PERSONS WITH DISABILITIES AND THEIR SEXUAL, REPRODUCTIVE, AND PARENTING RIGHTS: AN INTERNATIONAL AND COMPARATIVE ANALYSIS

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Abstract Despite important gains in human rights, persons with disabilities — and in particular women and girls with disabilities — continue to experience significant inequalities in the areas of sexual, reproductive, and parenting rights. Persons with disabilities are sterilized at alarming rates; have decreased access to reproductive health care services and information; and experience denial of parenthood. Precipitating these inequities are substantial and instantiated stereotypes of persons with disabilities as either asexual or unable to engage in sexual or reproductive activities, and as incapable of performing parental duties. The article begins with an overview of sexual, reproductive, and parenting rights regarding persons with disabilities. Because most formal adjudications of these related rights have centered on the issue of sterilization, the article analyzes commonly presented rationales used to justify these procedures over time and across jurisdictions. Next, the article examines the Convention on the Rights of Persons with Disabilities and the attendant obligations of States Parties regarding rights to personal integrity, access to reproductive health care services and information, parenting, and the exercise of legal capacity. Finally, the article highlights fundamental and complex issues requiring future research and consideration.

Keywords disability, Convention on the Rights of Persons with Disabilities, human rights, parenting, sexual and reproductive rights

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INTRODUCTION

In 2012, in the US, the parents of Mary Moe, a 32-year-old pregnant woman with a psychiatric disability, petitioned a court for her guardianship in order to precipitate an abortion.1 Despite Moe’s fervent opposition owing to religious beliefs, the trial court appointed her parents as co-guardians and authorized that she be “coaxed, bribed, or even enticed…by ruse” into a hospital for an abortion.2 The judge also ordered that Moe be sterilized “to avoid this painful situation from recurring in the future.”3 The decision was reversed on appeal, with the appellate court noting in regard to the sterilization order, “No party requested this measure, none of the attendant procedural requirements has been met, and the judge appears to have simply produced the requirement out of thin air.”4

In Israel, in 2015, Ora Mor Yosef, a woman with a physical disability unsuccessfully challenged that country’s surrogacy laws.5 Yosef always wanted to be a mother but her doctors cautioned that she would likely face significant complications from pregnancy due to her disability.6 After a tumultuous and lengthy endeavor, Yosef had a surrogate

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2 Id. at 353.
3 Id.
4 Id.
6 Id.
child through her niece who underwent the procedure in India and gave birth in Israel. There, child welfare officials immediately declared the newborn to be in “danger” and placed her in foster care. Yosef fought for more than 2 years to regain custody of her daughter. According to the Israel Supreme Court, Yosef’s case marks “a crossroad between advanced technology, individual disability, the universal yearning for parenthood and the evolution of Israeli law.” However, because they are not biologically connected, Israeli courts refuse to recognize Yosef as the child’s mother.

Across the globe, more than 1 billion individuals, approximately 15% of the world’s population, live with disabilities. Although different in many respects, Moe and Yosef’s respective cases illustrate a common and continuing phenomenon affecting this population. Despite important gains in human rights, persons with disabilities — and in particular women and girls with disabilities — continue to experience significant inequalities in the areas of sexual, reproductive, and parenting rights. Central to these inequities are substantial and prevailing stereotypes that affect girls and women with

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7 Id.
8 Id.
9 Id.
10 Id.
11 Id.
13 Roberta Cepko, Involuntary Sterilization of Mentally Disabled Women, 8 Berkeley Women’s Law Journal 122, 123–124 (1993) (discussing the US, “[o]nly a few of the dozens of cases regarding involuntary sterilization involve the sterilization of males. Therefore, sterilization practice is interwoven with the issue of control of female reproductive rights and, to some extent, of female expression”). But see In re Guardianship of Kennedy, 845 N.W.2d 707 (Iowa Apr. 18, 2014) (appeal brought by a 21-year-old man with intellectual disabilities challenging the legality of a vasectomy his guardian had arranged for him without obtaining a court order); Renu Barton-Hanson, Sterilization of Men with Intellectual Disabilities: Whose Best Interest Is It Anyway?, Medical Law International (2005), available at http://mli.sagepub.com/content/early/2015/06/26/0968532155924444.full.pdf+html (last visited Jan. 19, 2016) (examining recent cases concerning sterilization of men with intellectual disabilities and noting the frequent justification as allegedly promoting sexual freedom).
14 World Health Organization & United Nations Population Fund, Promoting Sexual and Reproductive Health for Persons with Disability, 7 (2009); see also World Health Organization, Sexual Health, Human Rights and the Law 24 (2015), available at http://www.who.int/reproductivehealth/publications/sexual_health/sexual-health-human-rights-law/en/ (last visited Jan. 19, 2016) (“Health-care providers may consider that people with intellectual disabilities or other disabilities should not have a sexual life, reproduce or look after children, and therefore should not need sexual and reproductive health services. Furthermore, healthcare settings may be physically inaccessible and health information may be unavailable in different formats”).
15 Jennifer Kern, Across Boundaries: The Emergence of an International Movement of Women with Disabilities, 8 Hastings Women’s Law Review 233, 244 (1997) (“An example of an insidious and destructive phenomenon disabled women face throughout the world is the limitation to reproductive freedom and choices”).
disabilities in double measure because of their disability and gender.\textsuperscript{16} Stemming from prejudiced constructs of sexuality,\textsuperscript{17} persons with physical or sensory disabilities are often misperceived as asexual,\textsuperscript{18} while those with intellectual or psychiatric disabilities are wrongly assumed incapable of appropriate (meaning, non-promiscuous) sexual relations.\textsuperscript{19} Because of these stereotypes, persons with disabilities — principally women with intellectual\textsuperscript{20} or psychiatric\textsuperscript{21} disabilities — are sterilized at alarming rates. Strikingly, involuntary or coercive sterilization of persons with disabilities endures across the globe in many countries including the US,\textsuperscript{22} Mexico,\textsuperscript{23} India,\textsuperscript{24}

\textsuperscript{16} Id. at 235 (asserting that “stereotypes of disabled women impinge on efforts at self-determination and autonomy, and undermine attempts to change unjust policies that oppress disabled women worldwide”).


\textsuperscript{22} National Council on Disability, \textit{Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children}, 44 (2012) (the “Rocking the Cradle”) (“[S]everal states still have some form of involuntary sterilization laws on their books”).

\textsuperscript{23} Disability Rights International, \textit{Twice Violated: Abuse and Denial of Sexual and Reproductive Rights of Women with Psychosocial Disabilities in Mexico City}, Feb. 15, 2015, available at http://www. driadvocacy. org/disability-rights-international-dri-research-reveals-shocking-abuses-against-women-with-disabilities-in-m exico-city/ (last visited Jan. 19, 2016) (42% of the women interviewed, all with psychosocial or psychiatric disabilities, had been forcibly surgically sterilized or had been coerced by their families to undergo the procedure. Moreover, certain institutions for children with disabilities in Mexico City require sterilization of every girl admitted).

Erroneous cultural conventions about disability also result in decreased access to reproductive health care services. For instance, women with disabilities often encounter significant barriers to obtaining information, medical care, and services necessary for ensuring their reproductive needs. Correspondingly, disabled persons are at an increased risk of exposure to HIV/AIDS, because of limited access to education, information, and prevention services. For women with intellectual disabilities, not


26 Laurent Servais, Robert Leach & Denis Jacques et al, Sterilization of Intellectually Disabled Women, 19 European Psychiatry 428 (2004) (citing a 2004 Belgium study finding that sterilization of women with intellectual disabilities is three times higher than that in the general population and is highly correlated with institutionalization and severity of disability).


