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**Human Rights Committee**

**Submission for List of Issues Prior to Reporting for the United States of America on**

**Women, Girls, and Nonbinary Persons with Disabilities**

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[Women Enabled International](https://www.womenenabled.org/) (WEI) is an organization based in the United States of America (U.S.) that works at the intersection of gender and disability rights to advance the rights of women and girls with disabilities worldwide. Globally, WEI fosters cooperation across movements to increase international attention to and strengthen human rights standards on issues such as violence against women, sexual and reproductive health and rights, access to justice, education, legal capacity, and humanitarian emergencies.

WEI and the endorsing organizations and individuals appreciate the opportunity to contribute to the Human Rights Committee’s consideration of the U.S.’s List of Issues Prior to the Reporting (LOIPR). This is a preliminary submission that will provide a brief overview of some of the civil and political rights violations facing women, girls, and nonbinary persons with disabilities in the U.S., and we look forward to providing updated and more detailed information in the coming years, ahead of the Human Rights Committee’s interactive dialogue with the U.S.

Women and girls with disabilities account for approximately 16 percent of all women in the U.S.,[[1]](#endnote-1) and although gender identity is not included in the U.S. Census, there are a significant number of nonbinary persons with disabilities in the U.S., as well.[[2]](#endnote-2) Despite their prevalence in the population, women, girls, and nonbinary persons with disabilities encounter a number of barriers to their full exercise of civil and political rights, as a result of discrimination based on their gender and/or gender identity and disability, among other statuses. In particular:

* Women, girls, and nonbinary persons with disabilities still face significant barriers to accessing needed **sexual and reproductive health** information, goods, and services, due to barriers placed on all women and nonbinary persons but also due to disability discrimination and stereotypes, and are still subjected to forced reproductive health interventions, including **forced sterilization**.
* Persons with disabilities face profound violations of their right to parent and found a family, as they are much more likely to have their **parental rights** terminated, to have their children temporarily or permanently removed from their care, or to be denied access to assistive reproductive technologies, based on disability.
* Women, girls, and nonbinary persons with disabilities face higher rates of **gender-based violence** in the U.S. and increased barriers to accessing social supports and services following violence.
* They also face higher rates of **incarceration and abuse in prisons and jails**, including gender-based violence and solitary confinement.

These disparities persist, despite the adoption of various pieces of legislation to ensure the rights of women and of persons with disabilities. This includes the 1990 adoption of the Americans with Disabilities Act (ADA)—a piece of national legislation that was intended to address discrimination against persons with disabilities in many aspects of their lives.

This submission provides a brief factual overview of the violations women, girls, and nonbinary persons with disabilities face concerning sexual and reproductive health, parenting, gender-based violence, and incarceration. It further provides suggestions for questions that the Human Rights Committee could include in its LOIPR on these topics as they affect women, girls, and nonbinary persons with disabilities.

*A Note on the Federal System*

The U.S. has a federal system of government, and many laws, policies, and practices on the issues described in this submission vary from state to state. As the Human Rights Committee has found, this federal system does not limit the U.S.’s obligation to ensure the respect, protection, and fulfilment of human rights throughout its states and territories.[[3]](#endnote-3) This submission focuses primarily on national laws and policies that impact the civil and political rights of women, girls, and nonbinary persons with disabilities and, where available, also provides information on state laws and practices.

1. ***Sexual and Reproductive Health and Rights*: Women, girls, and nonbinary persons with disabilities face significant barriers to accessing needed sexual and reproductive health information, goods, and services and continue to experience forced reproductive health interventions in violation of Articles 3, 7, 17, 23, and 26 of the ICCPR.**

Having a disability and being in good health are not mutually exclusive.[[4]](#endnote-4) However, in the U.S., there are many challenges women, girls, and nonbinary persons with disabilities face in accessing quality health information and services to keep them in good health. These challenges are frequently created by discrimination and stereotypes based on their gender, gender identity, and disability,[[5]](#endnote-5) including stereotypes that they are asexual, hypersexual, unable to make decisions for themselves, or unable to be good parents.[[6]](#endnote-6) Furthermore, providers are often not trained to work with persons with disabilities—one study in the U.S. found that 40–50 percent of gynecologists felt somewhat to completely unprepared to treat adolescents with disabilities[[7]](#endnote-7)--and this lack of training helps reinforce the effects of stereotypes these providers hold about disability. For instance, the prevalence of stereotypes and lack of provider training make healthcare providers significantly less likely to ask women with disabilities about their use of or need for contraceptives,[[8]](#endnote-8) meaning that women, girls, and nonbinary persons with disabilities in the U.S. may be more susceptible to unplanned pregnancies that can have a significant impact on their health and well-being. Anecdotal evidence indicates that providers are also less likely to ask persons with disabilities about their gender identity or sexual orientation, limiting the sexual health care they are provided, which is a significant problem as potentially more than one-third of LGBTQ persons in the U.S. also identify as persons with disabilities.[[9]](#endnote-9) Barriers to accessing needed health information, goods, and services are compounded for persons with disabilities who identify as transgender or nonbinary. For instance, a 2017 study of social service provision to transgender and gender non-conforming persons in the U.S. indicated that those with disabilities faced higher rates of discrimination in accessing certain services, including mental health services.[[10]](#endnote-10)

