



Women Enabled International’s Submission to the Working Group on Discrimination against Women in Law and Practice – Health and Safety of Women with Disabilities

I. Introduction

[Women Enabled International](#) (WEI) appreciates the opportunity to provide comments to the UN Working Group on the issue of discrimination against women in law and practice regarding the right to health and safety of women and girls with disabilities in the United States. WEI advocates and educates for the human rights of all women and girls, emphasizing women and girls with disabilities, and works tirelessly to include women and girls with disabilities in domestic and international resolutions, policies, and programs addressing women’s human rights and development.

In this submission, WEI provides information on how laws and practices in the United States discriminate against women with disabilities¹ with regard to the right to health and to safety. According to the most recent U.S. Census Bureau analysis, approximately 18.7 percent, or 56.7 million people, had a disability in 2010 in the civilian population, not including individuals in institutions or nursing homes.² 17.4 % of men and 19.8 % of women had a disability.³ This submission addresses the key issues highlighted in the Working Group’s call for submissions: sexual and reproductive health and rights, gender-based violence in the public sphere, and access to justice to secure the rights to health and safety. We attempt to address a number of the issues and questions posed in the Working Group’s questionnaire, but have submitted our information in a format more conducive to addressing the specific and unique forms of discrimination that women with disabilities face in these areas. We also include an annex (p. 18) that provides greater detail on U.S. judicial decisions concerning forced and non-consensual sterilization of women with disabilities should you require additional information on this subject.

II. Legal Framework

A. International Human Rights Law

The U.S. is has signed, but not ratified, several international human rights treaties that protect the rights of women and people with disabilities, including the Convention on the Rights of Persons with Disabilities (CRPD), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the Convention on the Rights of the Child (CRC), and the International Covenant on Economic, Social and Cultural Rights (ICESCR). The U.S.’s failure to ratify these instruments was raised by a number UN Human Rights Council (HRC) member States in the last Universal Periodic Review (UPR) in 2015. However, as a signatory to these

¹ For purposes of this submission, all references to “women with disabilities” should be understood to refer to girls, adolescents, young women, and women.

² U.S. CENSUS BUREAU, *Americans with Disabilities: 2010*, 1, 4 (2012), www.census.gov/prod/2012pubs/p70-131.pdf.

³ U.S. CENSUS BUREAU, *Age-Adjusted and Unadjusted Disability Rates by Gender, Race, Hispanic Origin: 2005 and 2010*.

treaties, the U.S. is “obliged to refrain from acts which would defeat the object and purpose” of these treaties.⁴

In addition to CEDAW’s protections for the right to health and safety cited by this Working Group in its call for submissions, the CRPD obligates States parties to ensure all appropriate measures including legislative, administrative, social, and educational are in place to protect persons with disabilities both within and outside of the home from all forms of exploitation, violence and abuse. States are obligated to ensure that protection services are age, gender and disability sensitive and that independent authorities monitor the facilities and programmes.⁵ The CRPD further obligates States to eliminate discrimination against persons with disabilities and ensure they enjoy the rights on an equal basis with others when it comes to founding a family, and protects the right to decide on the number and spacing of their children and the information and means necessary to enable them to exercise their rights, as well as the right to retain fertility.⁶ The CRPD also provides for the right to the highest attainable standard of health without discrimination on the basis of disability and that the health services are gender sensitive and include sexual and reproductive healthcare services.⁷

In addition to being a signatory to the aforementioned treaties, however, the U.S. has ratified other international instruments that commit the United States to ending gender discrimination, promoting equality, and addressing ill treatment, specifically the International Covenant on Civil and Political Rights, the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, and the International Convention on the Elimination of All Forms of Racial Discrimination. As expressed in periodic reviews of treaty implementation, the U.S. understands its treaty obligations to include ending violence against women and ensuring access to sexual and reproductive health services for all.⁸

B. U.S. Legislation and Regulatory Framework

The United States is a federal system, and many laws and policies on sexual and reproductive health, including on abortion and surgical sterilization, gender-based violence, and marriage and divorce vary from state to state. This submission focuses primarily on national laws and policies that impact the health and safety of women with disabilities.

The **Americans with Disabilities Act, as amended, 2008 (ADA)** enumerates requirements regarding non-discrimination and access to violence against women and sexual and reproductive health services and facilities. The ADA prohibits healthcare providers, hospitals, and domestic and sexual violence shelters and programs from discriminating on the basis of disability in the full and equal enjoyment of goods, services, facilities, privileges, advantages or accommodations.⁹

⁴ Vienna Convention on the Law of Treaties, art. 18, May 23, 1969, 1155 U.N.T.S. 331, 8 I.L.M. 679 (*entered into force* Jan 27, 1980).

⁵ Convention on the Right of Persons with Disabilities (CRPD), art. 16, Dec. 13, 2006, U.N. Doc. A/RES/61/106 (*entered into force* May 3, 2008).

⁶ *Id.*, art. 23.

⁷ *Id.*, art. 25.

⁸ See *Fourth Periodic Report: United States*, U.N. Doc. CCPR/C/USA/4 (Dec. 30, 2011); *Seventh to Ninth Periodic Reports of States Parties due in 2011: United States of America*, U.N. Doc. CERD/C/USA/7-9 (June 13, 2013).

⁹ Americans with Disabilities Act (ADA) of 1990, 42 U.S.C. § 12181 et seq. (2008) [hereinafter ADA].

Stereotypes regarding the danger of procreation by women with disabilities are enshrined in state law. Eleven states retain statutory language authorizing a court to order the involuntary sterilization of a person with a disability.¹⁰ Courts in the U.S. have addressed these issues, though not always consistent with the requirements of the ADA.¹¹ Courts are divided on the legal capacity of women with disabilities to decide about their reproductive lives, particularly regarding the forced sterilization of young women and girls with disabilities, and there is no clear judicial standard that ensures reproductive decision-making resides with women.¹²

Section **504 of the Rehabilitation Act of 1973** requires that any program receiving federal financial assistance be accessible to and usable by persons with disabilities.¹³ U.S. Department of Health and Human Services (HHS) Office for Civil Rights (OCR) handles Section 504 complaints regarding healthcare services. In 2010, OCR published guidelines for medical providers concerning accessibility, but these are not binding regulations.¹⁴ OCR has enforcement power under additional legislation relating to disability discrimination in health¹⁵ and family violence protection.¹⁶

Through the **Violence Against Women Act of 2013 (VAWA)**,¹⁷ the Department of Justice's (DOJ) Office on Violence Against Women funds a limited number of programs, including programs specifically designed to address violence and abuse of women with disabilities.¹⁸ Very few programs receive this funding, especially since funding was reduced from \$10 million to \$9 million in the VAWA 2013 reauthorization. In fiscal year 2013 there were only nine disability grant recipients in seven states and the total amount allocated through the Disability Grant Program was a devastatingly inadequate 1.02% of the total allocated by OVW.¹⁹

¹⁰ Arkansas (ARK. CODE ANN. §20-49-101 (2010)); Colorado (COLO. REV. STAT. §27-10.5-130 (2012)); Delaware (16 DEL. CODE ANN. §5712 (2013)); Georgia (GA. CODE ANN. §31-20-3 (2010)); Maine (34-B Me. Rev. Stat. §7010 (2011)); North Carolina (N. C. GEN. STAT. §35A-1245 (2010)); Oregon (OR. REV. STAT. §436.205 (2011)); Utah (UTAH CODE ANN. 1953 §62A-6-102 (2011)); Vermont (18 VT. STAT. ANN. §8705 et seq. (2009)); Virginia (VA. CODE ANN. §54.1-2975 et seq. (1988)); West Virginia (W. VA. CODE §27-16-1 et seq. (2013)).

¹¹ ADA, *supra* note 9.

¹² Courts granting nonconsensual sterilization of females with disabilities are the following: *Matter of A.W.*, 637 P.2d 366 (Colo. 1981); *Estate of C.W.*, 640 A.2d 427 (Pa. Super. 1994); *Matter of Mildred J. Terwilliger*, 304 A.2d 1376 (Pa. Super. 1982); *Conservatorship of Person and Estate of Maria B.*, 160 Cal. Rptr. 3d 269 (Cal. Ct. App. 2013). Courts denying nonconsensual sterilization of females with disabilities are the following: *Wentzel v. Montgomery General Hosp.*, 447 A.2d 1244 (Md. 1982); *Matter of Truesdell*, 329 S.E.2d 630, 636 (N.C. 1985); *Conservatorship of Valerie N.*, 40 Cal. 3d 143 (Cal. 1985); *Matter of Romero*, 790 P.2d 819 (Colo. 1990).

¹³ Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 355 (codified as amended in scattered sections of 15 U.S.C., 20 U.S.C., 29 U.S.C., 36 U.S.C., 41 U.S.C., and 42 U.S.C.), § 504 (Sept. 26, 1973).

¹⁴ U.S. Dep't of Justice, *Access to Medical Care for Individuals with Mobility Disabilities*, Civil Rights Div., Disability Rights Section (July 2010).

