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Reproductive Health Justice for Women with Disabilities

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Preface: This Paper has been drafted on behalf of the National Organization for Women (NOW) Foundation by the NOW Disability Rights Advisory Committee. The Disability Rights Advisory Committee is comprised of NOW members who are currently living with disabilities and/or who serve as disability allies in their personal and professional lives. Through advocacy, education and action, the Committee strives to advance the full participation of women and girls with disabilities in the United States and throughout the world.

Since the dawn of the post–World War II era, women with disabilities, family members, activists, and advocates have worked to create what has evolved into the modern Disability Rights Movement, to effect critical changes towards the empowerment and enfranchisement of all people with disabilities. In the United States despite significant achievements in human and civil rights, many of which were won as a result of hallmark legislation and litigation during the second half of the twentieth century, women with disabilities still experience lagging equality in access to adequate reproductive health care, and face double discrimination on the basis of gender and ability (Blank and Adya, 2007; Shapiro, 1994).

Globally, women and girls with disabilities also continue to experience marginalization, deep health inequities, and gross human injustices. In addition, due to complex socio-ecological circumstances in differing parts of the world, women with disabilities are too often excluded from making any health care decisions whatsoever on their own behalf. Disability, from the perspective of many diverse cultural interpretations, is often still viewed as a hindrance on a family or as a symbol of evil phenomena within a community, thus increasing the chances that women and girls -- who may already experience gender-related discrimination while exhibiting varying disabilities -- will be targeted as the embodiment of this negative stereotype. As a result, women and girls with disabilities suffer greater incidences of violence, sexual assault, abuse, adverse health outcomes, and lower quality of life around the world (Burns et al., 2010; United Nations Population Fund, 2010).

This paper highlights the added discrimination that women with disabilities often face in the context of their disparate access to health care, especially in the areas of reproductive health services and sexual health education, and offers recommendations for a twenty-first century

response to the vast health care gaps that impact this population. The scope of this paper is primarily domestic, and focuses on US policies, demographics, and data on women and girls with disabilities living in the United States and the reproductive health disparities they experience. Disability is defined broadly to include physical, cognitive, behavioral, learning, psychiatric, and multiple disabilities. A global perspective is also presented to make the case for the adoption of political and social policies that include women with disabilities around the world in order to improve their reproductive health status and outcomes. In addition, this paper demonstrates the ways in which United States ratification of the *UN Convention on the Rights of Persons with Disabilities* and the *UN Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)* would make a significant impact on access to health care services for women and girls with disabilities in the US and globally.

Most importantly, this paper serves as a call to health care activists, practitioners, and policymakers for twenty-first century action on closing the health status gaps that persist between women and girls living with disabilities and their counterparts in society. In the last section of the paper, a comprehensive “*Women with Disabilities’ Health Resource Bibliography & Toolkit*” is provided, in order to bridge the achievements of the past decades with new policy advocacy sources for increased health care literacy, education, and access among women with disabilities in future years.

Reproductive Health and Rights Disparities: An Overview by Emily Kronenberger and Joanne L. Tosti-Vasey

In the United States, members of the disability community encounter yawning disparities in the areas of broad health status indicators, including incidence of such chronic illnesses as diabetes and obesity and such mental health conditions as depression. People with disabilities also experience underlying health determinants that translate into their poorer health outcomes, such as greater exposure to environmental risks, lack of economic, social, and political opportunities, poverty, and social isolation. Women and girls with disabilities in the US, as in many other parts of the world, experience these disparities to an greater degree, especially in the area of reproductive health and rights. Often, women with disabilities encounter discrimination and barriers when they attempt to access appropriate sexual health education programs, accessible reproductive health services, and family planning. Women and girls with disabilities also experience violence, assault, and abuse at alarmingly high rates, and are frequently denied access to tools that would assist in prevention, raising awareness, and self-defense (Center for Research on Women with Disabilities (CROWD), 2005; Centers for Disease Control and Prevention (CDC), 2002; United Nations World Health Organization, n.d.).

According to the Center for Research on Women with Disabilities (CROWD) at Baylor College of Medicine, it is estimated that of the 132 million women in the United States over age 5, approximately 19 percent are currently living with some type of disability -- including physical, intellectual, cognitive, developmental, behavioral and other disabilities. This number does not include women with disabilities who presently live in state institutions. When combined with the number of women currently living in nursing home placements, the total for women with disabilities living in the U.S. reaches approximately 24 percent of US women (CROWD, 2010a). Among children, over 4 percent of all non-institutionalized children ages 5 to 15 in the US are currently living with a disability and the numbers from the 2010 Census are projected to be even higher (US Census Bureau, 2000).

Many stereotypes and misguided assumptions around sexual and reproductive health issues still endure regarding people with disabilities, both in the larger society and even from within the public health and human services professions. Despite recent study findings which show that people with disabilities are sexually active and young women with disabilities may be initiating their sexual careers during their teen years, people with disabilities continue to be excluded from school-based comprehensive sexuality education and resources. In a 2008 study published in the *Journal of School Health*, researchers found that girls with certain disabilities, such as learning and cognitive disabilities, who received special education services in high school settings may be at higher risk for contracting sexually transmitted infections (STIs) than their typically developed peers (Mandell, et al, 2008).