Additionally, because physicians frequently see women, girls, and nonbinary persons with disabilities as sexually inactive and thus not in need of reproductive health care,[[11]](#endnote-11) and because transportation and health facilities are frequently inaccessible,[[12]](#endnote-12) persons with disabilities are also less likely to receive needed health screenings for reproductive and breast cancer,[[13]](#endnote-13) a situation that can lead to significant and costly long-term health problems and risks to their lives. According to the National Council on Disability, an independent federal agency advising the President and Congress on disability matters, due to poverty, women with disabilities are also more reliant than others on government health insurance, including Medicaid and Medicare.[[14]](#endnote-14) By law, these programs do not cover abortion,[[15]](#endnote-15) a service that is essential to ensuring that women can make decisions about their health and lives.

U.S. law provides some health protections for persons with disabilities. For instance, the amended ADA prohibits healthcare providers and hospitals from discriminating on the basis of disability in the full and equal enjoyment of goods, services, facilities, privileges, advantages or accommodations, which includes health facilities and services.[[16]](#endnote-16) Furthermore, the Patient and Protection Affordable Care Act of 2010 (frequently called the Affordable Care Act or ACA) mandates coverage in health plans for preventive reproductive health care, including contraception, and prohibits discrimination by health insurers against those with pre-existing conditions, including those with disabilities.[[17]](#endnote-17) In 2012, the U.S. Access Board recommended, pursuant to the ACA, improved accessibility standards for medical diagnostic equipment (e.g., exam tables, chairs, tables) inclusive of sexual and reproductive healthcare access.[[18]](#endnote-18) Although standards on this issue have been developed, the U.S. Department of Justice has not yet made them mandatory for healthcare providers and equipment manufacturers, although it has issued guidelines on this topic that do contain some legal guidance.[[19]](#endnote-19)

Furthermore, women, girls, and nonbinary persons with disabilities in the U.S. are also still subjected to forced and coerced reproductive health interventions, including forced sterilization and forced gender assignment surgeries. Women and girls with disabilities are more likely to have hysterectomies at a younger age and for a non-medically necessary reason, including by request of a parent or guardian.[[20]](#endnote-20) Women with disabilities also frequently encounter pressure from doctors, guardians, social service workers, parents, and society to abort a pregnancy because of a misperception of the possibility of passing on disabilities to their children—even if the disability is not genetic.[[21]](#endnote-21) Women and girls with disabilities also frequently are not provided with accessible sexuality education that is applicable to their lives, which can prevent them from making informed decisions about their sexual and reproductive health and from protecting themselves from violence and abuse.[[22]](#endnote-22) Furthermore, some states require that persons, including persons with disabilities, undergo sex reassignment surgery in order to have their gender and/or name changed on their identity cards or birth certificates,[[23]](#endnote-23) surgeries that can also result in sterilization.

Erroneous stereotypes regarding the danger of procreation of persons with disabilities, particularly women with disabilities, are enshrined in U.S. state law. As of 2015, eleven states retained statutory language authorizing a court to order the involuntary sterilization of or forced contraceptive use by a person with a disability.[[24]](#endnote-24) Courts in the U.S. also have addressed these issues, not always consistent with the requirements of Title II of the ADA, which prohibits state and local governments from discriminating on the basis of disability in government services, programs, or activities.[[25]](#endnote-25) Courts are divided on the legal capacity of persons with disabilities to decide about their reproductive lives, particularly regarding the forced sterilization of young women and girls with disabilities, and there is no clear judicial standard that ensures reproductive decision-making resides with these individuals.[[26]](#endnote-26)

*Questions for U.S. List of Issues*

* What is the U.S. government doing to ensure that the ADA’s requirement of non-discrimination and reasonable accommodation is enforced concerning health facilities and services, particularly sexual and reproductive health facilities and services, and that the gaps in service provision between disabled and non-disabled persons are addressed?
* What is the U.S. government doing to clarify the legal obligations that states have regarding sterilization of persons with disabilities, and what steps is it taking to ensure that states eliminate laws and practices that force or coerce sterilization and limit the legal capacity of persons with disabilities concerning their reproductive lives?
* What is the U.S. doing to ensure that health-related information is in accessible language or alternative format?