28 See Sterilization of Women and Girls with Disabilities, fn. 25 at 2; Rocking the Cradle, fn. 22 at 252–257.

29 Id.; Stein, fn. 19 at 1079 (“The prevailing presumption is that if women with disabilities will not or cannot engage in sexual activity, then they do not need access to gynecological health care”); Lori Ann Dotson, Jennifer Stinson & Leeann Christian, “People Tell Me I Can’t Have Sex”: Women with Disabilities Share Their Personal Perspectives on Health Care, Sexuality, and Reproductive Rights, 26 Women & Therapy 195, 196 (2003) (women with disabilities often do not receive family planning counseling because health care providers do not view them as sexual beings); Sibusiswe Siphelele Mavuso & Pranitha Maharaj, Access to Sexual and Reproductive Health Services: Experiences and Perspectives of Persons with Disabilities in Durban, South Africa, 6 Agenda: Empowering Women for Gender Equity (Jun. 29, 2015), available at http://dx.doi.org/10.1080/10130950.2015.1043713 (last visited Jan. 19, 2016) (finding a large divide between the need for sexual and reproductive health services and access to such services by persons with disabilities, particularly family planning services and information about contraceptives).

receiving sex education and information leads to higher rates of sexually transmitted
diseases as well as victimization of sexual abuse, along with a limited ability to report
those abuses due to lack of knowledge.\(^\text{31}\)

Deprivation of sexual, reproductive, and parenting rights results in the denial of the
opportunity to parent by persons with disabilities.\(^\text{32}\) In addition to the insurmountable
biological barriers created by sterilization, prospective parents with varying disabilities
are also more likely to face discrimination when attempting to adopt (domestically or
internationally)\(^\text{33}\) or to access fertility treatments.\(^\text{34}\) Among those persons with
disabilities who do become parents, research from Canada, the US, Australia, New
Zealand, and the UK reports that parents with intellectual disabilities have their children
permanently removed by child welfare agencies at rates ranging from 30% to 80%.\(^\text{35}\)
Similarly, research indicates that parents with psychiatric disabilities face
disproportionately high rates of removal, with estimates as high as 70% to 80%.\(^\text{36}\)


\(^{32}\) See generally *Rocking the Cradle*, fn. 22; see also Virginia Kallianes & Phyllis Rubenfeld, *Disabled Women and Reproductive Rights*, 12 Disability & Society 203, 207 (1997) (for disabled women, the reproductive rights movement is broad and “encompasses the right to be recognized as sexual, to bear children—even a disabled child—to be seen as ‘fit’ to mother”).

\(^{33}\) See generally *Rocking the Cradle*, fn. 22 at 181–204. Prospective parents with disabilities are increasingly prohibited from adopting internationally because of “procedural and substantive restrictions on foreign adoption.” See James G. Dwyer, *Inter-Country Adoption and the Special Rights Fallacy*, 35 University of Pennsylvania Journal of International Law 189 (2013).


This article examines the sexual, reproductive, and parenting rights of persons with disabilities from an international and comparative perspective. Part I provides a historical perspective by analyzing the rationales used by courts over time and across jurisdictions to justify the denial of sexual, reproductive, and parenting rights to persons with disabilities. Next, Part II examines the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and its applicability to sexual and reproductive rights vis-à-vis the rights to personal integrity, access to reproductive health care services and information, parenthood and family, and exercise of legal capacity. Part III concludes by highlighting fundamental and complex issues at the heart of the realization of these human rights that require additional research and consideration.

I. RATIONALES FOR DEPRIVING RIGHTS

A long and shameful practice exists of curtailing the sexual, reproductive, and parenting rights of persons with disabilities. Forced sterilizations were initially grounded in eugenic reasons. Over time, this practice lost broad social consensus — or at least public discussion and approbation. Nevertheless, the ideology undergirding eugenic sterilization continues to curtail sexual, reproductive, and parenting rights of persons with disabilities, such that individuals with disabilities continue to be sterilized in many parts of the world. Also prevailing is the misconception that persons with disabilities lack the capacity to make choices and perform social roles. What has changed in the modern era is that the rationales offered in justification of “the awesome power to deprive a human being of his or her fundamental right to bear or beget offspring,” have shifted, at least superficially. Common justifications for sterilizing persons with disabilities fall into three broad categories: eugenic ideologies; the espoused best interest of the individual and/or others; and the perceived unfitness of the individual to parent.

This Part explores how these three encompassing rationales have been applied in

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37 See Powell, fn. 34.
38 See Volz, fn. 20 at 216 (“An examination of the history of United States sterilization procedures against individuals with disabilities is helpful in comprehending the government’s paternalistic tendencies towards making decisions for citizens it deems are unable to make such choices for themselves”); Elizabeth Tilley, Sarah Earle & Jan Walmsley et al, “The Silence Is Roaring”: Sterilization, Reproductive Rights and Women with Intellectual Disabilities, 27 Disability & Society 413, 414 (2012) (“[a]lthough involuntary sterilization is probably no longer a widespread practice in most western countries, its history sheds light on contemporary practices that can be regarded as constituting a continuation of eugenic practices by other means”).
39 See generally Open Society Foundations, fn. 27.
domestic courts across the globe, as well as how those courts perceive and engage the notion of legal capacity in those cases.

A. Eugenics-Based Rationale

In the US, forced sterilization of those deemed “socially inadequate,” and especially women with disabilities, began in the early 20th century with the eugenics movement. Based on the premise that the “human race [could] be gradually improved and social ills simultaneously eliminated through a program of selective procreation,” eugenics targeted “the mentally defective, the mentally diseased, the physically defective, such as the blind, the deaf, the crippled and those ailing from heart disease, kidney disease, tuberculosis and cancer.” Indeed, the eugenics movement centered on preventing those who society viewed as “unfit for parenthood” from reproducing. The eugenics movement led to the passage of compulsory sterilization laws in more than 30 states, with over 65,000 Americans sterilized by 1970.

Involuntary sterilization of persons with disabilities was in no way limited to the US. While accounts vary as to the actual number, it is generally agreed upon that within 1 year of enacting its eugenics law, Germany sterilized as many as 60,000 to 100,000 persons in an attempt to prohibit reproduction of those deemed defective and eliminate their genes from the human race. In Canada, between 1927 and 1972, the Eugenics Board of Alberta (a remote province) alone authorized 2,500 sterilization procedures.

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44 See Medicine, Eugenics, and the Supreme Court, fn. 43 at 1.
45 See Landman, fn. 42 at 400.
46 Eric M. Jaegers, Note, Modern Judicial Treatment of Procreative Rights of Developmentally Disabled Persons: Equal Rights to Procreation and Sterilization, 31 University of Louisville Journal of Family 947, 948 (1992–1993) (“The purpose of these laws was to protect and streamline society by preventing reproduction by those deemed socially or mentally inferior”). The eugenic movement also inspired a number of states to enact laws that prohibited persons with disabilities from marrying. For instance, the language used in one Connecticut state statute was typical; it prohibited “epileptics, imbeciles, and feebleminded persons” from marrying or having extramarital sexual relations before the age of forty-five. Robert J. Cynkar, Comment, Buck vs Bell: “Felt Necessities” vs Fundamental Values?, 81 Columbia Law Review 1418, 1432 (1981).
47 See Medicine, Eugenics, and the Supreme Court, fn. 43 at 1–2.
48 See Three Generations, No Imbeciles, fn. 43 at 104 & 116.
Forced sterilizations of marginalized women, particularly disabled women, was common in a number of other countries, such as Denmark, Finland, Switzerland, Sweden, England, Norway, Iceland, Belgium, Austria, India, China, Japan, and parts of Australia.51

The eugenics argument for sterilizing persons with disabilities, particularly women and girls with intellectual or psychiatric disabilities, is borne out of fear that they will reproduce children with similar disabilities. This line of reasoning underscored the infamous Buck vs Bell decision in the US.52 Carrie Buck was an allegedly “feebleminded” woman institutionalized in Virginia.53 She was likewise the daughter of a “feebleminded” mother committed to the same institution. At age 17, Buck became pregnant after being raped; her daughter Vivian allegedly also had an intellectual disability and deemed feebleminded as well.54 Following Vivian’s birth, the institution sought to sterilize Buck in accordance with Virginia’s sterilization statute. After a series of appeals, the statute upheld as constitutional on the premise that it served “the best interests of the patient and of society.”55 Concluding this historical decision, Justice Oliver Wendell Holmes, Jr. declared, “Three generations of imbeciles are enough.”56

The eugenics-based rationale for forcibly sterilizing persons with disabilities endures across time and jurisdiction. For example, in 2004, the Family Court of Australia authorized the sterilization of a 12-year-old intellectually disabled girl with tuberous sclerosis, a genetic condition with a 50% inheritance risk factor.57 While the prognosis of tuberous sclerosis is highly variable, with many who are diagnosed leading typical lives,58

52 274 U.S. 200 (1927) [the Buck vs Bell].
53 Id. at 205; see Three Generations, No Imbeciles, fn. 43 (asserting that Buck was actually not “feebleminded” but rather institutionalized as a way to hide her rape).
54 See Buck vs Bell, fn. 52 at 205.
55 Id. at 206.
56 Id. at 208 & 205–206 (Holmes, J.: “experience has shown that heredity plays an important part in the transmission of insanity, [and] imbecility”).
57 Re H [2004] FamCA 496.
the court accepted testimony from a medical specialist that sterilization was in the best interests of the young girl, stating, in part, “Given the genetic nature of her disorder and the 50% inheritance risk thereof, this would in my view be of great benefit to H.”