¹⁵ Social Security Act (as amended 1989), 42 U.S.C. § 708 (2008); Public Health Service Act (as amended 1992), 42 U.S.C. § 300x-57 (2011).

¹⁶ Family Violence Prevention and Services Act (as amended 2010), 42 U.S.C. § 10406 (2011).

¹⁷ Violence Against Women Reauthorization Act of 2013, Pub. L. No. 113-4, Overview (Mar. 7, 2013) (hereinafter VAWA).

¹⁸ U.S. Dep't of Justice, *Education, Training and Enhanced Services to End Violence Against and Abuse of Women with Disabilities*, Grant Programs, Office of Violence Against Women.

¹⁹ U.S. Dep't of Justice, *FY 2013 OVW Grant Awards By Program*, Awards, Grant Programs, Office of Violence Against Women (OVW) (reporting that the nine states that received funds were: DC, IL, MO, WI, MN, NC, and SD with IL and MN receiving two grants). OVW disability-related grants totaled \$3,875,000, a mere 1.02% of the overall total allocated by OVW Grant Program of \$378,964,893.

The **Prison Rape Elimination Act of 2003²⁰ (PREA)** recognizes that inmates with psychosocial and other disabilities are at “increased risk of sexual victimization.”²¹ However, the DOJ has failed to document or collect data on violence against female prisoners with disabilities, as required by PREA.²²

The **Patient and Protection Affordable Care Act of 2010 (ACA)** mandated coverage in health plans for women’s preventive health care, including contraception.²³ In 2012, the U.S. Access Board recommended, pursuant to the ACA, improved accessibility standards for medical diagnostic equipment (e.g., exam tables, chairs, tables) inclusive of sexual and reproductive healthcare access.²⁴ Yet, as of September 2014, no standards have been finalized, leaving women with disabilities without access to services important for their health.²⁵ The ACA also acknowledges that existing abortion restrictions impact all health plans offered through the state exchanges, and it all allows state insurance plans to exclude abortions. An executive order signed by President Obama following passage of the legislation creates an enforcement mechanism to ensure no federal funding covers abortion according to the terms of the Hyde Amendment, which prohibits federal insurance coverage for abortion under Medicaid except in the very limited circumstances of rape, incest or life endangerment.²⁶ The Hyde Amendment disproportionately impacts women with disabilities because most receive their insurance through Medicare (the federal health insurance program for those over age 65 and for certain younger people with disabilities) or Medicaid (a joint federal and state program that covers low-income Americans). Only 17 states fund all or most medically necessary abortions beyond the federal requirements.²⁷

Proposed regulations to **Title IX of the Education Amendments of 1972 (Title IX)²⁸** draw on VAWA and would require schools and educational institutions to compile statistics on incidents of dating violence, domestic violence, sexual assault, and stalking and to include certain policies, procedures, and programs pertaining thereto, including to prevent and address complaints of such violence.²⁹ Female students with disabilities frequently experience sexual and gender-based violence in schools³⁰ and thus require greater recognition in campus gender-based violence

²⁰ Prison Rape Elimination Act of 2003, Pub. L. No. 108-79, 117 Stat. 972, 42 U.S.C. §§ 15601-609 (Sept. 4, 2003) [hereinafter PREA].

²¹ *Id.*

²² Joye Whatley, *Violence Against Women with Disabilities: Policy Implications of What We Don’t Know*, 13 IMPACT 3 (2000), available at <http://ici.umn.edu/products/impact/133/over3.html>.

²³ U.S. Dep’t of Health and Hum. Serv., *Section 1157 of the Patient Protection and Affordable Care Act*; see also U.S. Dep’t of Health and Hum. Serv., *Affordable Care Act Expands Prevention Coverage for Women’s Health and Well Being*.

²⁴ See U.S. Access Board, *Advancing Equal Access to Diagnostic Services: Recommendations on Standards for the Design of Medical Diagnostic Equipment for Adults with Disabilities* (Dec. 6, 2013), available at <http://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking/advisory-committee-final-report/5-recommendations>.

²⁵ *Id.*

²⁶ Exec. Order No. 13535, C.F.R. 15599 (2010).

²⁷ Guttmacher Institute, *State Policies in Brief: State Funding of Abortion Under Medicaid* (Sept. 1, 2014), available at http://www.guttmacher.org/statecenter/spibs/spib_SFAM.pdf.

²⁸ Title IX of the Education Amendments of 1972 (discrimination based on sex or blindness), 20 U.S.C. §§ 1681 et. seq., (West Supp. 2006); U.S. Dep’t of Educ., *Questions and Answers on Title IX and Sexual Violence*, 5 (2014).

²⁹ U.S. Dep’t of Educ., *Violence Against Women Act, Proposed Rule*, 34 C.F.R. 668, § 668.46 (June 20, 2014).

³⁰ Stephanie Ortoleva & Hope Lewis, *Forgotten Sisters - A Report on Violence Against Women with Disabilities: An Overview of its Nature, Scope, Causes and Consequences*, NORTHEASTERN UNIVERSITY SCHOOL OF LAW, Research Paper No. 104-2012 (Aug. 21, 2012), available at <http://ssrn.com/abstract=2133332> [hereinafter *Forgotten Sisters*];

prevention and complaint processes and proposed Title IX regulations fail significantly in this regard.³¹

Individuals with Disabilities Education Act of 2004 (IDEA) regulations require a “free appropriate public education” for all children with disabilities.³² Although IDEA regulations mandate a variety of educational programs, they fail to include requirements for essential sexual and reproductive health education.³³

III. Discrimination against Women with Disabilities in Practice

A. Sexual and Reproductive Health and Rights

Women and girls with disabilities lack appropriate, consistent, non-discriminatory, and affordable access to sexual and reproductive health services. The numerous barriers to access cause women with disabilities to avoid seeking out regular gynecological care.³⁴ As a result, they are less likely to receive preventive reproductive health care such as pelvic and breast exams that detect reproductive cancers or to speak with health professionals about their reproductive options.³⁵

1. Physical Access to Health Facilities

The most common reason women with disabilities do not obtain preventive reproductive health services is the lack of physical accommodation in health facilities.³⁶ For example, many facilities lack accessible exam and diagnostic equipment such as mammogram machines and adjustable examination tables. The lack of physical accessibility, combined with transportation difficulties to healthcare facilities, prevent women with disabilities from seeking necessary reproductive health services such as breast cancer screenings.³⁷ A 2010 study by the Center for Disease Control found that 61% of women with disabilities aged 50-74 had gone for a mammogram in

Jesse Krohn, *Sexual Harassment, Sexual Assault, and Students with Special Needs: Crafting an Effective Response for Schools*, 17 U. PA. J. L. & SOC. CHANGE 29 (2014), available at <http://scholarship.law.upenn.edu/cgi/viewcontent.cgi?article=1163&context=jlasc> [hereinafter Sexual Harassment, Sexual Assault, and Students with Special Needs].

³¹ See Women Enabled International, *Comments on U.S. Dept. of Education Title IX Sex Assault and Harassment Regulations* (July 21, 2014).

³² Individuals with Disabilities Education Improvement Act of 2004, Pub. L. 108-446, 20 U.S.C. 1400 (Dec. 3, 2004), available at <http://nichcy.org/wp-content/uploads/docs/PL108-446.pdf> [hereinafter Individuals with Disabilities Education Improvement Act].

³³ *Id.*

³⁴ National Council on Disability, *The Current State of Health Care for People with Disabilities*, pg. 56 (Sept. 30, 2009), available at <http://www.ncd.gov/publications/2009/Sept302009#Health and Health Disparities Research> [hereinafter Current State of Health Care].

³⁵ The National Center for Health Statistics found that as of 2005, 65-71% of women with disabilities have had a Pap test compared to 83% of women without disabilities. *Id.*, at 41. See also Elizabeth Pendo, *Reducing Disparities through Health Care Reform: Disability and Accessible Medical Equipment*, 4 UTAH L. REV. 1057, 1065 (2010) [hereinafter Reducing Disparities]; Drew Rivera et al., *Disability and Pap Smear Receipt among U.S. Women, 2000 and 2005*, 42 PERSP. ON SEXUAL AND REPROD. HEALTH, 258-66 (2010).

³⁶ Association of State and Territorial Health Officials, *Access to Preventive Healthcare Services for Women with Disabilities* (2013), available at <http://www.astho.org/Access-to-Preventive-Healthcare-Services-for-Women-with-Disabilities-Fact-Sheet/> [hereinafter Access to Preventive Healthcare Services].