In addition, women with disabilities continue to receive less preventive health care services, such as recommended reproductive cancer screenings and health promotion interventions to prevent chronic diseases such as obesity (CROWD, 2005). Women with disabilities also face an uphill battle when they try to access routine health care services through a complex health delivery system that does not appropriately meet their needs. For example, medical staff members and professionals may not be adequately trained to address the needs of women with disabilities, particularly in the area of gynecological and reproductive health care. As a result, women can experience humiliation, sub-standard care, and even refusal of care when they enter a facility that is not equipped to serve their needs. These experiences also contribute to a self-perpetuating cycle of under-service and lack of access, as women with disabilities may be hesitant to seek reproductive health care because of prior adverse experiences and may be especially apprehensive about the gynecological exam process (CROWD, 2010b; Practice Without Pressure, 2010).

Poverty and marginalization from employer-based health care frameworks also play a large, detrimental role in the lives of women and girls with disabilities (CROWD, 2010a). An overwhelming number of women living with disabilities also currently live in poverty, yet they experience barriers even in trying to access health care programs such as Medicaid, which serve lower income individuals, due to stringent work requirements. In addition, women with disabilities who successfully receive Medicaid services may face difficulties in locating and accessing reproductive health care providers who accept and participate in their insurance programs (Limontas-Salisbury, 2010).

Although support for expanded sexual and reproductive health services for women and girls with disabilities is widespread among national organizations, agencies, and health officials, women and girls with disabilities are not receiving the educational, preventive, and ongoing health care that they need to live full and productive lives. More research is needed in the areas of effective public health interventions and educational protocols for women and girls with disabilities, as well as greater funding for services, and increased sensitivity and competency training for providers working within the health and human service workforce.

Women and Girls with Disabilities: Health and the International Framework by Stephanie Ortoleva and Joanne L. Tosti-Vasey:

Both the **United Nations Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)** (United Nations, 1979) and the **United Nations Convention on the Rights of Persons with Disabilities (CRPD)** (United Nations, 2006) are important documents to advance the rights of women and girls with disabilities and their access to safe and appropriate health care services. Both Conventions recognize women's agency and

the right of women to make decisions about health care. Ratification of both of these Conventions, and engagement with their Committees (which monitor the implementation of the Conventions in those countries which have ratified them), also presents a good opportunity for advocacy by women and girls with disabilities for their rights with respect to accessible and affordable health care services and reproductive justice.

The 1995 Beijing Declaration clearly recognized the need to address the concerns of women with disabilities and the correlated need to include women with disabilities in decision making. It draws on the “Standard Rules on the Equalization of Opportunities for Persons with Disabilities,” to ensure nondiscrimination and equal enjoyment of all human rights and fundamental freedoms by women and girls with disabilities, including their access to information and services (United Nations, 1995). Significantly, drawing on the disability-inclusive nature of the original Beijing Declaration itself, the 2000 Special Session of the UN General Assembly (Beijing Plus Five) that reviewed the progress of the outcomes of the Fourth World Conference on Women also recognized the importance of addressing the diverse needs of women and girls with disabilities in the provision of appropriate health care and services and basic social services (United Nations, 2000).

Sheikha Hessa Khalifa A. Al Thani, Special Rapporteur on Disability of the Commission for Social Development, noted the absence of women with disabilities in discussions of women’s human rights and stated: “You hardly find anything about women with disabilities in any programmes and activities.... Even after the Beijing conference, there has been hardly anything specific about women with disabilities in action plans, etc. (...) I believe that women with disabilities face multiple discrimination” (Khalifa A. Al-Thani, 2006).

According to the women who led the effort to ensure that the rights of women with disabilities were incorporated into the CRPD: “Gender is one of the most important categories of social organization, and patterns of disadvantage are often associated with the differences in social position of women and men. These gendered differences are reflected in the different life experiences of women with disabilities and men with disabilities. While women with disabilities have much in common with men with disabilities, women with disabilities have to face multiple discrimination in many cases, so that they are often more disadvantaged than men with disabilities in similar circumstances” (Arnade, S. & Haefner, S., 2006).

This intersection of gender and disability was significantly recognized in the groundbreaking approach of the CRPD, which came into force on May 3, 2008 and which a significant number of States have now ratified. As of December 9, 2010, 96 states had ratified the CRPD and 60 had ratified the Optional Protocol (United Nations, 2010a). The CRPD has adopted a gender lens in its terms and provisions, in the Preamble Paragraph (q), (s), Article 3, Article 6 and also throughout the CRPD in provisions of specific concern to women and girls (United Nations, 2006, 2010c).

Additionally, the CRPD and the CEDAW share many common principles. In the CRPD Article 8 and in the CEDAW Article 5(a), the negative role that stereotypes can play in the lives of persons with disabilities, including women with disabilities, and in the lives of all women are emphasized. Under both Conventions, States have the responsibility to take steps “to combat stereotypes, prejudices and harmful practices” (CRPD, Art. 8, 1(b)) and to eliminate “prejudices and customary and all other practices” (United Nations, 1979, 2006). The CRPD takes the CEDAW stereotype provisions one further step and recognizes that, in the case of women with disabilities, it is important to consider how gendered stereotypes coincide with stereotypes of persons with disabilities to harm and discriminate against them in compounded ways, thereby

recognizing the intersection of both gender and disability stereotypes in the case of women and girls with disabilities.