Regrettably, the belief that disability is a personal tragedy that is to be avoided at all costs is not limited to the judicial system. In fact, persons with genetic disabilities often encounter substantial resistance from health care professionals and family members if they want to procreate because of the possibility their children would inherit their disability. Public reaction to news stories regarding disabled women further demonstrates that eugenics-based beliefs persist.

The residue of eugenics-based beliefs continues to have profound and alarming consequences for persons with disabilities, particularly women and girls. As highlighted by Rashida Manjoo, the United Nations Special Rapporteur on Violence against Women, “Although society’s fear that women with disabilities will produce so-called ‘defective’ children is for the most part groundless, such erroneous concerns have resulted in discrimination against women with disabilities from having children.”

B. “Best Interest” Rationales

1. “Best Interest” of the Individual. — Involuntary sterilization is commonly justified under the auspices that the procedure is in the “best interest” of the individual. Indeed, women with disabilities are often “forcibly sterilized or forced to terminate wanted pregnancies — under the paternalistic guise of ‘for their own good.’” For example, in

59 See Re H, fn. 57 at 49.
60 See Rocking the Cradle, fn. 22 at 47.
64 Id. at 36.
England, court authorization was sought to sterilize “Jeanette,” a 17-year-old girl with an intellectual disability and epilepsy. Jeanette had begun “showing signs of sexual awareness and sexual drive,” and her mother along with local authorities expressed concerns regarding the potential for pregnancy that they felt could pose significant emotional risks for Jeanette. Since Jeanette would become of legal age within 6 months and the court was uncertain it could retain parens patriae jurisdiction, it treated the matter as urgent. The court ruled, and the House of Lords agreed, that the welfare and best interest of Jeanette were of “paramount concern” and she thus warranted sterilization. The court also noted that less invasive birth control was unrealistic and could interact negatively with her epilepsy medication. Further, that in the absence of sterilization, Jeanette’s obesity might limit others from discovering she was pregnant until it was too late into her term for an abortion to be performed.

Likewise, in the UK, a court recently held a vasectomy was “overwhelmingly” in the best interests of DE, a 37-year-old man with an intellectual disability. Questions arose concerning DE’s capacity to engage in sexual relations after DE’s long-term girlfriend, who also had an intellectual disability, became pregnant, and significant limitations were imposed to keep the couple from being alone together. Thereafter, DE’s parents and the national health authorities sought court approval to force DE to undergo a vasectomy, reasoning that such a procedure would “restore as much independence as possible” while preventing additional pregnancies. The court found that DE lacked the capacity to decide whether to consent to the procedure; declared the vasectomy lawful and in DE’s best interest; and authorized local health officials to take all necessary steps to carry out the procedure. The court reached this decision despite DE’s ambivalence to a vasectomy and his desire to use condoms.

Disturbingly, some courts have justified involuntary sterilization of women and girls with disabilities on the basis that doing so will protect them from sexual abuse and the consequences of abuse, despite the irrelevance of the former and the improperly directed

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66 Id. at 208.
67 Id. at 199.
68 Id. at 199.
69 Id. at 203.
70 Id. at 208.
71 A NHS Trust vs DE [2013] EWHC 2562 (the “DE’s case”) at 93.
72 Id. The girlfriend’s mother was appointed guardian of their child and raised the child.
73 Id. at 3 & 32. Notably, during the proceedings it was also determined that DE had the capacity to consent to sexual relations.
74 Id. at 4.
75 Id. at 5.
76 Id. at 52.
concerns of the latter. For example, the court in *Re H* authorized the sterilization of a 12-year-old girl on the basis that “If she were to be the victim of sexual assault, and to become pregnant, this would be a very complicated situation, both ethically and medically. The hysterectomy would remove the chance of an unwanted pregnancy and further medical complications associated with a pregnancy.”

Equally irrelevant and offensive, courts have cited an individual’s “attractive” appearance as justification for forcibly sterilizing women and girls with disabilities. Although women and girls with intellectual disabilities are at increased risk of sexual abuse, research consistently finds that depriving the rights of women with disabilities does nothing to protect them from abuse and may actually serve to perpetuate these crimes due to contraception or sterilization reducing the chance of the abusers being caught.

2. “Best Interest” of the Individual and Others. — Some courts have postulated that not sterilizing persons with disabilities unduly “burdens” others, usually family members, but also, as in *Buck vs Bell*, society-at-large. These cases often justify sterilization as being in the best interest of the individual and others because it

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77 Of course, not all judges agree. Notably, Justice Brennan, *In re Marion*, correctly disavowed this rationale, recognizing the fallacy of protecting against abuse via sterilization. However, his view was raised in dissent. See *In re Marion*, infra note 188 at 276 (Brennan, J., dissenting).

78 See *Re H*, fn. 57 at 57.

79 See e.g. *Re Katie* [1995] FamCA 130 (“It is highly unlikely that Katie will ever have the capacity to understand and voluntarily enter into a sexual relationship…It is however well documented that disabled children are particularly vulnerable to sexual abuse and Katie is quite an attractive girl”); *Re A Teenager* [1988] FamCA 17 (“[I]t is unlikely she will have any form of relationship involving sexual intercourse. She could, of course, be the victim of a sexual assault and with her normal physical development and attractive looks that cannot be discounted”).


81 Beverly Horsburg, *Schrodinger’s Cat, Eugenics, and the Compulsory Sterilization of Welfare Mothers: Deconstructing an Old/New Rhetoric and Constructing the Reproductive Right to Natality for Low-Income Women of Color*, 17 Cardozo Law Review 531, 572 (1996) (today, sterilization of women with disabilities, particularly psychiatric or intellectual, is “driven by parents, guardians, and social service providers who are uneasy…[that] they will incur the additional burden of caring for the offspring”).

82 See *Buck vs Bell*, fn. 52 at 207 (“It is better for all over the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind”).

83 See Tilley, Earle & Walmsley et al, fn. 38 at 415 (“An argument used in the United States and the Nordic countries was that some women were unfit for parenthood, indeed incapable of parenting adequately; sterilization would liberate such women, enabling them to live outside institutions without the danger of pregnancy”). See also Richard K. Sherlock & Robert D. Sherlock, *Sterilizing the Retarded: Constitutional, Statutory and Policy Alternatives*, 60 North Carolina Law Review 943, 951–953 (1982) (noting the use of best interest justifications).
suppresses or manages menstruation, while ignoring the reality that sterilization is only one option for menstrual management.84

In 2010, the Family Court of Australia authorized a hysterectomy for Angela, an 11-year-old girl with Rett’s Syndrome, which caused significant physical and intellectual impairments as well as epilepsy.85 Angela’s parents had sought approval to sterilize Angela to prevent menstruation, asserting that less-invasive contraceptive was ineffective.86 During the proceeding, it was submitted that the effects of sterilization on Angela would be “relatively minimal” and the “menstrual problems” would be resolved.87 In holding sterilization was in Angela’s best interest, the court also accepted that due to the nature of Angela’s disability, “she would not have the psychological capabilities to consider a pregnancy into the future” and so sterilization would remedy this as well.88 Moreover, in accepting “without hesitation”89 the evidence of an obstetrician and gynecologist, the court found the sterilization “would certainly be a social improvement for Angela’s mother which in itself must improve the quality of Angela’s life.”90 Other courts have made similar findings.91

The American “Ashley X”92 case provides another basis for analyzing the legal and social policy constructs embodying sterilization of persons with disabilities, particularly as it relates to being purportedly in the best interest of both the individual and others. Ashley has intellectual disabilities and was described by her physicians as being “non-ambulatory” with “severe, combined developmental and cognitive disabilities.”93 In

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85 Re Angela [2010] FamCA 98 (Austl.).