³⁷ Nancy Mele et al., *Access to Breast Cancer Screening Services for Women with Disabilities*, 34 J. OF OBSTETRIC, GYNECOLOGIC, & NEONATAL NURSING 453-64 (July 2005) [hereinafter Mele, Breast Cancer Screenings].

the past two years, compared to 75% of women without disabilities.³⁸ These barriers place women with disabilities at a high risk for breast cancer incidence and death.³⁹

2. Lack of Health Information Specific to Women with Disabilities

Communication barriers also limit access for women with disabilities, especially those who are deaf or blind, as limited health facilities have sign language interpreters, personnel willing to read information to patients, or alternative means of delivering information.⁴⁰ People with developmental disabilities report communication difficulties with some providers; there is often not enough time allotted during visits to have a comprehensive discussion of complex health issues, and information is often not delivered in an appropriate format.⁴¹

Sexuality education is essential to empowering women and girls with the necessary information to protect themselves from sexual abuse; negotiate contraceptive use in order to prevent unwanted pregnancies and sexually transmitted infections (STIs), including HIV/AIDS; and access sexual and reproductive health services on the basis of free and informed consent. Yet sexuality education is generally not offered in education programs designed for people with disabilities,⁴² and young people with disabilities are often excluded from school-based sexuality education and resources.⁴³ One U.S. study showed that only 19% of physically disabled women surveyed had received sexuality counseling, and women with paralysis, impaired motor function or obvious physical disability were rarely offered contraceptive methods or information.⁴⁴ This poses potentially significant negative health outcomes for girls with disabilities; a 2008 study found that girls with learning and cognitive disabilities might [do we need to say “might” rather than “are placed at”?] be at an increased risk of contracting STIs than their peers without developmental disabilities.⁴⁵ Lack of sexuality education also deprives girls with disabilities with the skills to recognize and prevent sexual abuse, which women with disabilities experience at higher rates than women without disabilities.⁴⁶

3. Lack of Affordable Care

Because women with disabilities have higher rates of unemployment and poverty than the general population, they are far less likely to have private insurance to cover reproductive health

³⁸ Centers for Disease Control and Prevention (CDC), *Women with Disabilities and Breast Cancer Screening* (Nov. 14, 2013), available at <http://www.cdc.gov/features/breastcancerscreening/> (last accessed Sept. 5, 2014).

³⁹ Mele, Breast Cancer Screenings, *supra* note 37; see also Rie Suzuki et al., *Multi-level Barriers to Obtaining Mammograms for Women with Mobility Limitations*, 37 AM. J. HEALTH BEHAV. 711-718 (2013).

⁴⁰ Erin Billups, *Women with Disabilities Have Trouble Receiving Gynecology Services in City*, N.Y. TIMES (Apr. 15, 2014); see also CROWD, *supra* note 40, at 56, 64-68.

⁴¹ Access to Preventive Healthcare Services, *supra* note 36; CROWD, *supra* note 40, at 50-51.

⁴² See generally Individuals with Disabilities Education Improvement Act, *supra* note 32 (withholding a requirement that persons with disabilities receive sexual and reproductive health education).

⁴³ Bethany Stevens, *Politicizing Sexual Pleasure, Oppression and Disability: Recognizing and Undoing the Impacts of Ableism on Sexual and Reproductive Health*, CTR. FOR WOMEN & POL'Y STUDIES (2011); Emily Kronenberger et al., *Reproductive Health and Rights Disparities: An Overview*, CTR. FOR WOMEN & POLICY STUDIES (2011).

⁴⁴ Haefner et al., *Contraception in Women with Special Needs*, 24 COMP. THER. 229, 238 (1998).

⁴⁵ David Mandell et al., *Sexually Transmitted Infection Among Adolescents Receiving Special Education Services*, 78 J. SCHOOL HEALTH 382-88 (2008).

⁴⁶ Nancy Murphy & Ellen Roy Elias, *Sexuality of Children and Adolescents with Disabilities*, 118(1) PEDIATRICS 398, 400-01 (July 1, 2006).

goods and services.⁴⁷ Pursuant to the ACA, Medicaid beneficiaries enrolled in Alternative Benefit Plans no longer have to pay cost sharing for preventive services including mammograms and Pap smears. However, women with disabilities can face difficulties in locating and accessing reproductive healthcare providers who have the training and clinics that are able to accommodate their needs.⁴⁸ Unfortunately, the Centers for Medicare and Medicaid Services do not conduct oversight of ADA compliance by states, health plans, or medical providers.⁴⁹

4. Discrimination and Provider Bias

Negative stereotypes about women with disabilities interfere with quality of and access to care. Research has shown that women with disabilities and non-disabled women have similar attitudes towards motherhood, but mothers with disabilities are less likely to want another child than are mothers without disabilities.⁵⁰ However, the National Council on Disability has found that physicians see women with disabilities as sexually inactive and, thus, not in need of reproductive care.⁵¹ Other studies reveal that physician's attitudes towards patients with disabilities are sometimes more negative than that of the general public, including that physicians "underestimate the quality of life of persons with disabilities"⁵² and view every woman with a disability as incapable of making their own decisions.⁵³

Research shows that physicians not only lack training in treating patients with disabilities⁵⁴ but also feel uncomfortable and reluctant to treat persons with disabilities.⁵⁵ The National Council on Disability has noted that "the absence of professional training on disability competency issues for healthcare practitioners is one of the most significant barriers preventing people with disabilities from receiving appropriate and effective healthcare."⁵⁶ Women with disabilities report feeling humiliated and frustrated, concerned about physician competence, and lacking in trust for their physician.⁵⁷ For example, women with schizophrenia not only experience higher rates of unintended pregnancy than women from the general population, but they experience higher rates of obstetric complications and may be more susceptible to episodes of schizophrenia during the

⁴⁷ CROWD, *supra* note 40, at 54.

⁴⁸ Individuals with Disabilities Education Improvement Act, *supra* note 32.

⁴⁹ Access to Preventive Healthcare Services, *supra* note 36; *see also* CROWD, *supra* note 40, at 21.

⁵⁰ Carrie L. Shandra et al., *Planning for Motherhood: Fertility Attitudes, Desires and Intentions Among Women with Disabilities*, 46 PERSP. ON SEXUAL AND REPROD. HEALTH (Dec. 2014).

⁵¹ Erin Billups, *Women with Disabilities Have Trouble Receiving Gynecology Services in City*, N.Y. TIMES (Apr. 15, 2014), http://www.ny1.com/content/lifestyles/health_and_medicine/207001/women-with-disabilities-have-trouble-receiving-gynecology-services-in-city.

⁵² Current State of Health Care, *supra* note 34, at 1078.

⁵³ Vanessa Volz, *A Matter of Choice: Women with Disabilities, Sterilization, and Reproductive Autonomy in the Twenty-First Century*, 27 WOMEN'S RTS. L. REP. 203, 212 (2006).

⁵⁴ Current State of Health Care, *supra* note 34, at 1078-1079.

⁵⁵ *Id.*, at 1079.

⁵⁶ CROWD, *supra* note 40, pg. 42; Reducing Disparities, *supra* note 35 (noting that studies reveal a lack of training and education on disability issues for physicians); Nechama Greenwood & Joanne Wilkinson, *Sexual and Reproductive Health Care for Women with Intellectual Disabilities: A Primary Care Perspective*, (Oct. 2013), INT'L J. OF FAM. MED. 2 (showing that a lack of education for health care providers on disability issues creates "barriers to effective healthcare" for persons with intellectual disabilities).

⁵⁷ Billups, *supra* note 51. *See also* Current State of Health Care, *supra* note 34, at 1057.

postpartum period. In spite of these challenges, the reproductive health needs of women with psychiatric disorders are often overlooked.⁵⁸

The prevalence of stereotypes and lack of provider training make healthcare providers significantly less likely to ask women with disabilities about their use of or need for contraceptives.⁵⁹ This is especially troubling because women with disabilities are at an increased risk of unintended pregnancy due to the difficulty of using barrier contraceptives and heightened risks of complications from using birth control pills in conjunction with other medications they might be taking.⁶⁰ Evidence also indicates that women with disabilities are denied access to reproductive technologies,⁶¹ not provided guidance on pregnancy or prenatal care, and are often pressured into obtaining abortions or genetic testing.⁶² Additionally, women with disabilities are often discouraged from getting screened for STIs because many doctors believe women with disabilities are not sexually active and could not contract such diseases.⁶³ Many who do get screened avoid future routine visits to gynecologists because of this lack of provider knowledge and sensitivity that often leads to “uncomfortable, embarrassing, or painful examinations.”

B. Gender-Based Violence in the Public Sphere

Although women with disabilities experience many of the same forms of violence all women experience, when gender and disability intersect, violence takes on unique forms, has unique causes, and results in unique consequences. Multiple and intersecting forms of discrimination contribute to and exacerbate the violence, and women with disabilities who are also people of color or members of minority or indigenous peoples or religious groups, who are lesbian, transgender or intersex, who are older, or who live in poverty can be subject to particularized forms of violence and discrimination.⁶⁴ Violence against women with disabilities occurs in various spheres including the home and the community. Violence is perpetrated and/or condoned by the State and private actors within public and private institutions and in the transnational sphere. The forms of violence to which women and girls with disabilities are subjected are varied, including physical, psychological, sexual or financial violence, neglect, social isolation, entrapment, degradation, detention, denial of health care and forced sterilization and psychiatric treatment, among others.

