs usually fail because they do not address advances in medical technology and aging population).

Id.
such testing procedures represent the most widespread application of genetic technology to humans. Tests exist for genetic factors associated with more than 400 human conditions ranging from ones (like Tay Sachs) that are universally acknowledged as severely disabling to others that many people dismiss as insignificant afflictions.

These tests are typically used in three basic situations. Predictive gene testing involves testing at-risk individuals for certain disabilities that may manifest themselves later in life, such as Huntington’s disease and breast or colorectal cancer. Carrier testing involves testing at-risk prospective parents for disabling recessive genes, such as the testing of Ashkenazi Jews for Tay-Sachs disease and Mediterranean peoples for Beta Thalassemia. Prenatal testing involves testing at-risk fetuses for disabilities (such as cystic fibrosis) that run in their families or ethnic groups. In time, the number of identifiable disabling genes and the ease of testing for them may so increase that widespread screening of individuals, populations, and fetuses may become the norm.”)

225 See Pauline W. Chen, M.D., Can Concierge Medicine For The Few Benefit The Many? N.Y. TIMES, Aug. 26, 2010, http://www.nytimes.com/2010/08/26/health/26pauine-chen.html (last visited Oct. 29, 2012). (noting that in concierge medicine, patients pay a high retainer fee in exchange for personalized attention by their Provider, which allows for longer visits in addition to enjoying “…personalized coordination of hospital care and, in some cases, even house calls” and “…accompanied visits to specialists.”). However, in the mind of this Author, this practice can further diminish healthcare access to minorities, which begs the question why Providers, who are supposed to constitute members of the “healing profession,” fail to furnish this level of services to all patients regardless of their wealth status, and also can be seen to be connected with healthcare reform. Healthcare reform involves a complex omnibus statutory scheme with what are certainly many potential positives and negatives and both the far left and the far right discuss its monolithic nature.


228 See G.A. Res. 61/106, supra note 65, at E4 (noting that the Convention aims to address discriminatory legislation and practices affecting persons with disabilities across the world).

229 See also http://www.newvision.co.ug/PA/8/459/612441 (noting that the double discrimination occurs when a woman faces discrimination as a female and as a person with a disability, which compounds problems including lack of access to health care services and information). See also Dr. Jacqueline Laing, Information Technology And Biometric Databases: Eugenics And Other Threats To Disability Rights, 3 J. LEGAL TECH. RISK MGMT. 9, 9 (2008).

230 See Pendo, supra note 127, at 20 (discussing how women with disabilities are receiving unequal care including a 1998 study that women with disabilities were less likely to receive adequate cervical cancer exams within the recommended time period).


232 See Gable, supra note 52, at 541 (“Often the acculturation of new rights into a state’s law and practice takes time.” (citing R. Goodman and D. Jinks, How to Influence States: Socialization and International Human Rights Law, 74 DUKE L.J. 621-703 (2004)).

233 See id. at 538 (noting that health-related rights are commonly recognized in national law through “national health or disability legislation”).

234 See id. at 538 (noting that health-related rights are commonly recognized in national law through “national health or disability legislation”).
ANNEX: WORKING GROUP RECOMMENDATIONS

Listed below are recommendations that will serve to advance the use of international human rights instruments and standards as tools to review and reform health policies, plans, programs and laws.

These recommendations have been suggested by the Working Group on Disabilities and Mental Health that convened on March 21 and 22, 2012 at the Inaugural Conference on Global Health, Gender and Human Rights, which was organized by the American University Washington College of Law and PAHO/WHO. These recommendations do not necessarily reflect the views of the author(s) of the preceding article.

The recommendations are divided by the following set of questions based on principles extracted from the PAHO Resolution “Health and Human Rights” (CD 50 R.8):

**Taking into account the national context, financial and legal framework and budgetary constraints of countries:**

a. Which areas require special attention from government agencies?

- Strengthen the technical capacity of the health authority to work with the corresponding governmental human rights entities to evaluate and oversee the implementation of the applicable international human rights instruments to protect persons with disabilities;
- Improve the capacity and mechanisms of ministries of health and health services to include a human rights norms and standards into their policies, plans and services;
- Strengthen the technical capacity of health care workers, authorities and stakeholders to understand and implement the applicable legislation and international human rights instruments to protect women with disabilities. (Consider the possibility of including people with disabilities as trainers);
- Improve coordination and articulation between the different ministries and gender and disabilities areas;
- Create a gender office and/or focal point in the Ministry of Health;
- Mainstream human rights of women with disabilities in all policies and plans of the different ministries, including ministries of Economy and the design and implementation of the budget;
- Create gender-based monitoring mechanisms to prevent violence and abuse against women with disabilities;
- Establish gender based mechanisms to implement the CRPD’s supported decision-making mandate in article 12;
- Improve data collection about people with disabilities disaggregate by sex to give attention to the size and scope of the problem;
- Create services and protections in the community to ensure people are not segregated from society within their own homes and by their own family; and
- Establish mechanisms to protect private patients’ information and provide access to their own information (medical files, etc.).

b. What key factors should be identified and included by health authorities and other governmental actors when formulating national health policies and plans consistent with the applicable international human rights instruments that protect persons with disabilities, in particular women’s with disabilities rights to physical and mental health and other related human rights as enshrined in the UN Convention on the Rights of Persons
with Disabilities (CRPD) and the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities?