86 Id. at 20.

87 Id. at 23.

88 Id.

89 Id. at 17.

90 Id. at 22–23.

91 See e.g. Re K vs Public Trustee (1985) 19 D. L. R. (4th) 255 (the British Columbia Court of Appeal ruled that a surgeon could perform a hysterectomy on a 10-year-old girl with an intellectual disability with the consent of her parents because of an anticipated adverse reaction to menstruation); Re H, fn. 57 at 37, 68 (finding H would likely always need assistance managing menstruation and sterilization would prevent menstruation); see also Sec’y, Dep’t of Health & Cmty. Svcs vs JWB (the “In re Marion”), [1992] 175 CLR 218, 260 (Austl.) (“[I]n the circumstances with which we are concerned, the best interests of the child will ordinarily coincide with the wishes of the parents”).


93 Id.
2004, at age 6, a hospital, with Ashley’s parent’s approval, performed a series of procedures including growth attenuation via hormone therapy, a hysterectomy, and bilateral breast bud removal.\textsuperscript{94} In allowing these procedures, her physicians and doctors justified the permanent alteration of her body by contending that the procedures ensured “the best possible quality of life,” by permitting her to be more easily cared for by her family, while also allowing her to “retain more dignity in a body that is healthier, more of a comfort to her, and more suited to her state of development.”\textsuperscript{95} Justifying the hysterectomy, Ashley’s parents asserted, “Ashley has no need for her uterus since she will not be bearing children.”\textsuperscript{96} Further, Ashley’s physicians argue that the hysterectomy benefited both Ashley and her family because it “eliminate[d] the complications of menses.”\textsuperscript{97} Thus, Ashley’s “best interest was equated with her parents’ ability to maintain her at home and being easily able to carry and move her.”\textsuperscript{98} Remarkably, Ashley’s parents permitted these procedures with just the approval of an internal ethics board, sans adjudication.\textsuperscript{99} A few years later, an investigation revealed that the hospital had violated state law in this matter.\textsuperscript{100} Nonetheless, the “Ashley Treatment” remains popular across the globe, with more than 100 families subjecting their children to similar procedures while thousands more are said to have considered it.\textsuperscript{101}

C. Unfitness to Parent

Perceived inability to parent is another common justification for sterilizing persons with disabilities. Indeed, “[c]urrent sterilization statutes bring into question the competency of a woman as a parent in determining whether sterilization is appropriate.”\textsuperscript{102} In other words, “[i]n the sterilization context, the main question turns on whether a woman with a disability would be a competent parent if she were to become

\textsuperscript{94} Id.
\textsuperscript{95} Id.
\textsuperscript{96} See \textit{The “Ashley Treatment,” Towards a Better Quality of Life for “Pillow Angels,”} available at http://pillowangel.org/Ashley\%20Treatment.pdf (last visited Aug. 3, 2015) (the “\textit{Pillow Angels}”).
\textsuperscript{97} See Gunther & Dickema, fn. 92.
\textsuperscript{99} Id.
\textsuperscript{102} See Volz, fn. 20 at 209.
pregnant and bear a child. Such questions of competency depend upon the type and severity of the disability, which may vary greatly in degree.” Accordingly, women with disabilities, particularly those with intellectual disabilities, must contend with pervasive stereotypes concerning their parenting fitness.

In Jeanette’s case, for example, the United Kingdom’s House of Lords authorized sterilization, in part, because of “…her inability ever to desire or care for a child, the operation would be in her best interests.” Moreover, Lord Hailsham declared, “To talk of the ‘basic right’ to reproduce of an individual who is not capable of knowing the causal connection between intercourse and childbirth, the nature of pregnancy, what is involved in delivery, unable to form maternal instincts or to care for a child appears to me wholly to part company with reality.” Thus, the Lords were more worried about Jeanette’s parenting ability than her capacity to make an informed choice.

Likewise, the presumed unfitness to parent influenced a 2011 Argentinian case, where the Superior Tribunal de Justicia approved sterilization of J. V. A., a 23-year-old woman with an intellectual disability, asserting primary consideration to her right to health and an adequate standard of living, following a petition from her aunt (guardian). The lower court declined authorization to sterilize, giving substantial weight to J. V. A.’s expressed desire to someday have children. On appeal, the court acknowledged international human rights norms yet considered them not legally binding, but rather “the efforts on the international level to dignify the lives of persons with disabilities.” Moreover, the court held that the petition to sterilize J. V. A. was not motivated merely by a desire to avoid pregnancy but by a desire to “remove all obstacles from ensuring the effective enjoyment of her human rights on an equal basis with others.” Citing an Inter-American Court of Human Rights advisory opinion, the court observed that not all

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103 Id.
104 Id.
105 See Jeanette’s case, fn. 65.
106 Id. at 199.
107 Id. at 204.
108 Superior Tribunal de Justicia RNg. [STJ] [Superior Tribunal of Justice], 17/6/2011, “Asesor de Menores e Incapaces No 1 c. (A., J. V.)/insania/casacion” (the “In re J. V. A.”), No. 24837/10, Sentence No. 48 (translation on file with author) (J. V. A.’s aunt submitted a number of justifications, including (1) sterilization ensured a greater exercise of J. V. A.’s personal, expressive, and sexual freedom; (2) it was impossible for her to take care of and educate a child; (3) there were no relatives available to assist her in the event of a birth; (4) it was possible for her to pass her disability to her children; (5) she had experienced sexual violence and abuse; (6) she was vulnerable; (7) persons with her disabilities were more likely to experience abuse; (8) there would be negative consequences resulting from an abortion or adoption should she become pregnant; (9) it was difficult to find persons willing to adopt children with disabilities; (10) it was impossible for the guardian to ensure that she regularly follow other contraceptive regimens; and (11) alternative methods were less effective in preventing pregnancies).
109 Id.
110 Id. at 4–5.
111 Id.
legal distinctions are discriminatory, given that there exist “de facto inequalities (among them, the inability to comprehend the effects of procreation and to exercise self-determination) that legitimately may be translated into differences in treatment before the law without leading to injustice.” 112 Instead, the court found that justice requires distinctions made on the basis of actual inequalities, particularly “to realize justice through the protection of those who appear in the eyes of the law to be weak or vulnerable.” 113 In reaching its decision, the court discussed J. V. A.’s functional limitations, her indigence, and her guardian’s advanced age. 114 At the same time, the court endeavored to strike a balance to best protect her rights to health, a full sexual life, personal integrity, an adequate standard of living, form a family, and leisure and recreation. 115 While the court acknowledged there may be an “overlapping or conflict of rights,” it was satisfied that J. V. A.’s rights, if “analyzed independently,” “may be properly rearranged to arrive at the best solution to the case.” 116 Thus, the court found that sterilization was the only contraceptive measure to ensure that J. V. A. might enjoy “a full sexual life,” while also avoiding a pregnancy that “would impede her from giving effect to her rights.” 117

Finally, a recent Colombian Constitutional Court decision 118 has drawn considerable criticism from dozens of national and international human rights organizations dissatisfied by the Court’s failure to prohibit sterilization of minors with disabilities without their consent. 119 Specifically, in allowing the continued practice of sterilizing minors with certain disabilities, the Court reasoned that “[A] person who cannot understand the nature of the sterilization procedure nor its consequences, as in the case of persons with severe and profound mental disabilities, is a person who will have difficulty in assuming the responsibilities of parenthood” in consequence of which it held that sterilization was “a form of protection of persons with disabilities.” 120

II. CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The right to bodily integrity and the right to make reproductive choices are each

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112 Id. at 6.
113 Id.
114 Id.
115 Id.
116 Id.
117 Id.
118 Decision of the Colombia Constitutional Court: Case 131/14 (Mar. 11, 2014) (the “Colombia decision”).
120 See Colombia decision, fn. 118 at 6.4.2.
enshrined in several human rights treaties and instruments.\textsuperscript{121} So, too, is the right to be free from torture and inhuman treatment, which the United Nations Special Rapporteur on Torture recently interpreted as potentially extending to the practice of involuntary sterilization of persons with disabilities (and others).\textsuperscript{122} Nevertheless, as demonstrated in Part I, persons with disabilities continue to experience systemic and pervasive discrimination that results in concurrent widespread denial of their sexual, reproductive, and parenting rights.