Women with disabilities are more likely to experience domestic violence and other forms of gender-based and sexual violence as non-disabled women, are likely to experience abuse over a longer period of time, and often suffer more severe injuries as a result of the violence. National

⁵⁸ See Kim Best, *Mental Disabilities Affect Method Options*, 19(2) WINTER 19, 20 (1999).

⁵⁹ CROWD, *supra* note 40, at 56.

⁶⁰ Sue McGreevey, *Health Care Disparities for Disabled: People with Disabilities Face Lack of Access to Facilities, Services*, HARVARD GAZETTE (Oct. 6, 2011).

⁶¹ Judith Daar, *Accessing Reproductive Technologies: Invisible Barriers, Indelible Harms*, 23 BERKELEY J. GENDER L. & JUST. 18, 35 (2008), available at <http://scholarship.law.berkeley.edu/bglj/vol23/iss1/2>.

⁶² JoAnn M. Thierry, *The Importance of Preconception Care for Women With Disabilities*, 10 MATERNAL CHILD HEALTH J. S175 (2006); JUDITH ROGERS, *THE DISABLED WOMAN'S GUIDE TO PREGNANCY AND BIRTH* 94 (2005). See also Erin E. Andrews, *Pregnancy with a physical disability: One psychologist's journey*, Spotlight on Disability Newsletter (Dec. 2011), available at <http://www.apa.org/pi/disability/resources/publications/newsletter/2011/12/pregnancy-disability.aspx>.

⁶³ Current State of Health Care, *supra* note 34, at 56.

⁶⁴ Forgotten Sisters, *supra* note 30.

“studies estimate that almost 80% of people with disabilities are sexually assaulted on more than one occasion and 50% of those experienced more than 10 victimizations,”⁶⁵ and women with disabilities are raped and abused at least two to three times more than women without disabilities. As many as 83% of female adults with developmental disabilities are victims of sexual assault,⁶⁶ and women with disabilities living in institutions and nursing homes are particularly at risk.⁶⁷ Women with disabilities living in institutions and nursing homes report a “33% prevalence” of experiencing interpersonal violence, compared to 21% of women without disabilities in such institutions.⁶⁸ Their abuser may also be their caregiver, someone that the individual is reliant on for personal care or mobility. Women with disabilities frequently do not report the violence and are not always privy to the same information available to non-disabled women, particularly where such information is not available in alternative formats.

1. Violence in Schools

Girls with disabilities experience sexual harassment and sexual abuse in schools at an unacceptably high rate.⁶⁹ Over twice as many deaf female undergraduates experienced an incident of sexual coercion from their partner compared to hearing female undergraduates (61% compared to 28%).⁷⁰ Disabled girls often are also subjected to bullying and teasing by peers in school based on disability and gender.⁷¹ Such bullying can negatively impact a girl’s emotional and cognitive development and can also cause low self-esteem.⁷² This harassment and abuse is compounded by lack of sexual education afforded to girls with disabilities.⁷³

2. Violence in Prisons

Female prisoners with disabilities are at a particularly high risk of violence.⁷⁴ They may be actively targeted by both guards and other inmates based on their disability, or their needs for accommodations may be neglected.⁷⁵ Once incarcerated, violence and poor conditions in prison leads many to develop a disability, and those who already are disabled are likely to develop an aggravated disability.⁷⁶ PREA recognizes that jails house more persons with psycho-social

⁶⁵ *Sexual Violence Against Individuals with Disabilities*, MAINE COALITION AGAINST SEXUAL ASSAULT, available at <http://www.mecasa.org/index.php/special-projects/individuals-with-disabilities>.

⁶⁶ *Id.*

⁶⁷ Margaret Nosek et al., *Vulnerabilities for Abuse Among Women with Disabilities*, 19 *SEXUALITY & DISABILITY* 177 (2001).

⁶⁸ K.A. Barrett, et al., *Intimate Partner Violence, Health Status, and Health Care Access Among Women with Disabilities*, 19 *WOMEN’S HEALTH ISSUES* 94 (2009).

⁶⁹ Sexual Harassment, Sexual Assault, and Students with Special Needs, *supra* note 30, at 5.

⁷⁰ Melissa Anderson et al., *Interpersonal Violence Against Deaf Women*, 16 *AGGRESSION & VIOLENT BEHAVIOR* 200, 203 (2011).

⁷¹ Sexual Harassment, Sexual Assault, and Students with Special Needs, *supra* note 30, at 3-4.

⁷² Jonathan Young et al., *Briefing Paper: Bullying and Students with Disabilities*, Nat’l Council on Disability, (2011) (discussing bullying in the United States); see also Laetitia Antonowicz, *Too Often in Silence: A Report on School-Based Violence in West and Central Africa*, UNICEF 35 (Mar. 2010).

⁷³ Sexual Harassment, Sexual Assault, and Students with Special Needs, *supra* note 30, at 5.

⁷⁴ United Nations Office on Drugs and Crime (UNODC), *Handbook on Prisoners with Special Needs*, at 45 (2009).

⁷⁵ UNODC, *Handbook for Prison Managers and Policymakers on Women and Imprisonment*, at 45 (2009) (*hereinafter* UNODC, *Handbook for Prison Managers*).

⁷⁶ Beth Ribet, *Naming Prison Rape as Disablement: A Critical Analysis of the Prison Litigation Reform Act, the Americans with Disability Act, and the Imperatives of Survivor-Oriented Advocacy*, 17 *VA. J. SOC. POL’Y & L.* 281,

disabilities than all of the country's psychiatric hospitals combined.⁷⁷ The psychological trauma of rape that occurs in prison is compounded because the victim has very limited options to escape the perpetrator.⁷⁸ Additionally, people who are raped in prison may suffer humiliation or stigmatization from other inmates and prison staff because the assaults are often known throughout the prison. Those trying to cope with the psychological trauma of prison rape and sexual assault are often in facilities that do not offer rape counseling or mental health treatment.⁷⁹ The lack of required data collection limits the ability of the U.S. government to address the high incidence of rape and sexual assault of women with disabilities in prisons.

3. Violence by Forced, Non-Consensual Sterilization

Women and girls with disabilities face coercion from healthcare providers regarding their reproductive decision-making. Women with disabilities are more likely to have hysterectomies at a younger age and for a non-medically necessary reason, including by request of a parent or guardian.⁸⁰ These issues rose to public attention in 2007 when the parents of a nine-year-old girl with developmental disabilities gave their consent to have her undergo a surgical procedure to stunt her growth and remove her reproductive organs prior to reaching puberty.⁸¹ Since 2012, there have been 12 confirmed cases and over 100 suspected cases of families subjecting their disabled children to similar treatment.⁸² Women with disabilities also frequently encounter pressure from doctors, guardians, social service workers, parents and society to abort a pregnancy because of a misperception of the possibility of passing on disabilities to their children—even if the disability is not genetic.⁸³

Stereotypes regarding the danger of procreation by women with disabilities are enshrined in state law in the United States. As mentioned above, eleven states retain statutory language authorizing a court to order the involuntary sterilization of a person with a disability,⁸⁴ and judicial decisions

294 (2010).

⁷⁷ PREA, *supra* note 20.

⁷⁸ UNODC, Handbook for Prison Managers, *supra* note 75, at 288.

⁷⁹ *Id.*, at 288-89.

⁸⁰ Julia A. Rivera Drew, *Hysterectomy and Disability Among U.S. Women*, 45 PERSP. ON SEXUAL AND REPROD. HEALTH 157, 161 (2013); Elizabeth Pendo, *Disability, Equipment Barriers, and Women's Health: Using the ADA to Provide Meaningful Access*, 2 SLU JOURNAL OF HEALTH LAW & POLICY 44-45 (2008) available at <http://ssrn.com/abstract=1435543>.

⁸¹ Ed Pilkington & Karen McVeigh, 'Ashley Treatment' on the Rise Amid Concerns from Disability Rights Groups, THE GUARDIAN (Mar. 15, 2012), <http://www.guardian.co.uk/society/2012/mar/15/ashley-treatment-rise-amid-concerns/print>.

⁸² *Id.*

⁸³ Anne Finger, *Forbidden Fruit*, 233 THE NEW INTERNATIONALIST (July 1992) available at <http://www.newint.org/issue233/fruit.htm>; see also Carolyn Frohmader, *Moving Forward and Gaining Ground: The Sterilisation of Women and Girls with Disabilities in Australia*, Women With Disabilities Australia, 6-7 (2012), available at http://wwda.org.au/wp-content/uploads/2013/12/Moving_Forward_Gaining_Ground.pdf; see generally Law Students for Reproductive Justice, *Women with Disabilities*, at 3 (2008), available at http://lsrj.org/documents/factsheets/08-09_Women_with_Disabilities.pdf.