As noted above, several Articles of the CRPD are related to or specifically address access to health care services, including sexual and reproductive health, parenting, and habilitation and rehabilitation, with specific reference to the health care needs of women and girls with disabilities. Article 6 specifically recognizes the unique discrimination to which women and girls with disabilities are subjected and requires special measures to address those needs: Article 9 calls for accessibility, including access to medical facilities and to information; Article 16 requires States parties to take measures to protect persons with disabilities from violence and abuse, including gender-based violence and abuse; Article 22 asserts the equal rights of persons with disabilities to privacy, including privacy of personal health information; Article 23 requires States to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood, and relationships, including in the areas of family planning, fertility, and family life; Article 25 requires that States ensure equal access to health services for persons with disabilities, with specific mention of sexual and reproductive health services and population-based public health programmes, as well as access to health services that are gender-sensitive; and, Article 26 requires States to enable persons with disabilities to attain and maintain maximum independence, full inclusion, and participation in all aspects of life through expanded habilitation and rehabilitation services and programmes (United Nations, 2006).

Even before the CRPD came into force, the CEDAW Committee began to recognize that issues of concern to women with disabilities had an important role in their work. The CEDAW Committee “recommends that States parties provide information on disabled women in their periodic reports, and on measures taken to deal with their particular situation, including special measures to ensure that they have equal access to education and employment, health services and social security, and to ensure that they can participate in all areas of social and cultural life” (United Nations, 1991).

In another General Recommendation, the CEDAW Committee also referenced issues of concern to women with disabilities -- recognizing that societal factors may be determinative of health status and that special attention should be given to health needs of women with disabilities, among other vulnerable groups (United Nations, 1999). Additionally, the International Conference on Population and Development Programme of Action (ICPD PoA) recognizes the basic right of all individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. It also includes their right to make decisions concerning reproduction free of discrimination, coercion and violence. Significantly, this Programme of Action also recognized that these rights specifically apply to persons with disabilities (United Nations, 1994).

In 2009, the United Nations World Health Organization (WHO) developed its Guidance Note on Promoting Sexual and Reproductive Health for Persons with Disabilities. This Guidance Note recognized that to be a woman with a disability is to be doubly marginalized and also highlighted numerous obstacles faced particularly by women and girls with disabilities, as quoted below:

Survival rates: In many societies the survival rate for women with disabilities is lower than that for men with disabilities. For example, [...] in Nepal the long-term survival rate of women who were disabled by polio is only half that of men who had polio.

Unstable relationships: Considered in some societies as less eligible marriage partners, women with disabilities are more likely to live in a series of unstable relationships, and thus have fewer legal, social and economic options should these relationships become abusive.

Maternal morbidity and mortality: Women with disabilities are not only less likely to receive general information on sexual and reproductive health and are less likely to have access to family planning services, but should they become pregnant, they are also less likely than their non-disabled peers to have access to prenatal, labour and delivery and post-natal services. Physical, attitudinal and information barriers frequently exist. Often community level midwifery staff will not see women with disabilities, arguing that the birthing process needs the help of a specialist or will need a Cesarean section - which is not necessarily the case. Of equal concern is the fact that in many places women with disabilities are routinely turned away from such services should they seek help, often also being told that they should not be pregnant, or scolded because they have decided to have a child.

Women without disabilities in households with family members with a disability: Parents of children with disabilities often find themselves socially isolated. Stigma, poverty, and lack of support systems take a toll on such families. The burdens often fall disproportionately on women in such households. Thus, support systems for care providers, as well as for persons with disabilities, are crucial – both formal systems, such as social security and health insurance, and informal social networks, such as community support groups. Furthermore, in a number of societies, if a child is born with a disability, it is assumed that the mother has been unfaithful or has otherwise sinned. She suffers significantly as a result of this assumption. Even without such stigma, the physical, mental and financial stresses, coupled with social isolation, result in rates of divorce and desertion often twice as high among mothers of children with disabilities as among their peers who do not have children with disabilities (United Nations World Health Organization, 2009).

Despite limited awareness of the importance of access to health care services for women and girls with disabilities, significant barriers still exist. The international community as well as the United States must do more to integrate women and girls with disabilities into policies and programs on women and health generally (United States Agency for International Development, n.d.). For example, the Millennium Development Goal 5 focuses on the improvement of maternal health, and states: “Goal 5: Improve maternal health Target 5.A: Reduce by three quarters, between 1990 and 2015, the maternal mortality ratio and Target 5.B: Achieve, by 2015, universal access to reproductive health” (United Nations, 2010b). These goals do not mention women with disabilities, despite the fact that now Article 25 of the CRPD ensures women with disabilities access to such services on an equal basis with other women.

Viewing the international legal framework clarifies the extent to which women and girls with disabilities share many concerns for access to health care services, including sexual and reproductive health and justice, with all women and girls. We must all work together to ensure that all of our rights are protected and guaranteed and we must continue to vigorously advocate for these rights. The CEDAW and the CRPD both recognize this right and also afford an opportunity for advocacy. Therefore it is urgent that all countries, including the United States, ratify these two important international Conventions and women and girls with disabilities should join in this campaign for ratification, not only for ourselves but for all of the women and girls with disabilities around the world.

Inequalities in Access to Sexual Health Education and Prevention by Heidi A. Case:

According to the WHO, health is understood to be the state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, and is the fundamental right of every human being (Hunt, 2003; United Nations World Health Organization, 2002). Health is *indispensable* for the exercise of other human rights (Hunt, 2003; United Nations Committee on Economic, Social and Cultural Rights (CESCR), 2000). Sexual and reproductive health care rights are one part of these human rights to health and are critical to the long term quality of life for women and girls with disabilities. The Arc of the United States' 2008 *Position Statement on Sexuality* expresses concern for the loss of an individual's right to sexuality, which is essential to human health and well-being. This loss has negatively affected people with disabilities, particularly those with emotional and intellectual disabilities, in the areas of gender identity, friendships, self-esteem, body image and awareness, emotional growth, and social behavior (Arc of the United States, 2008).