Prospects for countering this dire situation for persons with disabilities reside in the UNCRPD,\textsuperscript{123} the first and most comprehensive human rights convention of the 21st century, as well as the first legally binding international human rights convention specifically applying human rights to persons with disabilities.\textsuperscript{124} Adopting the human rights paradigm,\textsuperscript{125} the UNCRPD is mandated “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”\textsuperscript{126} Hence, the UNCRPD demonstrates a significant shift in attitudes and approaches to persons with disabilities in international instruments, markedly departing from the traditional medical or charitable models of disability that are still embedded in many domestic law and policy.


\textsuperscript{126} See UNCRPD, fn. 123, Art. 1.
frameworks. The UNCRPD also reflects the social model of disability by acknowledging disability “as an evolving concept” generated by “the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.” To address the widespread and systemic discrimination endured by persons with disabilities, the UNCRPD sets forth general principles that inform its overall approach and apply across the treaty: (1) dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons; (2) nondiscrimination, participation, and inclusion in society; (3) respect for difference; (4) equality of opportunity; (5) accessibility; (6) equality between men and women; and (7) respect for the evolving capacities of children with disabilities.

The UNCRPD is particularly important in guaranteeing the sexual, reproductive, and parenting rights of persons with disabilities. While the UNCRPD ensures the rights of all persons with disabilities, it also recognizes that certain groups experience multiple or heightened forms of discrimination, including women and girls with disabilities who are “often at greater risk…of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation.” Moreover, although the UNCRPD does not explicitly proscribe nonconsensual sterilization, it ascertains a number of rights that protect against such procedures. Indeed, the UNCRPD’s monitoring committee of experts (UNCRPD Committee) has unfailingly recommended that States Parties implement measures to address the nonconsensual sterilization of persons with disabilities. Moreover, because the UNCRPD requires not just formal equality but also substantive equality, States Parties have affirmative obligations (e.g. supporting persons with disability in parenting).

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129 See UNCRPD, fn. 123, Preamble (e).
130 Id. Art. 3.
131 See generally Rocking the Cradle, fn. 22 at 77–82.
132 See UNCRPD, fn. 123, Preamble (q).
134 See UNCRPD, fn. 123, Arts. 34–38 (establishing a Committee to monitor States Parties’ periodic reports, assess information transmitted by civil society, issue recommendations to States Parties, and adopt general comments interpreting the UNCRPD).
The following sections consider how the contents of specific rights enshrined in the UNCRPD protect the sexual, reproductive, and parenting rights of persons with disabilities.

A. Personal Integrity

Sexual, reproductive, and parenting rights are grounded in one’s right to personal integrity. Both Articles 15 and 16 relate to abuse and mistreatment of persons with disabilities and should be interpreted to include forced and coerced sterilization. Akin to other human rights instruments, Article 15 proscribes torture, cruel, inhuman, or degrading treatment, or punishment while also adding a prohibition on medical and scientific experimentation without consent.136 Focusing on prevention, Article 15 obliges States Parties to take “all effective legislative, administrative, judicial or other measures” to avert torture and other forms of mistreatment.137 Moreover, Article 16 declares that persons with disabilities have the right to be free from exploitation, violence, and abuse while delineating States Parties’ obligations to take, “all appropriate measures” to prevent such abuse, including providing information to persons with disabilities, families, and caregivers on how to “avoid, recognize and report” such abuse.138

In addition, Article 16 obligates States Parties to ensure that all facilities and programs designed to serve persons with disabilities are “effectively monitored by independent authorities” and to ensure access to “recovery, rehabilitation and reintegration” of disabled victims of exploitation, violence or abuse.139 Article 16 also requires governments to investigate and prosecute allegations of exploitation, violence, or abuse as well as ensure persons with disabilities enjoy effective access to justice, which includes the provision of appropriate accommodations as required.140 Moreover, Article 16 requires that States Parties develop and implement effective legislation and policies, including women and child focused legislation and policies, to ensure that instances of exploitation, violence, and abuse against persons with disabilities are identified, investigated, and prosecuted. This is especially relevant with regard to sexual and reproductive rights because women and girls with disabilities are at a heightened risk of

136 See UNCRPD, fn. 123, Art. 15.
137 Id.
138 Id. Art. 16.
139 Id.
140 Id.; see generally Janos Fiala-Butora, fn. 122 (examining the obligation on States Parties to investigate torture).
experiencing violence and abuse, including, *inter alia*, sexual abuse.141

Relatedly, Article 17 establishes an affirmative right to “respect for mental and physical integrity on an equal basis with others.”142 Article 17 addresses nonconsensual medical interventions, such as forced treatment or surgery on persons with disabilities, including the nonconsensual sterilization of persons with disabilities, as well as the failure to provide interventions.143 Whereas the UNCRPD Committee has not explicitly addressed forced and coerced sterilization under Article 17, this UNCRPD Article stipulates additional protection for the rights of persons with disabilities in circumstances where they have not traditionally benefitted from them.144

**B. Reproductive Health Care Services and Information**

Although access to appropriate and accessible reproductive health care services and information is vital to ensuring sexual, reproductive, and parenting rights, persons with disabilities continue to encounter significant barriers to accessing reproductive health care services and information which detrimentally affects their wellbeing.145 Recognizing its importance, the initial draft language of the UNCRPD encompassed a separate “right to sexual and reproductive health services,” originating, in part, from the Standard Rules, which stipulated that “Persons with disabilities must have the same access as others to family-planning methods, as well as to information in accessible form on the sexual functioning of their bodies.”146 Nevertheless, access to reproductive services was instead incorporated into Articles 23 and 25, relating to family life and health, respectively.

Specifically, Article 25 requires States Parties to provide “the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health

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142 See UNCRPD, fn.123, Art. 17.


144 Indeed, the UNCRPD Committee may have intended to address sterilization when recommending “the abolition of surgery and treatment without the full and informed consent of the patient.” UNCRPD Comm., Concluding Observations on the initial state report of Tunisia, 5th sess., Apr. 11–15, 2011, UN Doc. CRPD/C/TUN/CO/1, 29 (May 13, 2011).

145 Id. Introduction, for discussion on barriers to reproductive health care services and information.

In other words, the same services provided to the general population must also be provided to persons with disabilities on the same terms. In addition, Article 25 necessitates “including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.” Thus, sterilization procedures may only be performed when individuals have given their “free and informed consent.” Finally, Article 25 prohibits discrimination against persons with disabilities in the provision of health insurance and prevents discriminatory denial of health care or health services based on disability.

In addition, Article 9 applies to reproductive health care services and information. Pursuant to Article 9, “States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.” The accessibility requirements also apply to “private entities that offer facilities and services which are open or provided to the public” and include both physical access as well as the delivery of information in an accessible manner.

C. Family and Parenthood

Across the globe, the right to raise a family is unquestionably one of the most cherished rights. Indeed, “[t]he desire to become a parent traverses all cultural, physical,

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147 See UNCRPD, fn.123, Art. 25.
148 Id.
149 Notably, Art. 23, discussed infra, states that persons with disabilities must have the right “to decide freely and responsibly on the number and spacing of their children and... [the right to] retain their fertility on an equal basis with others.” Hence, the UNCRPD should be interpreted to permit persons with disabilities to undergo sterilization when two conditions are satisfied: they “decide freely” to do so and also give their “free and informed consent.”
150 See UNCRPD, fn. 123, Art. 25.
151 Id. Art. 9.
152 Id.; Persons with disabilities regularly encounter structural barriers that preclude them from receiving adequate reproductive health care. For instance, women with disabilities regularly encounter inaccessible medical equipment, such as examination tables, pelvic exam equipment, scales, and mammography machines, which results in subpar — or no — reproductive health care. See generally Elizabeth Pendo, Disability, Equipment Barriers and Women’s Health: Using the ADA to Provide Meaningful Access, 2 St. Louis University Journal of Health Law and Policy 15 (2008); Persons with disabilities also encounter barriers to receiving appropriate reproductive information. For example, women who are deaf or blind regularly experience communication impediments, such as access to sign language interpreters, providers willing to read information to patients, or information in alternative formats. Id.; In addition, persons with intellectual disabilities confront communication barriers, including information not being delivered in an appropriate and accessible manner, such as sexuality education. See generally Swango-Wilson, fn. 31.
and political boundaries.” Nonetheless, examples abound of persons with disabilities being denied this most basic right.