⁸⁴ Arkansas (ARK. CODE ANN. §20-49-101 (2010)); Colorado (COLO. REV. STAT. §27-10.5-130 (2012)); Delaware (16 DEL. CODE ANN. §5712 (2013)); Georgia (GA. CODE ANN. §31-20-3 (2010)); Maine (34-B Me. Rev. Stat. §7010 (2011)); North Carolina (N. C. GEN. STAT. §35A-1245 (2010)); Oregon (OR. REV. STAT. §436.205 (2011)); Utah (UTAH CODE ANN. 1953 §62A-6-102 (2011)); Vermont (18 VT. STAT. ANN. §8705 et seq. (2009)); Virginia (VA. CODE ANN. §54.1-2975 et seq. (1988)); West Virginia (W. VA. CODE §27-16-1 et seq. (2013)).

addressing these issues are not always consistent with federal requirements under the ADA.⁸⁵ Courts are divided on the legal capacity of women with disabilities to decide about their reproductive lives, particularly regarding the forced sterilization of young women and girls with disabilities, and there is no clear judicial standard that ensures reproductive decision-making resides with women themselves.⁸⁶ As recently as 2013, a state court granted a parent the authorization to subject a daughter with cognitive disabilities to a hysterectomy.⁸⁷ Annex I (p. 18) provides an in-depth summary and analysis of judicial decisions on forced and nonconsensual sterilizations of women with disabilities.

These court proceedings demonstrate the urgent need for social workers, psychologists and psychiatrists, and judges to educate themselves on the rights of women and girls with disabilities in the context of sexuality, reproduction, parenthood and other related issues. People in such positions of confidence and authority have an obligation to develop a comprehensive understanding of these issues.

Sterilization impacts not just the health and wellbeing of the individual but also the wellbeing of society as a whole. The right to procreate is “fundamental to the very existence and survival of the human race” and it is a basic liberty that is “forever deprived” if an individual is forced to be sterilized.⁸⁸ Further, sterilization surgically invades the integrity of an individual’s person and destroys “an important part of a person’s social and biological identity.”⁸⁹

In 2009, the American College of Obstetricians and Gynecologists (ACOG) reaffirmed their ethics opinion on the sterilization of women, including women with disabilities.⁹⁰ The ACOG characterizes sterilization as an elective procedure with extensive and often permanent consequences. As such, physicians who are in a position to perform sterilizations should counsel patients without bias and to as full an extent as possible. Informed consent includes “comprehensive and individualized counseling on reversible alternatives to sterilization.”⁹¹ For patients with developmental or cognitive disabilities, it becomes even more vital that physicians thoroughly assess the capacity of patients to give their informed consent. When capacity is limited, the physician has a duty to “consult with the patient’s other caregivers in reaching a decision, which is based on the patient’s best interests and preserves her autonomy to the maximum extent possible.”⁹²

⁸⁵ ADA, *supra* note 9, § 12181.

⁸⁶ Courts granting nonconsensual sterilization of females with disabilities are the following: *Matter of A.W.*, 637 P.2d 366 (Colo. 1981); *Estate of C.W.*, 640 A.2d 427 (Pa. Super. 1994); *Matter of Mildred J. Terwilliger*, 304 A.2d 1376 (Pa. Super. 1982); *Conservatorship of Person and Estate of Maria B.*, 160 Cal. Rptr. 3d 269 (Cal. Ct. App. 2013). Courts denying nonconsensual sterilization of females with disabilities are the following: *Wentzel v. Montgomery General Hosp.*, 447 A.2d 1244 (Md. 1982); *Matter of Truesdell*, 329 S.E.2d 630, 636 (N.C. 1985); *Conservatorship of Valerie N.*, 40 Cal. 3d 143 (Cal. 1985); *Matter of Romero*, 790 P.2d 819 (Colo. 1990).

⁸⁷ *Conservatorship of Person and Estate of Maria B.*, 160 Cal. Rptr. 3d 269 (Cal. Ct. App. 2013)

⁸⁸ *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942).

⁸⁹ *In re Grady*, 426 A.2d 467, 472 (N.J. 1981).

⁹⁰ *Sterilization of Women, Including Those With Disabilities*, THE AMERICAN CONGRESS OF OBSTETRICIANS AND GYNECOLOGISTS, <https://www.acog.org/Resources-And-Publications/Committee-Opinions/Committee-on-Ethics/Sterilization-of-Women-Including-Those-With-Mental-Disabilities>.

⁹¹ *Id.*

⁹² *Id.*

In June 2011, the International Federation of Gynecology and Obstetrics (FIGO) released an updated set of ethical guidelines on sterilization.⁹³ These recommendations reflected the views of AGOC substantially yet different in certain specific areas. Recommendations highlighted the need for obtaining informed consent before proceeding with sterilization, including requirements to provide detailed information on non-permanent contraceptive options. The guidelines also highlighted that sterilization is not an emergency procedure and that consent to sterilization must not be conditioned on the receipt of any other form of medical care, including HIV/AIDS treatment and the medical termination of pregnancy.⁹⁴ The report also focuses on the ethical boundaries of medical practitioners relating to the informed consent of their patients, noting that it is unethical and a clear violation of a patient's human rights to perform sterilization procedures on women who have not fully and freely requested such a procedure. The FIGO report closely examines the individual autonomy of patients and mandates that "family members, including husbands, parents, legal guardians, medical practitioners and, for instance, government or other public officers, cannot consent on any woman's or girl's behalf."⁹⁵

C. Access to Justice

1. Physical Access

Physical accessibility poses a significant barrier for individuals with disabilities in accessing courthouses. In the U.S., the Guiding Principles for Federal Architecture were first promulgated in 1962 and called for buildings to be "accessible to persons with disabilities." However, there were no enforcement methods in place to ensure accessibility.⁹⁶ Architectural and aesthetic aspirations to create grand courthouses made entrances difficult to negotiate. For example, processional entryways created by staircases effectively created a functional barrier for people who could not walk. The law was expanded in 1990 with the Americans with Disabilities Act (ADA), which ordered accessibility for both state and private facilities.⁹⁷ Title II of the ADA states that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."⁹⁸ However, compliance with the accessibility mandate continued to be problematic. For example, in the 1990s during public hearings about accessibility in California, approximately 60 percent of the speakers referred to issues created by physical barriers to courts and mobility problems for individuals who could not make it past the entrance.⁹⁹

In *Tennessee v. Lane*, the U.S. Supreme Court upheld a provision of the ADA allowing individuals to seek monetary damages from states for a failure to comply with the federal laws governing access to courts for people with disabilities.¹⁰⁰ The Plaintiff, George Lane, used a

⁹³ *New Ethics Guidelines 2011*, INTERNATIONAL FEDERATION OF GYNECOLOGY AND OBSTETRICIANS, <http://www.figo.org/news/new-download-new-ethics-guidelines-2011-003772>.

⁹⁴ *Id.*

⁹⁵ *Id.*

⁹⁶ Judith Resnik & Dennis Curtis, *Representing Justice: Invention, Controversy, and Rights in City-States and Democratic Courtrooms* (2011), available at: <http://documents.law.yale.edu/representing-justice>.

⁹⁷ 28 C.F.R. § 35, § 35 (2015).

⁹⁸ 42 U.S.C. § 12132 (1990).

⁹⁹ Resnik & Curtis, *supra* note 96.

¹⁰⁰ *Tennessee v. Lane*, 541 U.S. 509 (2004).

wheelchair as a result of paraplegia. He had “crawled up two flights of stairs to get to the courtroom” (the courthouse had no elevator access to the upper floors of the courthouse) in Tennessee for a criminal trial in which he was the defendant.¹⁰¹ The U.S. Supreme Court held that the states were not immune from damage actions, explaining that “affirmative obligations” stemmed from the fact that access to courts was a fundamental constitutional value.¹⁰² In describing accessibility issues, the Court “[recognized] that failure to accommodate persons with disabilities will often have the same practical effect as outright exclusion.”¹⁰³ Additionally, the U.S. Supreme Court also held that included in states’ duty to accommodate persons with disabilities, is the obligation to “...afford to all individuals a meaningful opportunity to be heard’ in its courts.”¹⁰⁴

A 2006 report illustrated how the design of courthouses continues to impede physical access to justice for people with disabilities.¹⁰⁵ Specifically, the design of courthouses poses challenges to access due to unique features, such as inaccessible witness chairs and jury boxes, courtroom areas that are elevated within confined spaces, failure to provide accessible signage and listening systems for persons with hearing disabilities, and many other common errors that challenge the physical access to the courthouse.¹⁰⁶

2. Competency to Testify

The justice system often fails to see women and girls with disabilities as competent witnesses, either because of stereotypes and or difficulties in communication without accommodations. The mere fact that a woman has a disability or requires assistive communication or accommodations may result in the justice system viewing her as lacking credibility.¹⁰⁷ However, the chances of a woman or child with disability coming in contact with the justice system is greater than it is for individuals without disabilities.¹⁰⁸ Women and girls with disabilities are more likely to come in contact with the justice system as victims, experiencing higher incidents of both physical and sexual abuse because they are viewed as more vulnerable targets.¹⁰⁹ Furthermore, children with disabilities are targeted because assailants believe they either will not report the abuse or are incapable of reporting it because of their disability.¹¹⁰ Likewise, like women with disabilities, girls with disabilities have a higher risk of experiencing abuse than non-disabled girls.¹¹¹

¹⁰¹ *Tennessee v. Lane*, 541 U.S. at 514.