While youth and adults with disabilities develop sexually in similar ways to their peers without disabilities, sexuality influences cognitive, emotional, physical and social aspects of life -- regardless of disability (ASHA, 2009). Research indicates that individuals with disabilities can experience unique barriers to sexual health because of exceptionalities, and that these barriers can result in sexual exploitation, sexual assault, unintended pregnancy, and sexually transmitted infections (Murphy and Young, 2005). The United States Department of Justice (USDOJ) estimates that 68 to 83 percent of women with developmental disabilities will be sexually assaulted in their lifetimes. This increased risk for sexual violence and sexual health problems among women and girls with disabilities can be traced to some specific deficiencies in their experience (Keshav and Huberman, 2006).

People with intellectual or developmental disabilities frequently lack access to appropriate sex education in schools and other settings (ASHA, 2009). Loretta Ross, former Executive Director of the Washington DC Rape Crisis Center (DCRCC) says they have found that in order for sexual violence prevention education to be effective, it must be founded on a strong foundation of quality sex education. Professional organizations and sexual health education experts, such as the American School Health Association (ASHA) and the American Association on Intellectual and Developmental Disabilities (AAIDD) have continuously validated the importance of developmentally appropriate, comprehensive, high-quality, medically accurate, and skills-based sex education programs for students with disabilities. According to The National Dissemination Center for Children with Disabilities (NICHCY), sexuality education should be ability-centered, age-appropriate, developmentally sensitive, culturally competent, and accommodated to meet the individual needs and learning styles of the student (American School Health Association, 2009).

However, there remains a scarcity of sexuality education materials for special education. This lack of appropriate sex education, which is essential in educating women and girls with disabilities about sexual violence and abuse prevention, further sets them up to experience higher rates of this kind of abuse. The American Academy of Pediatrics (AAP) reports that the likelihood of abuse may be reduced or eliminated when "sexual questions and behaviors of individuals are freely discussed.... [and] sexual development is promoted" (Murphy and Elias, 2006).

A further area of reproductive rights disparities that women and girls with disabilities face is in accessing appropriate birth control methods. Unfortunately, access to sexual health education, contraception, and other preventative birth control methods remains lacking in the

disability community (Kaplan, 2006). One of the greatest obstacles to reproductive health care for women with disabilities may stem from outdated belief systems still held by many health care professionals (including doctors), combined with a lack of education and support from caregivers and human service workers in residential settings, such as group homes. Bias against people with disabilities and value judgments about their sexual empowerment can be traced back even to medical and peer-reviewed literature. In an article published by the National Library of Medicine at the National Institutes of Health, it is recommended that “physicians should not advise oral contraceptive use for women who are mentally retarded, mentally ill, or are drug abusers since they either do not understand, cannot remember, or are not motivated to take oral contraceptives regularly” (Hakim-elahi, 1991).

As a result, there remains a generally accepted approach to promotion of contraception for many women with disabilities that is heavily focused upon birth control methods that are used and needed less frequently, particularly for individuals with cognitive and mental health disabilities. This has produced a limited number of birth control options being offered to women with disabilities, which has led to the prioritization of the use of such methods as Depo-Provera shots, intrauterine devices (IUDs), and even forced sterilization, all of which can have significant long-term consequences for the women (Kaplan, 2006). Furthermore, condoms -- which represent the method of birth control that most effectively serves as a prevention tool for sexually-transmitted infections (STIs) including HIV/AIDS -- are not included in the preferred options, because the necessity of their frequent and consistent use is not considered to be as viable as the less frequently-needed methods of birth control mentioned above.

This raises the importance of appropriate access to the full complement of reproductive health services for women with disabilities, which must include appropriate individualized birth control methods, family planning, prenatal care, and prevention and treatment of sexually transmitted infections (STIs). With respect to sexuality, The Arc of the United States says individuals with developmental disabilities have a right to: Develop friendships and emotional and sexual relationships where they can love and be loved and to begin and end a relationship as they choose; sexual expression and education, reflective of their own cultural, religious and moral values and of social responsibility; individualized education and information to encourage informed decision making, including education about such issues as reproduction, marriage and family life, abstinence, safe sexual practices, sexual orientation, sexual abuse, and sexually transmitted diseases; make their own decisions about using birth control methods within the context of their personal or religious beliefs (Arc of the United States, 2008).

Realization of these rights for all women and girls with disabilities will empower them to optimize their full potential and allow them to be productive, dynamic members of our communities. There is a developing movement through which women and girls with disabilities are becoming self-advocates in furtherance of these rights. For example, the Illinois Coalition Against Sexual Assault (ICASA) has developed a statewide program entitled “Our Rights, Right Now” to create collaborations between organizations that support persons with disabilities and disability rights groups with agencies that support women in dealing with acts of sexual violence. This training and curriculum is based on a 2008 needs assessment which asked women with disabilities what they needed and wanted if they had experienced sexual violence. It is driven by “self-advocates” speaking on behalf of themselves and by other women and girls with disabilities who are utilizing this opportunity for self-empowerment and self-realization.