Article 23 of the UNCRPD is the most pertinent assurance of the rights of persons with disabilities to create and maintain families. Precisely, Article 23 requires States Parties to “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...ensure the rights and responsibilities of persons with disabilities with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount...render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities...[and] ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child...” Thus, States Parties have very explicit obligations to ensuring the rights of parents with disabilities and their children, many which have not yet fully been afforded to persons with disabilities. For instance, “[i]n no case shall a child be separated from parents on the basis of disability of either the child or one or both of the parents.” However, substantial evidence suggests that children of parents with disabilities are commonly removed from their parents because of their parent’s disability.

153 See Rocking the Cradle, fn. 22 at 43.
154 See e.g. Re C (A Child), [2014] EWCA Civ 128 (In London, the child of a deaf father and mother with cognitive disabilities as well as speech and hearing impairments was placed in foster care and subsequently available for adoption after questions arose concerning the parents’ capacity to parent their daughter. Notably, social workers failed to provide interpreters prior to placing in the child in foster care. The lower court found them unable to care for their daughter due to their disabilities and the parents successfully appealed.); Philip Lee-Shanok, Disabled Parents Fight to Keep Newborn at Home, CBC NEWS (May 2, 2012), available at http://www.cbc.ca/news/canada/toronto/disabled-parents-fight-to-keep-newborn-at-home-1.1185318 (last visited Jan. 19, 2016) (In April 2012, a Canadian couple, both of whom have Cerebral Palsy, faced a fight to retain custody of their newborn after authorities threatened to remove the child if they did not obtain “round-the-clock care from an ‘able-bodied attendant’”); Christian Gysin, Couple with Learning Disabilities Given £12,000 Compensation after Their Newborn Child Was Taken from Them for More than a Year, Daily Mail (Oct. 30, 2014), available at http://www.dailymail.co.uk/news/article-2814395/Couple-learning-disabilities-given-12-000-compensation-newborn-child-taken-year.html (last visited Jan. 19, 2016) (A British couple with intellectual disabilities was reunited with their baby and awarded damages by a High Court in London after being separated from their child for nearly 18 months. Judge determined that social workers handled the case of “Baby H.” incorrectly when they removed the child from custody, placed her with a foster family, and failed to explain to her parents just why she’d been taken away in the first place. Meanwhile, it took more than a year for officials to properly and honestly assess whether Baby H.’s family was fit to parent. The sluggish action on the case was so appalling that the judge even felt compelled to comment on how authorities “dragged its feet”).
155 See UNCRPD, fn. 123, Art. 23.
156 See generally Rocking the Cradle, fn. 22; Stein, fn. 19.
In addition to ensuring the rights of parents with disabilities and their children in child protection and custody matters, Article 23 addresses the reproductive rights of persons with disabilities by requiring States Parties to guarantee “[t]he rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided.” In other words, States Parties must safeguard the reproductive rights of persons with disabilities, including their right to procreate if the individual so chooses. In addition, at least one commentator has opined that States Parties have affirmative obligations pursuant to Article 23 vis-à-vis surrogacy.

Finally, Article 23 should be interpreted broadly to fully guarantee the rights of persons with disabilities to create and maintain families. States Parties are explicitly prohibited from discriminating against parents with disabilities while correspondingly supporting persons with disabilities in their pursuit to become parents and raise families. In fact, at least one court has referenced the UNCRPD in denying India’s government’s request for authorization to terminate the pregnancy of a woman with an intellectual disability and ordered the local government to provide appropriate supports to the mother and child. Moreover, commentators and advocates have embraced the emphasis on supports and suggested its application to adaptive parenting equipment. In addition, Article 23 implicates States Parties’ adoption policies by forbidding bans on persons with disabilities becoming foster parents or adopting.

D. Legal Capacity

As previously discussed, questions concerning consent and recognition of capacity abound with regard to the sexual, reproductive, and parenting rights of persons with disabilities (particularly those with intellectual and psychiatric disabilities), and especially

157 See UNCRPD, fn. 123, Art. 23.
159 See Srivastava, infra note 225 Art. 26. (“We must also bear in mind that India has ratified the Convention on the Rights of Persons with Disabilities on Oct. 1, 2007 and the contents of the same are binding on our legal system”).
160 See Callow, Buckland & Jones, fn. 34 at 40.
161 See Rocking the Cradle, fn. 22 at 181–182 (“Adoption horror stories are all too common for prospective parents with disabilities. The adoption system is riddled with de facto and de jure discrimination that prevents countless prospective parents with disabilities from adopting. Examination of domestic and international adoption practices reveals that reforms are urgently needed across the broad spectrum of adoption practices and procedures”). In addition, some countries categorically deny prospective adoptive parents based on their disability, see id. at 199–202.
when cases involve sterilization. Indeed, “persons with disabilities remain the group whose legal capacity is most commonly denied in legal systems worldwide.” Such denial of legal capacity has resulted in the deprivation of various rights, *inter alia*, “the right to marry and found a family, reproductive rights, parental rights, [and] the right to give consent for intimate relationships and medical treatment[.]” Article 12 informs this topic, affirming, that States Parties must “recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.” Notably Article 12’s use of the phrase “‘legal capacity’ includes not simply the capacity to have rights (or passive capacity) but also the capacity to act or exercise one’s rights.” Accordingly, “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.” Importantly, the “use of the word ‘support,’ and the related concept of supported decision making, represents nothing less than a ‘paradigm shift’ away from well-established but increasingly discredited notions of substituted decision making.” Moreover, whereas the UNCRPD does not describe the exact population that “may require” support in exercising legal capacity, it applies to persons whom many States Parties have legally circumscribed from doing so.

To clarify States Parties’ obligations pursuant to Article 12, in April 2014, the UNCRPD Committee promulgated a General Comment, noting, “there has been a general failure to understand that the human rights-based model of disability implies a shift from the substitute decision-making paradigm to one that is based on supported decision-making.” According to the UNCRPD Committee, “concepts of mental and...
legal capacity have been conflated so that where a person is considered to have impaired decision-making skills, often because of a cognitive or psychosocial disability, his or her legal capacity to make a particular decision is consequently removed.\textsuperscript{172} Instead, the UNCRPD requires “[s]upport in the exercise of legal capacity must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making.”\textsuperscript{173} Thus, “States parties must holistically examine all areas of law to ensure that the right of persons with disabilities to legal capacity is not restricted on an unequal basis with others.”\textsuperscript{174}

When ensuring the sexual, reproductive, and parenting rights of persons with disabilities, States Parties must also be cognizant of their obligations pursuant to Article 23, which, in part, obligates that “the means necessary to enable them to exercise these rights [to decide freely and to have access to information] are provided.”\textsuperscript{175} Thus, States Parties must provide the necessary means to permit persons with disabilities to exercise their right to decide freely concerning sterilization. In other words, instead of establishing an exception for persons with disabilities who are perceived unable either to decide freely or to give their “free and informed consent,” the UNCRPD constructs an affirmative obligation to adopt measures so that persons with disabilities may themselves, with or without assistance, exercise this right.

Contrary to a number of domestic laws, the UNCRPD does not explicitly provide for any situations where the decision of a third party may operate as a permissible substitute for the decision of a person with disability.\textsuperscript{176} Instead, the UNCRPD requires that supported decision-making processes replace the existing substitute decision-making arrangements sanctioned by many States Parties’ laws.\textsuperscript{177} This supported decision-making mandate in Article 12(3) extends to all decisions that have legal effect, including

\begin{itemize}
\item \textsuperscript{172} Id. at 15; but see Melvin Colin Freeman, Kavitha Kolappa & Jose Miguel Caldas de Almeida, et al, \textit{Reversing Hard Won Victories in the Name of Human Rights: A Critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities}, The Lancet Psychiatry (2015), available at http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(15)00218-7/abstract (last visited Jan. 19, 2016) (asserting “the General Comment on Article 12 of the UNCRPD threatens to undermine critical rights for persons with mental disabilities, including the enjoyment of the highest attainable standard of health, access to justice, the right to liberty, and the right to life”).
\item \textsuperscript{173} Id. at 17.
\item \textsuperscript{174} Id. at 7.
\item \textsuperscript{175} See See UNCRPD, fn. 123, Art. 23 (emphasis added).
\item \textsuperscript{177} See UNCRPD, fn. 123, Art. 12; see also OHCHR Thematic Study at 43; see generally Dinerstein, fn. 166.
\end{itemize}
acts that require free and informed consent. Arguably, the decision to undergo sterilization is an example of one such decision. Hence, in light of Articles 23 and 25, combined with Article 12, States Parties must provide disabled persons the necessary means to make such choices, including the provision of decision-making supports, if necessary. Further, given the nature of sterilization and the long history of abuse, States Parties must establish safeguards “to prevent abuse in accordance with international human rights law.” In sum, decisions regarding sterilization of persons with disabilities must always reflect the individual’s wishes.