¹⁰² *Tennessee v. Lane*, 541 U.S. at 514.

¹⁰³ *Tennessee v. Lane*, 541 U.S. at 510-12.

¹⁰⁴ *Tennessee v. Lane*, 541 U.S. at 532 (citing *Boddie v. Connecticut*, 401 U.S. 371, 379 (1971)).

¹⁰⁵ U.S. Access Board, *Justice for All: Designing Accessible Courthouses* (Nov. 15, 2006).

¹⁰⁶ *Id.*

¹⁰⁷ Janine Benedet & Isabel Grant, *Hearing the Sexual Assault Complaints of Women with Mental Disabilities: Evidentiary and Procedural Issues*, 52 MCGILL LAW J. 515-522 (2007), available at <http://ssrn.com/abstract=1657128>.

¹⁰⁸ See Sharon Primor & Na’ama Lerner, *The Right of Persons with Intellectual, Psychosocial and Communication Disabilities to Access to Justice Accommodations in the Criminal Process*, BIZCHUT, THE ISRAEL HUMAN RIGHTS CENTER FOR PEOPLE WITH DISABILITIES 3 (2015).

¹⁰⁹ *Id.*

¹¹⁰ Wendy Murphy, *Traumatized Children Who Participate in Legal Proceedings Are Entitled to Testimonial and Participatory Accommodations Under the Americans with Disabilities Act*, 19 ROGER WILLIAMS U. L. REV. 361, 371 (2014).

¹¹¹ *Id.*, at 371-72.

Yet, paternalistic attitudes may cause the legal system to view women with disabilities as too fragile to withstand rigors of examination.¹¹² Believing women or children with disabilities are unable to provide reliable information, police officers may be reluctant to pursue reports of sexual assault and violence.¹¹³ Judges may require more corroborating evidence than in other cases, and prior mental health treatment may be used to discredit testimony. Exclusions of testimony are particularly problematic in gender-based violence and sexual assault cases, where the testimony of the parties and the credibility of the witnesses are exceptionally important, thereby placing women with disabilities at even greater risk, since perpetrators may be more likely to attack them because they know their complaints may be taken less seriously.¹¹⁴ If prior complaints were dismissed, they are less likely to report abuse in the future, perpetuating the violence.¹¹⁵

Once in the justice system, persons with disabilities oftentimes cannot meaningfully participate in the justice system because their access is further hampered by our intricate, complex, and stringent legal systems and procedures that fail to accommodate their disabilities.¹¹⁶ In each step of their contact with the justice system, women with disabilities are met with the negative attitudes and lack of understanding of police officers, prosecutors, lawyers, judges, and court systems.¹¹⁷ Without accommodations, women with disabilities do not experience equal treatment under the law or have equal rights under the law.¹¹⁸

In the landmark case *In re McDonough*, the Supreme Judicial Court of Massachusetts for the first time ruled that "...where a witness with a disability requests accommodation in order to testify, [the law] requires that the court provide such accommodation, so long as it is 'reasonable.'"¹¹⁹ The witness in this case was Ruby McDonough, who is a woman with expressive aphasia, a condition that severely restricts her ability to speak.¹²⁰ Ms. McDonough was the Commonwealth's witness in its prosecution case against the man that sexually assaulted her.¹²¹ During pretrial proceedings, the defendant challenged Ms. McDonough's competence to testify against him and asked that she be subjected to a competency hearing.¹²² During this hearing defendant's counsel purposefully took advantage of Ms. McDonough's disability by asking her open ended questions he knew she could not answer, and using intimidating tactics guaranteed to frustrate her attempt to testify.¹²³ Despite the expert's report and testimony that Ms. McDonough was competent to testify especially where accommodated with questions with a "yes" or "no" answer, or with simple gestures, the trial judge found her incompetent to testify.¹²⁴

¹¹² Primor & Lerner, *supra* note 108, at 4.

¹¹³ William Paul Deal & Viktoria Kristiansson, *Victims and Witnesses with Developmental Disabilities and the Prosecution of Sexual Assault*, The National Center for the Prosecution of Violence Against Women, http://www.ndaa.org/pdf/the_voice_vol_1_no_12_2007.pdf.

¹¹⁴ See Chris Jennings, *Family Violence & Sexual Assault: A Criminal Justice Response for Women with Disabilities*, <http://www.wvda.org.au/wp-content/uploads/2013/12/jennings4.pdf>.

¹¹⁵ *Id.*

¹¹⁶ Primor & Lerner, *supra* note 108, at 3-4.

¹¹⁷ *Id.*, at 4.

¹¹⁸ *Id.*

¹¹⁹ *In re McDonough*, 930 N.E.2d 1279, 1293 (Mass. 2010).

¹²⁰ *In re McDonough*, 930 N.E.2d at 1282.

¹²¹ *In re McDonough*, 930 N.E.2d at 1284.

¹²² *In re McDonough*, 930 N.E.2d at 1284.

¹²³ Murphy, *supra* note 110, at 366.

¹²⁴ *In re McDonough*, 930 N.E.2d at 1285.

Although the trial judge found that Ms. McDonough knew the “...difference between truth and falsehood, and her obligation to tell the truth...” he ultimately decided that she was not competent to testify because he found her easily confused by the phrasing of questions, and “incapable of providing any narrative.”¹²⁵ The trial judge also found that if Ms. McDonough was allowed to testify, the defendant would be robbed of his right to a meaningful cross examination and a fair trial.¹²⁶ On appeal, although the Supreme Judicial Court found that Ms. McDonough lacked standing to challenge the trial judge’s decision to exclude her testimony as a witness, it did however find that her rights had been violated.¹²⁷ The ruling in this case is important because it illustrates the extent our legal system renders women with disabilities powerless.¹²⁸ It shows that without accommodations, women with disabilities will be excluded from the justice system simply because of their disabilities.¹²⁹

When women with disabilities participate in the U.S. justice system, their credibility as a witness is questioned in a way that presents new barriers and challenges to meaningfully engage in the justice system.¹³⁰ For example, in *Tromello v. Dibuono*, the defendant, accused of psychiatric malpractice, sought to exclude plaintiff’s testimony simply because of her mental disability.¹³¹ Although the Court in *Tromello* ultimately admits plaintiff’s testimony, it does so with the caveat that evidence of her mental capacity and disability be admitted into evidence “to assist the jury in evaluating the weight, if any, to be given to the testimony.”¹³² Passing the test of competence is not enough; testimony is further evaluated and weighed in light of the severity or nature of their disability.¹³³

Furthermore, crimes committed against individuals with disabilities are often characterized as abuse and neglect instead of specific crimes such as assault, rape, and murder.¹³⁴ This often leads to the understatement of the problem of criminal victimization of individuals with disabilities. Additionally, from the perspective of a victim with a disability, there are significant barriers to reporting a crime, including “fear of loss of a caregiver, inability to verbally communicate as a result of the disability, and fear of not being taken seriously,” among other barriers.¹³⁵ Often individuals with disabilities are dependent upon their abusers who are caregivers, friends, or family members to assist with personal care and other needs. Additionally, even when people with disabilities do report crimes, prosecutors or the justice system may not take their claims seriously.¹³⁶ Likewise, cases involving individuals are often not prosecuted because of the

¹²⁵ *In re McDonough*, 930 N.E.2d at 1282.

¹²⁶ *In re McDonough*, 930 N.E.2d at 1285.

¹²⁷ *In re McDonough*, 930 N.E.2d at 1283.

¹²⁸ See Murphy, *supra* note 110, at 368.

¹²⁹ *Id.*

¹³⁰ *Tromello v. Dibuono*, 132 F. Supp. 2d 82, 85 (E.D.N.Y. 2000).

¹³¹ *Tromello v. Dibuono*, 132 F. Supp. 2d at 84.

¹³² *Tromello v. Dibuono*, 132 F. Supp. 2d at 85.

¹³³ *Tromello v. Dibuono*, 132 F. Supp. 2d at 85.

¹³⁴ Leigh Ann Davis, The Arc, *People with Intellectual Disabilities and the Criminal Justice System: Victims & Suspects*, <http://www.thearc.org/page.aspx?pid=2458>.

¹³⁵ *Violence Against Women Online Resources: Research in Brief*, “The Facts About Sexual Violence” Violence Against Women Online Resources 1, 3 (2009), available at <http://studentaffairs.duke.edu/sites/default/files/u7/sexualviolence-color.pdf>.