Forced Sterilization and Reproductive Justice by Lisa Alvares:

Policies supporting forced sterilization and medical experimentation characteristically have had racial, gender, and disability dimensions and the most common argument for such practices was genetics. One of the most horrific examples of racially-motivated medical experimentation was the Tuskegee Syphilis Experiments which were conducted on African American men without their consent by the US Public Health Service between 1932 and 1972 in Tuskegee, Alabama (Centers for Disease Control, 2009). During the experiment, investigators recruited 399 indigent African American sharecroppers with syphilis for research related to the natural progression of the untreated disease (Kevles, 1985). The Tuskegee scientists knowingly withheld penicillin from these patients and prevented them from gaining access to treatment programs; numerous deaths resulted from this denial of treatment. In addition, the wives of these men contracted the disease and their children were born with congenital syphilis (Kevles, 1985).

The United States was the first country to implement a compulsory sterilization program for the purpose of eugenics (Kevles, 1985). The principal targets of this program were people who were perceived -- in the terms of that era -- as “mentally ill,” “epileptic,” “the blind and visually impaired,” the “deaf and hearing impaired,” individuals with physical disabilities or deformities, children who were orphaned, and people who were identified as, or were believed to be, homosexuals (Kevles, 1985). In addition, there was an especially high incidence of forced sterilization among African American and Native American women immediately following childbirth and of women and men who were hospitalized for other reasons (Davis, 1983).

Forced sterilization of people with disabilities has a very long history in the United States. As the eugenics movement gained momentum, states began to enact laws encouraging the forced sterilization of people who were labeled as “insane” or “feeble-minded.” Indiana passed the first of these laws in 1907. By 1924, an estimated 4,000 people had been sterilized in the United States. At that point, several other states joined the eugenics bandwagon and passed laws similar to Indiana’s. For example, a 1924 Virginia law asserted that “heredity plays an important part in the transmission of insanity, idiocy, imbecility, epilepsy and crime...” It focused on “defective persons” whose reproduction represented “a menace to society” and was viewed as a tax saving measure because of the increasing number of people with these labels who had been confined to public facilities in the state. (Lombardo, n.d.). These laws were also written to protect doctors from malpractice suits when they performed these sterilizations. With the increasing number of states passing laws that encouraged eugenic sterilization, there were an estimated 60,000 people who were forcibly sterilized by the mid 1940’s (Lombardo, n.d.).

In the landmark 1927 Supreme Court case of *Buck v. Bell* that reviewed the constitutionality of the Virginia eugenics law, Chief Justice Oliver Wendell Holmes upheld the statute, stating that: “It is better for all 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...Three generations of imbeciles are enough” (*Buck v. Bell*, 1927).

Borrowing from this misguided precedent, Nazi Germany enacted similar legislation in 1933, resulting in the forced sterilization of at least 350,000 people by the end of World War II. The horrific genocide committed during the World War II era not only included the genocide, but also included non-consensual medical experimentation and sterilization of persons with disabilities (Lombardo, n.d.).

Despite decreasing public support for compulsory sterilization following the genocide and human slaughter committed during the Holocaust of World War II, forced sterilization in

various manifestations continued in the United States into the second half of the twentieth century. Through the mid-1950s in the United States, 27 states kept sterilization laws on the books (Davis, 1983). Large numbers of women also were sterilized in the United States throughout the 1960s and 1970s, including lower income women, women of color, Native American women who received health care from federal Indian Health Service facilities, and women in state institutions. These women were often misinformed, coerced and/or threatened into procedures that were not fully explained to them by health professionals who were providing their care (National Women's Health Network, 2008). According to the National Women's Health Network, state policy makers and health professionals intimidated "undesirable" women into agreeing to surgical sterilization – because of state fears of over population, welfare dependency, increased spending for public services, and illegitimate childbearing, generated by negative stereotypes about women of color, immigrant women, and women with disabilities (National Women's Health Network, 2008).

Forced sterilizations have also occurred in many other countries. In Japan during the 1920s, government officials promoted "healthy Japanese people," and sterilization and forced abortions were performed on people with mental illness and people with genetic diseases (Kimura, 1987). In India during the 1970s, the national family planning initiative conducted coercive sterilizations, where men were forced to receive vasectomies and women were forced to undergo tubal ligations (Ringheim, 1996). The Swedish Racial Hygiene Society promoted eugenic policies or genetic "integrity" to sterilize the "undesirable persons" of the social order. Coercive sterilizations occurred in Switzerland from the 1920s until 1976 to promote a "healthy" nation and ensure "racial purity" (Andrén, 2000; Czech Government, 2004). These policies have been in place for decades and family members of some people in China who refuse to be sterilized are currently being incarcerated until they submit to surgical procedures (Amnesty International UK, 2010, Sharp, 2010)

Governments that performed sterilization procedures in order to promote healthy nations and racial purity subscribed to a belief that one life was more important than another. The eugenic viewpoint focused on the prevention of the birth of descendants who were viewed as inferior and of the hereditary transfer of undesirable characteristics, which were believed to be a burden to society.

In summary, women and girls with disabilities must be empowered with the right to make choices about their reproductive lives. In any treatment or procedure performed by health care professionals through research or otherwise, both ethical and practical standards must require that the person be fully informed of the procedure and that they consent to treatment without any coercion or threat.