III. AREAS OF FUTURE RESEARCH

As this article demonstrates, issues concerning sexual, reproductive, and parenting rights of persons with disabilities are complex and require further information and consideration. Many issues remain for scholars, the legal profession, and policy makers to resolve. Given the historical treatment of the sexual, reproductive, and parenting rights of persons with disabilities, these contemplations will at times be initial ones for law and policy makers who will also need to overcome deeply embedded and pernicious stereotypes about the group. When engaging these issues, law and policy makers must honor the mandate and spirit of the UNCRPD by actively consulting with persons with disabilities and their representative organizations. In this Part, we highlight some issues for future attention.

A common absence across the cases addressing the sterilization of persons with disabilities cases is the question of whether the individual has consented to the requested sterilization procedure. Courts instead have presumed that the person with a disability is incapable of making an informed decision, and so have not required their consent. Thus, although the general presumption in bioethics is that “the interests or desires of the

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179 See UNCRPD, fn. 123, Art. 12 (“States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests”).


181 See General Comment No. 1, fn. 163 at 35.
medical patient reign supreme,” this same presumption has been “disregarded or dismissed as insignificant when considering the desires of a woman with a disability.” 182 Notably, even when judicial outcomes prohibit sterilization of persons with disabilities under the best interest standard, these same courts assume that persons with disabilities cannot determine or express their own best interests.

The leading Canadian Supreme Court case, *E. (Mrs.) vs Eve*, 183 provides a clear example of how even progressive courts fail to consider the individual’s wishes and instead assume she is incapable of deciding. Here, the mother of Eve, a 24-year-old woman with intellectual disabilities, sought court approval to force Eve to undergo a hysterectomy for the purpose of preventing pregnancy. 184 Despite the positive outcome, denial of involuntary sterilization, the Supreme Court nevertheless accepted the lower court’s categorization of Eve as incompetent. 185 Notwithstanding extensive evidence that Eve was fully integrated in her community, regularly attended a school for adults with disabilities, and had romantic interests in a peer, 186 the lower court found, and the Supreme Court accepted, that Eve was incapable of making decisions regarding her personal relationships and reproductive health. Ironically, the Supreme Court’s holdings were made while also pronouncing that “In the absence of the affected person’s consent, it can never be safely determined that [sterilization] is for the benefit of that person.” 187

Similarly, the landmark Australian case of *In re Marion*, 188 exemplifies how even well-intending courts often ignore an individual’s desires and assume incapacity. Here, the parents of a 14-year-old girl with an intellectual disability, severe deafness, epilepsy, and “behavioral problems” sought court authorization for a simultaneous hysterectomy and ovariectomy to prevent pregnancy. 189 In ultimately deciding against sterilization, the High Court of Australia did not consider Marion’s wishes, but instead determined that in the absence of valid therapeutic medical treatment, her best interests militated against the procedure. 190

Likewise, the court in *In re Estate of K. E. J.*, 191 disregarded the wishes of a person with a disability, while nonetheless denying authorization to sterilize a 29-year-old American woman with an acquired brain injury, which left her “mentally disabled.” 192 This case is particularly distinctive because it quoted K. E. J.’s expressed wishes

182 Volz, fn. 20 at 209.
183 [1986] 2 S.C.R. 388 (Can.).
184 Id. at 389.
185 Id. at 394 (accepting “that Eve is not capable of informed consent[.]”).
186 Id. at 393.
187 Id. at 390.
188 See *In re Marion*, fn. 91.
189 Id. at 221.
190 Id. at 250.
192 Id. at 708.
considerably, but nonetheless held that K. E. J.’s desires were not pertinent to determining her best interests because she was incapable of making decisions regarding sterilization and reproduction. The sterilization was denied on the ground that alternative, less invasive contraception options were available.

The above cases demonstrate how even when courts decide favorably for persons with disabilities, they often do so without considering the individual’s wishes because they assume the individual is not able to consent. Further, as demonstrated in Part I.B., the “best interest” standard in sterilization has perpetuated discriminatory attitudes against persons with disabilities and facilitated the practice of forced sterilization. Indeed, arguments surrounding “best interests” often have little to do with the rights of persons with disabilities. Rather, they relate to social factors such as avoiding inconvenience to caregivers, the lack of adequate safeguards to protect against sexual abuse and exploitation, and the absence of adequate and appropriate services to support persons with disabilities when deciding whether to parent.

In contrast, and as described in Part II, the issue of legal capacity permeates all informed decisions regarding the sexual, reproductive, and parenting rights by persons with disabilities. Strikingly, Article 12 of the UNCRPD and the UNCRPD Committee’s General Comment make clear that equal legal capacity can only be made operative within an environment where support is provided, when needed, for decision-making. Accordingly, States Parties must provide appropriate supports to enable the individual to decide whether to undergo a sterilization procedure — or any other determination affecting their sexual, reproductive, and parenting rights. But what would such support look like? How would it manifest? What safeguards are needed? And what else is required to enable the inherent decision-making abilities of persons with disabilities within a human rights-based mechanism? Governments, law and policy makers, academics, public health officials, and many others globally are grappling with these issues without consensus beyond the basic platitudes of honoring the dignity and autonomy of persons with disabilities and enabling their equal decision-making.

193 See e.g. id. at 710 (“However, she said that she did not want a tubal ligation. Instead, she wanted to have two children when she was married to a husband who would support her and help her take care of them”).
194 Id. at 718.
195 Id. at 721.
196 See UNCRPD, fn. 123, Art. 12.
197 General Comment No. 1, fn. 163.
198 See discussion in Part II.D.
The current default mechanism, in the US and elsewhere, requires courts to begin these cases by determining the capacity of the affected individual with a disability. Thus, a judge must first determine if the individual “is capable of making her own reproductive decisions.” If an individual has been “deemed incompetent for the purpose of giving informed consent,” courts apply one of three standards to determine whether to proceed with sterilization or termination: (1) the substituted judgment standard; (2) the mandatory criteria rule; or (3) the best interest standard. All three standards require court authorization as a way to “protect the interests of the mentally disabled.” Yet, as demonstrated throughout this article, courts are influenced by the same stereotypes regarding the decision-making capabilities of persons with disabilities that influence the rest of society, and in consequence render judgments that violate the legal personhood of individuals with disabilities when it comes to their sexual, reproductive, and parenting rights.

To ensure judicial impartiality, commentators have presented a range of recommendations to better guarantee the sexual and reproductive rights of persons with disabilities, namely vis-à-vis limiting forced and coerced sterilization. For instance, some opine, “courts should consider staying of this arena altogether,” while contending if the judicial system is going to continue to reign over these decisions, they must resolve to address the many existing weaknesses. For instance, “[c]ourts must devote more energy to examining the least restrictive means to prevent conception, both present means and what current research may show as plausible future contraceptives.” On a more basic level, these decisions must be made truly neutrally, based on the actual best interest of the person and not antiquated and false beliefs about persons with disabilities. Relatedly, some have argued a statutory and regulatory approach may be more apposite for resolving
the ongoing deprivation of persons with disabilities. Nevertheless, whether it is adjudicators or legislators, clearly there are “some very basic flaws in the process” that must be swiftly addressed. Indeed, “the power to authorize sterilization is so awesome, its exercise is so open to abuse, and the consequences of its exercise are generally so irreversible, that guidelines, if not rules, should be prescribed to govern it.”

Related to capacity and consent issues is the legal mechanism of guardianship. Regrettably, “[a]cross the world, adults with disabilities are stripped of their rights (including the right to refuse sterilization) through a process known as guardianship. If a court declares a person ‘incompetent,’ all of her decision-making rights are transferred to a guardian. In many countries, guardianship is both overused and abused. Indeed, a recent survey in the US found full guardianship continues to be favored while less-restrictive alternatives are not often discussed. Notably, the World Health Organization (WHO) recommends that persons with disabilities be provided supported decision-making rather than traditional substituted decision-making or guardianship. In addition, WHO has avowed, “Like any other contraceptive method, sterilization should only be provided with the full, free and informed consent of the individual.”