¹³⁶ Davis, *supra* note 134.

assumption and belief that such persons cannot be credible witnesses.¹³⁷ This belief prevails despite evidence showing that persons with disabilities are as competent as individuals without disabilities when asked to recall previously viewed recordings of crime.¹³⁸

Furthermore, courthouses and police stations may also not have the resources necessary to ensure that witnesses with disabilities have the ability to adequately communicate with the justice system or access information. During initial police questioning for example, sign language interpreters may not be readily accessible to assist women with hearing impairments; information may not be available in Braille or other alternative formats, making it more difficult for women with a visual disability to pursue their complaints.¹³⁹ The courts rarely have special accommodations to assist people with disabilities.¹⁴⁰ There generally are no specially trained court officers, police officers, advocates, or provisions for the use of videotaped or closed circuit television as a substitute for live testimony.¹⁴¹ Unlike other countries, the U.S. justice system generally has no special protection for persons with disabilities. For example, the courts in England require a special legal advocate to be present during the questioning of an individual (victim) with a disability.¹⁴² Oftentimes this advocate is someone close to the victim who helps the victim understand the questions being asked during the investigation.¹⁴³

A process called “facilitated communication” can be used to assist non-verbal women with disabilities, such as people with autism, in communication.¹⁴⁴ Specifically, facilitated communication is “a form of alternative and augmentative communication (AAC) in which people with disabilities and communication impairments express themselves by pointing (e.g. at pictures, letters, or objects) and, more commonly, by typing.”¹⁴⁵ Facilitated communication, involves a communication partner who not only supports communication, but also provides emotional encouragement. The communication partner works with persons with disabilities to help stabilize their movements and avoid impulsive pointing. Their role is one of support; they should not move or lead the person.¹⁴⁶ Unfortunately, some courts have refused to admit such statements because facilitated communication has not garnered wide acceptance by some in the scientific community as of yet, despite evidence of its reliability.¹⁴⁷ Even if a woman with a disability can fully understand police or attorney questioning, if she uses alternative forms of communication her credibility as a witness may also be called into question by a judge or jury.¹⁴⁸

¹³⁷ Joan Petersilia, *Invisible Victims: Violence Against Persons with Developmental Disabilities*, 27-WTR Hum. Rts. 9 (2000).

¹³⁸ *Id.*

¹³⁹ Stephanie Ortoleva, *Inaccessible Justice: Human Rights, Persons with Disabilities and the Legal System*, 17 ILSA J. INT'L & COMP. L. 281, 311 (2011).

¹⁴⁰ Petersilia, *supra* note 137, at 10.

¹⁴¹ *Id.*

¹⁴² *Id.*

¹⁴³ *Id.*

¹⁴⁴ Syracuse University School of Education, *What is Supported Typing?*, http://soe.syr.edu/centers_institutes/institute_communication_inclusion/what_is_supported_typing/default.aspx.

¹⁴⁵ *Id.*

¹⁴⁶ *Id.*

¹⁴⁷ See *State v. Warden*, 891 P.2d 1074, 1088 (Kan. 1995) (court admitted a statement made through facilitated communication). See also *DSS ex. rel. Jenny S. v. Mark S.*, 593 N.Y.S.2d 142 (N.Y. Fam. Ct. 1992) (court refused to admit such a statement due to scientific uncertainty as to its accuracy).

¹⁴⁸ Chris Jennings, *Family Violence & Sexual Assault: A Criminal Justice Response for Women with Disabilities*, <http://www.wwda.org.au/wp-content/uploads/2013/12/jennings4.pdf>. See also Brandon Tuck, *Preserving Facts*,

Jurors are expected to use their every day norms and judgments to decide which competing narrative presented by the parties or witnesses is most credible.¹⁴⁹ When faced with a nonconventional witness, or a witness with a disability, the legal system often prompts jurors to question the veracity and credibility of that witness' testimony.¹⁵⁰ In the same vein, a diagnosis of mental retardation can distort jurors' judgment, preventing them from objectively reviewing and considering the witness's evidence or testimony.¹⁵¹

Thank you for this opportunity to provide information regarding the right to health and safety of women with disabilities in the U.S. Please do not hesitate to contact us at the emails below or by telephone (+1-202-630-3818) should you have any questions or require additional information on any of the comments addressed herein.

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Form and Function when a Deaf Witness with Minimal Language Skills Testifies in Court, 158 U. PA. L.R. 905, 917-920 (2010).

¹⁴⁹ Tuck, *supra* note 148, at 917-920.

¹⁵⁰ *Id.*

¹⁵¹ William Paul Deal & Viktoria Kristiansson, *Victims and Witnesses with Developmental Disabilities and the Prosecution of Sexual Assault*, The National Center for the Prosecution of Violence Against Women, available at http://www.ndaa.org/pdf/the_voice_vol_1_no_12_2007.pdf.

Annex I: U.S. Judicial Decisions Regarding Sterilization of Women with Disabilities

As recently as the early part of the twentieth century, many states in the United States enacted compulsory sterilization laws in an attempt to lessen the impact and cost of care for those with disabilities.¹ More recently, the U.S. Supreme Court in *Griswold v. Connecticut*² and *Eisenstadt v. Baird*³ began to recognize a right to access contraception that accompanies a fundamental right to procreate. However, the U.S. Supreme Court has yet to fully protect an express right to voluntary, consensual sterilization. As such, sterilization falls in a murky area between the right to contraceptive access and the right to procreate, and there is no clear standard that addresses the level of competency needed to be able to choose between the two.

In the early 1980's, numerous state claims arose whereby the parents or guardians of women and girls with mental and cognitive disabilities sought the appointment of a special guardian who would be authorized to consent to sterilization.

The court cases in which a court denied nonconsensual sterilization of a woman with a disability are discussed as follows. In *Matter of Grady*,⁴ the parents of a non-institutionalized daughter requested a special guardian who could authorize sterilization by tubal ligation. In 1981, the Supreme Court of New Jersey determined that sterilization cannot be authorized without clear and convincing proof that sterilization is in the best interests of the individual whose health is at stake. The court must find that the individual “lacks capacity to make a decision about sterilization and that the incapacity is not likely to change in the foreseeable future.”⁵ Further, the court must consider a set of factors relating to the best interests of the individual:

- (1) “The possibility that the incompetent person can become pregnant. There need be no showing that pregnancy is likely. The court can presume fertility if the medical device indicates normal development of sexual organs and the evidence does not otherwise raise doubts about fertility.
- (2) The possibility that the incompetent person will experience trauma or psychological damage if she becomes pregnant or gives birth, and, conversely, the possibility of trauma or psychological damage from the sterilization operation.
- (3) The likelihood that the individual will voluntarily engage in sexual activity or be exposed to situations where sexual intercourse is imposed upon her.

¹ Arkansas (ARK. CODE ANN. §20-49-101 (2010)); Colorado (COLO. REV. STAT. §27-10.5-130 (2012)); Delaware (16 DEL. CODE ANN. §5712 (2013)); Georgia (GA. CODE ANN. §31-20-3 (2010)); Maine (34-B Me. Rev. Stat. §7010 (2011)); North Carolina (N. C. GEN. STAT. §35A-1245 (2010)); Oregon (OR. REV. STAT. §436.205 (2011)); Utah (UTAH CODE ANN. 1953 §62A-6-102 (2011)); Vermont (18 VT. STAT. ANN. §8705 et seq. (2009)); Virginia (VA. CODE ANN. §54.1-2975 et seq. (1988)); West Virginia (W. VA. CODE §27-16-1 et seq. (2013)); *See also Matter of Grady*, 85 N.J. 235 (1981) (“Lawmakers may have sincerely believed that the social welfare would improve if fewer handicapped people were born, but they were too quick to accept unproven scientific theories of eugenics.”).

² 381 U.S. 479 (1965).

³ 405 U.S. 438 (1972).

⁴ 426 A.2d 467 (N.J. 1981).

⁵ 426 A.2d at 482.

- (4) The inability of the incompetent person to understand reproduction or contraception and the likely permanence of that inability.
- (5) The feasibility and medical advisability of less drastic means of contraception, both at the present time and under foreseeable future circumstances.
- (6) The advisability of sterilization at the time of the application rather than in the future. While sterilization should not be postponed until unwanted pregnancy occurs, the court should be cautious not to authorize sterilization before it clearly has become an advisable procedure.
- (7) The ability of the incompetent person to care for a child, or the possibility that the incompetent person may at some future date be able to marry, and, with a spouse, care for a child.
- (8) Evidence that scientific or medical advances may occur within the foreseeable future which will make possible either improvement of the individual's condition or alternative and less drastic sterilization procedures.
- (9) A demonstration that the proponents of sterilization are seeking it in good faith and that their primary concern is for the best interests of the incompetent person rather than their own or the public's convenience."⁶

In concluding that the penultimate criterion is the best interests of the individual with disabilities, the court in *Matter of Grady* determined that the parents were unable to demonstrate by clear and convincing evidence that sterilization would be in the daughter's best interests under the set of factors outlined above.

In 1982, the parents of a thirteen year old girl with mental disabilities filed a petition to serve as her guardian in order to consent to her sterilization. In *Wentzel v. Montgomery General Hospital*,⁷ the Court of Appeals of Maryland found that a hysterectomy was not in the child's best interest or necessary for either her mental or her medical health. The court determined that the hysterectomy did not meet the "demonstrated need" formulation of measures taken to preserve life, physical health, or mental health.⁸ Neither pain nor irritation during her menstrual cycle, which the daughter was not able to understand, nor the possibility of pregnancy were justification for such an extreme operation at such a young age. The court therefore appropriately denied the parent's petition based on the "age and present circumstances, the absence of any evidence, much less clear and convincing evidence of any medical necessity for the sterilization procedure at this time."⁹

Similarly, in *Matter of Truesdell*,¹⁰ the Supreme Court of North Carolina in 1985 reaffirmed that the party petitioning for an order authorizing consent for sterilization must prove by clear, strong, and convincing evidence that sterilization would be in the constitutional best interests of the individual. In this case, the court determined that the Mecklenburg County Department of Social

⁶ 426 A.2d at 483.