References

- American School Health Association (ASHA) (2009). Quality sexuality education for students with disabilities or other special needs. American School Health Association. Retrieved October 10, 2010 from http://www.ashaweb.org/files/public/Resolutions/Quality_Sexuality_Education_Disabilities.pdf
- Amnesty International, UK (2010, April 22). China: Thousands at risk of forced sterilisation. Retrieved March 31, 2011 from http://www.amnesty.org.uk/news_details.asp?NewsID=18720.

- Andrén, C. (2000). Steriliseringsfrågan i Sverige 1935 – 1975 [Sterilization Question in Sweden 1935-1975]. Retrieved March 31, 2011 from <http://www.regeringen.se/content/1/c4/28/64/212fc81a.pdf>
- Arc of the United States. (2008). Position statement on sexuality. Retrieved from <http://www.thearc.org/Netcommunity/Page.aspx?pid=1375>
- Arnade, S. & Haefner, S. (2006). Gendering the comprehensive and integral international convention on the protection and promotion of the rights and dignity of persons with disabilities. Retrieved December 1, 2010 from http://v1.dpi.org/lang-en/resources/topics_detail?page=446
- Blanck, P., & Adya, M. (2007). Defying double discrimination. Retrieved December 1, 2010 from <http://www.un.org/womenwatch/daw/beijing/pdf/BDPfA%20E.pdf>
- Buck v. Bell*, 274 U.S. 200 (1927). Retrieved December 18, 2010 from <http://laws.findlaw.com/us/274/200.html>.
- Burns, A., Lovich, R., Maxwell, J. & Shapiro, K. (2010). *Where women have no doctor: A health guide for women*. San Francisco: Hesperian Publishing. Retrieved December 20, 2010 from http://www.hesperian.info/assets/wwhnd/Where_Women_00_Front_Matter.pdf.
- Center for Research on Women with Disabilities (2005). Health disparities. Center for Research on Women with Disabilities, Baylor College of Medicine. Retrieved December 12, 2010 from <http://www.bcm.edu/crowd/index.cfm?PMID=1331>
- Center for Research on Women with Disabilities (CROWD) (2010a). Demographics. CROWD, Baylor College of Medicine. Retrieved December 12, 2010 from <http://www.bcm.edu/crowd/index.cfm?PMID=1330>
- Center for Research on Women with Disabilities (2010c). Sexuality and reproductive health. CROWD, Baylor College of Medicine. Retrieved December 12, 2010 from <http://www.bcm.edu/crowd/index.cfm?pmid=1332>
- Centers for Disease Control (CDC) (2002). Sexual assault against persons living with disabilities. Atlanta, GA: Centers for Disease Control and Prevention. Retrieved December 13, 2010 from <http://www2a.cdc.gov/phtn/svprev/Disability.pdf>
- Centers for Disease Control (2009). Syphilis study at Tuskegee. (2009) United States Public Health Service. Retrieved February 12, 2009 from www.cdc.gov/tuskegee/timeline.htm
- Czech Government. (2004). Final statement of the public defender of rights in the matter of sterilizations performed in contravention of the law and proposed remedial measures. Retrieved from <http://www.2.ohchr.org/english/bodies/cerd/docs/.../Public-defender-rights.pdf>
- Davis, A. (1983). *Women, race and class*. New York: Random House, Inc.
- Hakim-elahi, E. (1991). Contraception for the disabled. *Female Patient*, 16(10), 19-20, 24, 27. Retrieved October 13, 2010 from <http://www.upmc.com/HospitalsFacilities/Hospitals/Magee/SpecialtyServicesWomen/womenwithdisabilities/Pages/default.aspx>
- Helander, E. (1999). Prejudice and dignity: An introduction to community-based rehabilitation, 2nd ed. New York: United Nations Development Programme.
- Hunt, P. (2003) Economic, social and cultural rights: The right of everyone to the enjoyment of the highest attainable standard of physical and mental health. Report of the United Nations Special Rapporteur of the Commission on Human Rights. Retrieved December 1, 2010 from <http://www.un.org/womenwatch/ods/E-CN.4-2003-58-E.pdf>.