- Ensure participation of women with disabilities and their organizations in the design, implementation and monitoring of national health policies and plans;
- Distribute and elaborate upon educational materials about the rights of women with disabilities;
- National health policies should take into account the different kinds of disabilities and also the diverse needs of girls and women;
- Identify and elaborate on a procedure to obtain informed consent and to verify it has been obtained; and
- Identify technology available in a particular country to help guarantee autonomy and to access information.

c. Which key provisions should be included by legislators and other actors when reviewing and reforming national health legislation, incorporating the international human rights instruments especially those protecting persons with disabilities?

- In general, CRPD should be translated into domestic legislation taking into account the different legal systems;
- Right to health and access to health care;
- Right to freedom of movement and mobility;
- Right to live in the community;
- Right to be free from discrimination and to have access and participate in all aspects of society, including culture, entertainment, political participation, etc.;
- Reproductive rights (Art 25 CRPD) should be explicitly recognized in the legislation;
- Right to determination of legal capacity (Art 12 CRPD);
- Right to be supported in parenting and raising a family;
- Right to information;
- Right to the protection of private data; and
- Right to be protected from forced sterilization.

d. What measures should governments take to ensure the effective implementation of national health policies, plans and laws that protect persons with disabilities?

- Ensure training to health personnel (GPs, nurses, etc) on international human rights standards and principles applicable to people with disabilities;
- Ensure training of people with disabilities and their organizations about their rights;
- Include people with disabilities in trainings (not just as facilitators);
- Revise existing curricula in universities to include rights of people with disabilities; and
- Make modules (user friendly and efficient) available on human rights instruments protecting human rights of people with disabilities.

e. Parliaments and domestic courts play a key role in promoting and protecting the human rights and fundamental freedoms of persons with disabilities. What concrete functions and contributions can those institutions make?

- Formulate and, if possible, adopt legislative, administrative, educational, and other measures to disseminate the applicable international human rights instruments on protecting the right to the enjoyment of the highest attainable standard of health and other related human rights among the appropriate personnel in the legislative and judicial branches and other governmental authorities;
- Elaborate handbooks for judges with specific indications on procedures to deal with specific disability-related cases; and
- Legislation should be critically revised according to international human rights instruments, including procedural aspects.

f. What measures could be taken by all those members of society at large who are involved
in protecting the human rights of persons with disabilities?

- Promote the dissemination of information and knowledge among civil society organizations at large and other social actors on the applicable international human rights instruments related to health, to address stigmatization, discrimination, and exclusion of persons with disabilities;
- Promote the inclusion of women with disabilities rights into the agenda of women organization;
- Promote peer-support programs;
- Promote the exchange of knowledge and sharing of best-practices (e.g. exchange with other countries, experiences with stronger roles of civil society groups); and
- Promote and facilitate the establishment of national patients’ associations.

**Taking into account the important role of international organizations, civil society and academic institutions on the promotion and protection of the right to health and other related human rights of persons with disabilities:**

a. What measures could be taken by PAHO and technical teams of Washington College of Law and other universities to strengthen technical cooperation with the human rights committees, organs and rapporteurships of the United Nations and Inter-American systems (such as the Inter-American Commission on Human Rights) in order to promote and protect the right to health and other related human rights of persons with disabilities?

- PAHO should play a role in assessment and review of governmental regulations and legislation;
- Formulation of technical opinions on health;
- Participation in thematic hearings;
- Visits to health centers and other institutions in countries; and
- Disseminate information about the use of Optional protocols of CRPD, the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the International Covenant on Civil and Political Rights (ICCPR) and the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT).

b. How could PAHO and other international agencies promote and stimulate collaboration and research with academic institutions, the private sector, civil society organizations and other social actors, when appropriate, to promote and protect human rights in keeping with the international human rights instruments that protect persons with disabilities?

- Coordinate joint initiatives in order to set up a network for global, regional and national action.

c. How could PAHO and other international agencies, governments and academic institutions and civil society promote the sharing of good practices and successful experiences among countries so as to prevent stigmatization, discrimination and exclusion of persons with disabilities?

- Design a website to disseminate information about the rights of people with disabilities and about best practices, legislative efforts, and other strategies for promoting those rights.