Echoing these sentiments, in 2011, the International Federation of Gynecology and Obstetrics (FIGO) adopted recommendations vis-à-vis obtaining an individual’s “free and informed consent” to undergo sterilization procedures. In so doing, the FIGO recognized, “Human rights include the right of individuals to control and decide on matters of their own sexuality and reproductive health, free from coercion, discrimination, and violence. This includes the right to decide whether and when to have children, and the means to exercise this right.” We agree with these principles. Nevertheless, the mechanisms whereby such decisions can be adequately supported, and in a manner that elicits genuine and

207 Id.; see generally Elizabeth Ann McCaman, Limitations on Choice: Abortion for Women with Diminished Capacity, 24 Hastings Women’s Law Journal 155 (2013) (examining issues related to abortion among women with disabilities who have been deemed to lack capacity and recommending a statutory and regulatory scheme for women with diminished capacity to have abortions).

208 See Cepko, fn. 13 at 164.

209 See In re Marion, fn. 91 at 272 (Brennan, J., dissenting).

210 Open Society Foundations, fn. 27 at 6.


213 Id. at 1.

informed consent, have not yet been elucidated.

Similarly linked to the issue of capacity and consent, and thus to guardianship as well, is the politically charged question of whether family members have a role to play in decisions relating to the sexual, reproductive, and parenting rights of persons with disabilities.\textsuperscript{215} Many of the cases described in this article portray situations where family members — at times against the express wishes of their progeny with disabilities, even those who are adults — use their legal role as guardians to seek and implement their children’s sterilization or abortion. That dynamic was clearly on display in the Ashley X case where a family authorized the performance of sterilization and growth attenuation procedures on their young daughter, citing their desire to improve Ashley’s quality of life.\textsuperscript{216} Families in sterilization cases involving individuals with intellectual disabilities regularly employ similar rationales.\textsuperscript{217} For that reason, FIGO has opined that “only women themselves can give ethically valid consent to their own sterilization” and that family members “cannot consent on any woman’s or girl’s behalf,”\textsuperscript{218} and some commentators have argued that such decisions be removed from parents to ensure impartiality.\textsuperscript{219} Discovering a suitable, human rights-based mechanism that empowers person with disabilities while also protecting them against possible misuse, will require time, resources, and much reflection.

Also connected to this discussion is the role, if any, of family. A specific article on the role of the family was not included in the final UNCRPD, yet the preamble requires that “persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities.”\textsuperscript{220} Further, for better or worse, in most parts of the world, families provide the primary support for persons with disabilities.\textsuperscript{221} This begs the question of whether family members have a role to play, whether via Article 12 in supporting decisions or otherwise, in the sexual, reproductive, and parenting rights of persons with disabilities. It raises, in stark relief, the question of how such a role could be implemented in a manner that truly honors the equal dignity,

\begin{itemize}
\item \textsuperscript{215} See generally Arie Rimmerman, Family Policy and Disability 175–195 (2015).
\item \textsuperscript{216} See Pillow Angels, fn. 96.
\item \textsuperscript{217} See e.g. In re Marion, fn. 91 at 306 (finding that caring for a child with an intellectual disability “adds a significant burden to the ordinarily demanding task of caring for children” and that subject to the child’s best interests, “the interests of other family members, particularly primary care-givers, are relevant to a court’s decision whether to authorise sterilisation.” Id. at 306).
\item \textsuperscript{218} See FIGO Guidelines, fn. 214 at 123.
\item \textsuperscript{219} Trynie Boezaart, Protecting the Reproductive Rights of Children and Young Adults with Disabilities: The Roles and Responsibilities of the Family, the State, and Judicial Decision-Making, 26 Emory International Law Review 69, 85 (2012).
\item \textsuperscript{220} See UNCRPD, fn. 123, Preamble (x).
\item \textsuperscript{221} See World Report on Disability, fn. 12 at 137 (“Most assistance and support comes from family members or social networks”).
\end{itemize}
value, worth and human rights of persons with disabilities as rights holders. Article 12 of
the UNCRPD obliges States Parties to implement supported decision-making procedures
that curtail conflicts of interest, but provides little guidance on what that means in
practice. The same is true for the UNCRPD Committee’s General Comment, which
requires that “the ‘best interpretation of will and preferences’ must replace the ‘best
interests’ determinations.” We agree once more with these general principles, but again,
have not discovered detailed programs that make clear how they ought to be implemented.
Who, for example, is to engage in such interpretation, and what safeguards should be put
into place to ensure that the inferred desires of these individuals are true? How will such a
mechanism avoid the current perils of guardianship?

Finally, States Parties’ obligations do not end at restraining themselves from
sterilizing persons with disabilities. Indeed, Article 23 of the UNCRPD requires States
Parties to support persons with disabilities in raising families. Such obligations were
recognized in a 2009 landmark decision, where the Supreme Court of India denied a
request to authorize an abortion on a woman with an intellectual disability, upholding her
right to parenthood. In addition, the Court recognized that the woman would likely
need assistance parenting and so directed the government to provide care to the woman
and her child. Future research should also consider approaches to implementation of
supports and services for parents with disabilities and their families. For some
governments, particularly those with limited resources, questions concerning allocation
judgment will arise. However, evidence suggests that in-home supports and services are
cost-effective compared to the long-term costs of termination of parental rights. Thus,
we recommend States Parties dedicate increased attention to the development and
implementation of supports and services for parents with disabilities and their families.

**CONCLUSION**

 Whereas sexual, reproductive, and parenting rights have largely been recognized as
one of the most basic rights, persons with disabilities continue to experience substantial
and pervasive discrimination in these areas. Indeed, for persons with disabilities,
adjudication of sexual, reproductive, and parenting rights has overwhelmingly centered
on involuntary sterilization, forced abortion, and the removal of children instead of on

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222 See UNCRPD, fn. 123, Art. 12.
223 General Comment No. 10, fn. 163 at 21.
224 See discussion Part II.C.
226 Id. at 31; see also id. at 19 (“It is evident that the woman in question will need care and assistance
which will in turn entail some costs. However, that cannot be a ground for denying the exercise of
reproductive rights”).
227 Dale Margolin, No Chance to Prove Themselves: The Rights of Mentally Disabled Parents under the
Americans with Disabilities Act and State Law, 15 Virginia Journal of Social Policy and the Law 112,
139–141 (2007).
equal access to sexual and reproductive health care services and information and parenting with a disability.

Deprivation of the sexual, reproductive, and parenting rights of persons with disabilities is largely the result of longstanding stereotypes that portray persons with disabilities either as asexual or as unable to engage in intimate relationships or sexual and reproductive activities. Sterilization exemplifies the significant stigma disabled persons face in the realm of sexual, reproductive, and parenting rights. As this article demonstrates, jurisprudence across time and diverse jurisdictions reflect a strong propensity toward restricting the rights of persons with disabilities. Historically, these decisions were openly grounded in eugenics ideology, whereas nowadays the influence of eugenics is more implicit. Consistent across time and jurisdictions are stereotypes regarding the inability of persons with disabilities to determine their own sexual, reproductive, and parenting needs. Indeed, even when prohibiting sterilization, courts fail to even consider what the individual with a disability wishes, assuming instead that they are unable to decide such matters.

The UNCRPD symbolizes a paradigm shift in the way sexual, reproductive, and parenting rights of persons with disabilities are to be considered and implemented. Breaking with historical stereotypes of persons with disabilities, the UNCRPD requires equal access to all types of health care — including that related to sexual and reproductive health services and information, mandates respect for family and parenting relationships, and requiring recognition of an individual’s autonomy even when their decisions require support mechanisms. Ensuring that these rights are operational, however, also requires specific programming and resource commitments, including the complex issue of structuring a human rights-based supported decision-making model for stakeholders who require such support.

Many issues remain for scholars, the legal profession, and policy makers to resolve. Further research and consideration must address highly significant issues involving capacity and consent as they relate to supported decision-making mechanisms. Future attention must also focus on approaches that can implement support and services for parents with disabilities and their families.