- Kaplan, C. (2006). Special issues in contraception: Caring for women with disabilities. *Journal of Midwifery & Women's Health*, 51(6), 450-456. Retrieved December 5, 2010 from [http://www.jmwh.com/article/S1526-9523\(06\)00339-4](http://www.jmwh.com/article/S1526-9523(06)00339-4)
- Keshav, D., & Huberman, B. (2006). Sex education for physically, emotionally, and mentally challenged youth. Advocates for Youth. Retrieved December 14, 2010 from <http://www.advocatesforyouth.org/publications/479-sex-education-for-physically-emotionally-and-mentally-challenged-youth?tmpl=component&print=1&page>
- Kevles, D. (1985). *In the name of eugenics: Genetics and the use of human heredity*. New York: Knopf.
- Khalifa A. Al-Thani, S. (2006). Interview by Sunil Deepak with Shiekha Hessa Khalifa A. Al-Thani, United Nations Special Rapporteur on Disability. Retrieved December 1, 2010 from <http://www.aifo.it/english/resources/online/books/cbr/SR-interview0506.htm>.
- Kimura, R. (1987). Bioethics as a prescription for civic action: The Japanese interpretation. *Journal of Medical Philosophy*, 12, 267-277.
- Limontas-Salisbury, A. (2010). Welfare job rules hit women with disabilities. Women's eNews. Retrieved December 10, 2010 from <http://womensenews.org/story/economyeconomic-policy/100831/welfare-job-rules-hit-women-disabilities?page=0.1>
- Lombardo, P. (n.d.). Eugenic Sterilization Laws. Charlottesville, VA: Dolan DNA Learning Center, Cold Spring Harbor Laboratory. Retrieved December 17, 2010 from <http://www.eugenicsarchive.org/html/eugenics/essay&text.html>.
- Mandell, D., Eleey, C., Cederbaum, J., Noll, E., Hutchinson, M., Jemmott, L., & Blank, M. (2008). Sexually-transmitted infection among adolescents receiving special education services. *Journal of School Health*, 78, 382-388.
- Murphy, N. & Elias, E. (2006) Clinical report: Sexuality of Children and Adolescents With Developmental Disabilities. *Pediatrics*, 118(1), pp. 398-403. Retrieved December 20, 2010 from <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;118/1/398>.
- Murphy, N., & Young, P.C. (2005). Sexuality in Children and Adolescents with Disabilities. *Developmental Medicine and Child Neurology*, 47(9), 640-644. Retrieved December 1, 2010 from <http://onlinelibrary.wiley.com/doi/10.1111/j.1469-8749.2005.tb01220.x>.
- National Women's Health Network (NWHN) (2008). Latinas and sterilization in the United States. (2008). National Women's Health Information Network. Retrieved from <http://nwhn.org/latinas-and-sterilization-united-states>
- Practice Without Pressure (2010). Women's health initiative: Hands-on learning for teens and women with disabilities. Practice Without Pressure. Retrieved December 10, 2010 from <http://www.pwpde.com/womenshealth.htm>.
- Ringheim, K. (1996). *Male involvement and contraceptive methods for men: Present and future*. *Social Change Magazine*. Retrieved October 7, 2010 from www.malecontraceptives.org
- Shapiro, J. (1994). *No pity: People with disabilities forging a new civil rights movement*. New York: Three Rivers Press.
- Sharp, P. (2010). China to sterilize 10,000 to curb births. Retrieved April 23, 2010 from <http://news.sky.com/skynews/Home/World-News/China-Authorities-Plan-To-Sterilise-10000-People-To-Ensure-They-Meet-Family-Planning-Targets/Article/201004415613125?f=rss>
- United Nations (1979). Convention on the elimination of all forms of discrimination against women. New: York: United Nations. Retrieved December 1, 2010 from <http://www.un.org/womenwatch/daw/cedaw/text/econvention.htm>.

- United Nations (1991). Convention on the elimination of all forms of discrimination against women gen. rec. No. 18. New York: United Nations. Retrieved December 1, 2010 from <http://www.un.org/womenwatch/daw/cedaw/recommendations/recomm.htm#recomb23>
- United Nations (1994). Report of the international conference on population and development. United Nations A/Conf.171/13. Retrieved December 9, 2010 from <http://www.un.org/popin/icpd/conference/offeng/poa.html>.
- United Nations (1995). Beijing declaration & report. New York: United Nations. Retrieved December 1, 2010 from <http://www.un.org/womenwatch/daw/beijing/pdf/BDPfA%20E.pdf>.
- United Nations (1999). Convention on the elimination of all forms of discrimination against women gen. rec. No. 24. New York: United Nations. Retrieved December 1, 2010 from <http://www.un.org/womenwatch/daw/cedaw/recommendations/recomm.htm>
- United Nations. (2000). Doc. A/RES/S-23/3. Retrieved December 1, 2010 from <http://www.un.org/womenwatch/daw/followup/ress233e.pdf>.
- United Nations (2006). Convention on the rights of persons with disabilities. New York: United Nations. Retrieved December 1, 2010 from <http://www.un.org/disabilities/convention/conventionfull.shtml>
- United Nations (2010a). Convention on the rights of persons with disabilities: Convention and optional protocols signatures and ratifications. New York: United Nations. Retrieved December 9, 2010 from <http://www.un.org/disabilities/countries.asp?id=166>.
- United Nations (2010b). Millennium development goals, goal 5, target 5.B. United Nations. Retrieved December 2, 2010 from <http://mdgs.un.org/unsd/mdg/Host.aspx?Content=Indicators/OfficialList.htm>.
- United Nations (2010c). Women and girls with disabilities: Using both gender and disability lens. (2010). New York: United Nations. Retrieved December 1, 2010 from <http://www.un.org/disabilities/default.asp?navid=37&pid=1514>.
- United Nations Committee on Economic, Social and Cultural rights (2000). General comment 14: The right to the highest attainable standard of health. E/C.12/2000/4. New York: United Nations.
- United Nations Population Fund. (2010). Improving reproductive health. New York: United Nations Population Fund. Retrieved December 9, 2010 from <http://www.unfpa.org/rh/index.htm>
- United Nations World Health Organization (2002). Twenty five questions and answers on health and human rights. *Health and Human Rights Publication Series*. Geneva, Switzerland: WHO; 2002.
- United Nations World Health Organization (2009). Promoting sexual and reproductive health for persons with disabilities New York: United Nations World Health Organization/ UNFPA Guidance Note. Retrieved December 9, 2010 from http://whqlibdoc.who.int/publications/2009/9789241598682_eng.pdf
- United Nations World Health Organization (n.d.). Gender and disparities and women's mental health: The facts. New York: United Nations: World Health Organization. Retrieved December 1, 2010 from http://www.who.int/mental_health/prevention/genderwomen/en/
- United States Agency for International Development (n.d.) Women with disabilities. New York: US Agency for International Development. Retrieved December 1, 2010 from http://www.usaid.gov/our_work/crosscutting_programs/wid/gender/wwd.html

United States Census Bureau (2000). Characteristics of the civilian non-institutionalized population by age, disability status, and type of disability: 2000 (Table 1). United States Census Bureau. Retrieved December 11, 2010 from <http://www.census.gov/hhes/www/disability/disabstat2k/table1.html>

Women and Girls with Disabilities' Health Resources

This resource bibliography is provided as a toolkit to share organizing ideas and information on the past, present, and future of the rights of women and girls with disabilities. This list is not exhaustive by any means, but is intended to create a bridge between the already well-established organizations and resources for women and girls with disabilities and those that are currently emerging and developing new insights into the struggle for human rights.