⁷ 447 A.2d 1244 (M.D. 1982).

⁸ 447 A.2d at 1254.

⁹ 447 A.2d at 1254.

¹⁰ 329 S.E.2d 630 (N.C. 1985).

Services failed to provide sufficient evidence to demonstrate that sterilization was in the best interests of the eighteen year old female whose reproductive health was at stake. The woman was capable of procreation, did not demonstrate possible trauma, and there was no evidence that she was likely to engage in sexual activity that might lead to procreation.¹¹ Further, there was insufficient evidence to prove that she was “in imminent danger for her life or that her health is severely jeopardized if a hysterectomy is not immediately performed.”¹² Moreover, findings were inadequate to determine whether there were less drastic means of preventing contraception. Therefore, the Supreme Court of North Carolina denied the petition of the County.

Also in 1985, the Supreme Court of California in *Conservatorship of Valerie N.*¹³ determined that the parents of an adult female with developmental disabilities were not entitled to have their daughter sterilized. No evidence was offered that the daughter was capable of conception; additionally, no evidence was offered outside of testimony by the immediate family and the family counselor that “alternative less intrusive methods of birth control are unavailable.”¹⁴ Further, no evidence was proffered that she was sexually active. Therefore, the court determined that sterilization was not in the best interests of the adult daughter at that point in time. The court denied the petition without prejudice to a renewed application if appellants were able to later provide adequate supporting evidence of the need for sterilization.¹⁵

However, the court also determined that the state statute prohibiting sterilization of individuals under conservatorship or guardianship impermissibly deprives those individuals of their own privacy and liberty guaranteed under federal and state Constitutions. The court found that the California legislature’s “omission of any provision in other legislation authorizing sterilization of A Woman’s Story: developmentally disabled persons... denied incompetent women the procreative choice that is recognized as a fundamental, constitutionally protected right of all other adult women.”¹⁶ The court disagreed with the conservators in the case, who alleged that the interest of the state in safeguarding the right to not be sterilized superseded the interests of conservatees who are personally unable to consent to sterilization themselves.¹⁷ After doing so, the Supreme Court of California determined that the state statute regarding sterilization was overbroad.

In *Matter of Romero*,¹⁸ the Supreme Court of Colorado found in 1990 that the mother and guardian of a daughter with disabilities was not able to prove by clear and convincing evidence that her daughter was incompetent to grant or withhold consent to sterilization. An individual who is incompetent in certain areas is not necessarily precluded as incompetent in all decisions.¹⁹ An individual should be considered competent in the context of sterilization if he or she “understands the nature of the district court’s proceedings, the relationship between sexual activity and reproduction and the consequences of the sterilization procedure.”²⁰ Given that the

¹¹ 329 S.E.2d at 636.

¹² 329 S.E.2d at 636.

¹³ 770 P.2d 760 (Cal. 1985).

¹⁴ 770 P.2d at 764.

¹⁵ 770 P.2d at 778.

¹⁶ 770 P.2d at 772.

¹⁷ 770 P.2d at 774.

¹⁸ 790 P.2d 819 (Colo. 1990).

¹⁹ 790 P.2d at 822.

²⁰ 790 P.2d at 823.

individual, whose reproductive abilities were impacted, showed during testimony that she understood the meaning between sexual intercourse and pregnancy, the court found that there was not sufficient determination that she was incompetent. In doing so, the court made clear that its own role is “not to pass judgment upon the wisdom of [the adult woman’s] decision or the importance she assigns to potential risks and benefits...if [she] is competent to make a decision, she must remain free to do so.”²¹ Thus, the sterilization order by the trial court was reversed.²²

In 1981, the Supreme Court of Colorado in *Matter of A.W.*²³ determined that state statutes pertaining to the sterilization of individuals with mental disabilities did not address the sterilization of a minor, which should be treated under a separate analysis. However, the court then determined that the court did have the authority to consider a petition to sterilize a minor with a mental disability and that it was under A.W.’s constitutional best interests to do so. This determination was made by the court with very little discussion of the factual, case-specific reasoning as to why it was in the best interests of the minor girl.

Beginning in the mid-1990s, a series of claims were resolved in favor of a guardian, parent, or conservator who desired authority to consent to sterilization. In *Estate of C.W.*,²⁴ the court determined that the best interest of the daughter were for the mother to be appointed her guardian with the authority to consent to tubal ligation. In its holding, the court relied on a best interest determination as originally outlined in *Matter of Mildred J. Terwilliger*,²⁵ where in order to succeed in a request for authorization, sterilization must be “the only practicable means of contraception, i.e. all less drastic contraceptive methods, including supervision, education and training are unworkable and detailed medical testimony must show that the sterilization procedure requested is the least significant intrusion necessary to protect the interests of the individual.” In this case, the Superior Court of Pennsylvania determined that the possibility of sexual activity and pregnancy did exist and that the alternative medical procedures would be more complicated and potentially less effective²⁶; therefore, the court concluded that the best interests standard required that a guardian be appointed with the authority to consent to a sterilization procedure.

In 2013, the Court of Appeals in California addressed the *Conservatorship of a Person in Estate of Maria B.*,²⁷ where the mother of a woman with cognitive disabilities petitioned the trial court for an order authorizing herself to consent to a hysterectomy and oophorectomy on her daughter’s behalf. The trial court had found that there was a probability that the daughter’s current condition could pose a serious threat to her mental health and that she lacked the capacity to give her informed consent for the recommended treatment.²⁸ The California Court of Appeals upheld the clear and convincing evidence standard and determined that the “need for the

²¹ 790 P.2d at 824.

²² 790 P.2d at 823-24.

²³ 637 P.2d 366 (Colo. 1981).

²⁴ 640 A.2d 427 (Pa. Super. Ct. 1994).

²⁵ 304 A.2d 1376 (Pa. Super. Ct. 1982).

²⁶ 640 A.2d at 439.

²⁷ 160 Cal Rptr.3d 269 (Cal. Ct. App. 2013).

²⁸ 160 Cal Rptr.3d at 274.

proposed hysterectomy and oophorectomy, and the consequences for Maria if she did not have the surgery amount to clear and convincing evidence” that support granting the petition.²⁹

There have also been several claims brought by women with mental disabilities against physicians and hospitals for past wrongful sterilization. In 1990, the Supreme Judicial Court of Maine found in *Chasse v. Mazerolle*³⁰ that the physician had not established sufficient indication that the complainant possessed sufficient competence to “comprehend and exercise her legal rights.”³¹ The physician had relied on the woman’s marriage and subsequent divorce as evidence of her competency, yet the court rejected this viewpoint and found that the physician did not adequately address all other considerations.³² The Supreme Judicial Court of Maine concluded that a claim of wrongful sterilization was precluded from summary judgment due to material questions of fact as to whether or not nonconsensual sterilization was appropriate, and the case was remanded to determine the level of the patient’s competency.

In 1997, the Third Circuit of the United States Court of Appeals addressed a claim brought by a woman with a mental disability and her husband in state court against the woman’s parents, the hospital, and several physicians.³³ The couple alleged their deprivation of their civil rights based on the nonconsensual sterilization of the woman when she was sixteen. The circuit court first found that a plaintiff’s status as a woman with mental disability placed her within a class entitled to protection under civil rights provisions of both 42 U.S.C. § 1985(3) and 42 U.S.C. § 1985.³⁴ The circuit court more broadly established that the that the mentally handicapped as a class are entitled to protection under civil rights laws, including § 1985(3), because [t]he fact that a person bears no responsibility for a handicap, combined with the pervasive discrimination practiced against the mentally retarded and the emerging rejection of this discrimination as incompatible with our ideals of equality convinces us that... an animus directed against the mentally retarded includes the elements of a class-based invidiously discriminatory motivation.³⁵

After remand and subsequent appeal, the Third Circuit found that a two-year statute of limitations claim for personal injury in Pennsylvania did not toll for the claims of a woman with a mental disability challenging a prior nonconsensual sterilization because she was “unable to appreciate the injury that was done to her when she was sterilized.”³⁶

²⁹ 160 Cal Rptr.3d at 283.

³⁰ 580 A.2d 155 (Me. 1990).

³¹ 580 A.2d at 157.

³² 580 A.2d at 157.

³³ 112 F.3d 682 (3rd Cir. 1997).

³⁴ 112 F.3d at 684.

³⁵ 112 F.3d at 688 (quoting *Novotny v. Great Am. Fed. Sav. And Loan Ass’n*, 584 F.2d 1235, 1243 (3rd Cir. 1978).

³⁶ 232 F.3d 360, 371 (3rd Cir. 2000).