Answer (Sex Ed Honestly)/ Center for Applied Psychology at Rutgers University,
<http://answer.rutgers.edu/>

The Arc of the United States' Position Paper on Sexuality,
<http://www.thearc.org/NetCommunity/Page.aspx?pid=1375>

BlogHer, Disability Blog Roll, <http://www.blogher.com/health-and-wellness-tags/disability>
Breast Health Access for Women with Disabilities, <http://www.bhawd.org/sitefiles/index2.html>

Disabled Women's Network Ontario, <http://dawn.thot.net/fact.html>

Empowered Fe Fe's (Program of Access Living),
<http://www.accessliving.org/index.php?tray=content&tid=top845&cid=180>

A Health Handbook for Women with Disabilities (a publication of the Hesperian Foundation available for order or free download),
http://www.hesperian.org/mm5/merchant.mvc?Screen=PROD&Store_Code=HB&Product_Code=B150&Category_Code=ENG

Human Rights Watch: Disability Rights, <http://www.hrw.org/en/disability-rights>

Independent Living Institute, <http://www.independentliving.org/>

International Disability Alliance, <http://www.internationaldisabilityalliance.org/>

Marsh Media's Special Needs Education and Resources,
<http://www.marshmedia.com/resources2/special.cfm>

Mobile Women, <http://www.mobilewomen.org/>

National Coalition Against Domestic Violence Position Paper on Women with Disabilities,
http://www.leanonus.org/images/Domestic_Violence_and_Disabilities.pdf

National Dissemination Center for Children with Disabilities Sexuality Education Resources,
<http://www.nichcy.org/Pages/sexed.aspx>

National Organization for Women (NOW): Disability Issues,
<http://www.now.org/issues/disability/index.html>

National Sexuality Resource Center, <http://nsrc.sfsu.edu/>

National Women's Health Information Center, <http://www.womenshealth.gov/>

National Youth Leadership Network (NYLN), <http://www.nyln.org/>

New Wave Grrrl, <http://newwavegrrrl.blogspot.com/>

Practice without Pressure, <http://www.pwpde.com/>

Quality Mall: Person-Centered Services Supporting People with Developmental Disabilities,
<http://www.qualitymall.org/main/>

The Riot! <http://www2.hsri.org/leaders/theriot/index.html>

Sexual Health Network's Resources for Disability and Illness,
<http://www.sexualhealth.com/channel/view/disability-illness/>

Sexuality Information and Education Council of the United States, <http://www.siecus.org>

Sins Invalid Performance Group, <http://www.sinsinvalid.org/>

Special Rapporteur of the Commission on Human Rights on the Right of Everyone to the
Enjoyment of the Highest Attainable Standard of Physical and Mental Health (This link
describes the mandate of the Special Rapporteur on Health),
<http://www2.ohchr.org/english/issues/health/right/>

Through the Looking Glass, <http://lookingglass.org/index.php>

The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disability, Chronic Pain
& Illness, by Miriam Kaufman, Cory Silverberg, and Fran Odette

University of Michigan's Sexuality Education for Youth with Disability or Chronic Illness
Resource Guide
<http://www.med.umich.edu/yourchild/topics/disabsex.htm>

Where Women Have No Doctor (a publication of the Hesperian Foundation available for order
or free download)
http://www.hesperian.org/mm5/merchant.mvc?Store_Code=HB&Screen=PROD&Product_Code=B080

Women, Disabled, Queer: Working Together for Our Sexuality and Rights
http://files.creaworld.org/files/Disability_Flyer.pdf

Women with Disabilities Health Education Program
<http://www.womenwithdisabilities.org/>

Women's Institute on Leadership and Disability (WILD)/ Mobility International USA
<http://www.miusa.org/wild>

Women Watch/ Women with Disabilities
<http://www.un.org/womenwatch/enable/>

Women with Disabilities Australia
<http://www.wwda.org.au/contents.htm>

World Bank, 2010 Reproductive Health and Disability,
<http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTHEALTHNUTRITIONANDPOPULATION/EXTPRH/0,,contentMDK:20286128~menuPK:632615~pagePK:148956~piPK:216618~theSitePK:376855,00.html>

World Health Organization, 25 Questions and Answers on Health and Human Rights, *Health and Human Rights Publication Series*. Geneva, Switzerland, 2002,
<http://www.who.int/hhr/information/25%20Questions%20and%20Answers%20on%20Health%20and%20Human%20Rights.pdf>

World Health Organization, Gender and Disparities and Women's Mental Health: The Facts,
http://www.who.int/mental_health/prevention/genderwomen/en/

World Health Organization, Promoting Sexual and Reproductive Health for Persons with
Disabilities, WHO/UNFPA Guidance Note, 2009,
http://whqlibdoc.who.int/publications/2009/9789241598682_eng.pdf