1. ***Parental Rights:* Persons with disabilities are much more likely to have their parental rights terminated, to have their children temporarily or permanently removed from their care, or to be denied access to assistive reproductive technologies, in violation of Articles 3, 17, 23, and 26 of the ICCPR.**

Parents with disabilities are disproportionately subject to state intervention in their parental role as a result of discrimination and stereotypes. According to the Committee on the Rights of Persons with Disabilities (CRPD Committee), “[h]armful gender and/or disability stereotypes such as incapacity and inability, can lead to mothers with disabilities facing legal discrimination. As such, they are significantly overrepresented in child protection proceedings and disproportionately lose contact and custody of their children[.]”[[27]](#endnote-27)

This concern is reflected in practices in the U.S., where rather than being presumed to be fit parents, parents with disabilities must frequently prove their competence as parents in the face of harmful and pernicious stereotypes.[[28]](#endnote-28) In the U.S., the child welfare system is generally located within state governments, rather than within the federal government. A 2012 report from the National Council on Disability highlighted that 37 U.S. states and the District of Columbia list some forms of disability—primarily psychosocial and intellectual disability, but also physical disability—as grounds for removing a child from a disabled parent.[[29]](#endnote-29) The 2012 report determined that the child welfare system’s “unfit parent” standard for removing children from parents is “one of the major threats to people with disabilities who choose to parent,” due to stereotypes about disability,[[30]](#endnote-30) and that the “best interests of the child” standard in this system frequently allows biases and misperceptions about disability to color attitudes about the child-rearing abilities of parents with disabilities.[[31]](#endnote-31) This then leads to “disproportionately high rates of involvement with child welfare services and devastatingly high rates of parents with disabilities losing their parental rights.”[[32]](#endnote-32)

For instance, a study in the U.S. state of Minnesota indicated that parents whose educational records indicated that they had a disability while attending school were more than three times as likely to have their parental rights terminated than was the population as a whole, and even those parents with disabilities who did not have their parental rights terminated were still more than twice as likely to have the child welfare system involved in their parenting than were their non-disabled peers.[[33]](#endnote-33)

Nationally, according to the 2012 National Council on Disability report:

* Researchers have found that parents with **psychosocial (mental health-related) disabilities** in the U.S., who face child removal rates of 70-80 percent, are overrepresented in the child welfare system because of the stereotype that they are dangerous.[[34]](#endnote-34) Indeed, several states still have “psychiatric disability” as a ground for termination of parental rights, while individuals who use state services (such as state-provided mental health services) are also under higher scrutiny in the child welfare system than are others.[[35]](#endnote-35)
* Parents with **intellectual disabilities**, who face a child removal rate of 40 to 80 percent, encounter negative expectations about their parenting, including “that children will eventually be maltreated and that parenting deficiencies are irremediable.”[[36]](#endnote-36) This leads to removal even when there is not any evidence of neglect or abuse.[[37]](#endnote-37) Parents with intellectual disabilities are also more likely to have frequent contact with service providers or government officials, who are also more likely to report them to the child welfare system and whose allegations may be taken more seriously within that system than reports from others, such as neighbors, teachers, or other family members.[[38]](#endnote-38)
* Parents with **physical disabilities** face a child removal rate of 13 percent, while parents who are **Deaf or blind** face overall removal rates that are also higher than the average for all persons.[[39]](#endnote-39)
* **Poverty and race** are exacerbating factors for the parental rights of persons with disabilities. Persons with disabilities between the ages of 25 and retirement age are more than twice as likely to live in poverty than are their nondisabled peers,[[40]](#endnote-40) and poverty is the most consistent factor in cases where a parent is deemed unfit or in families where child neglect is found.[[41]](#endnote-41) Parents with disabilities who also identify as a racial or ethnic minority are at even higher risk of termination of parental rights or other involvement from the child welfare system, due to multiple and intersecting discrimination.[[42]](#endnote-42)

Removal of parental rights particularly impacts the rights of women with disabilities in the U.S. It is most often women with disabilities who come to the attention of the child welfare system, because they remain the primary caretakers of children.[[43]](#endnote-43) Furthermore, women with disabilities in the U.S. are much more likely to stay in bad marriages than are other women, due to the fear that they will lose custody of their children.[[44]](#endnote-44)

They are also more likely to be denied access to assistive reproductive technologies (ARTs) because of discrimination and bias about disability that lead providers to believe that the welfare of a future child would be at risk, as well as financial barriers women with disabilities face in paying for ART.[[45]](#endnote-45) Many providers may also deny persons with disabilities access to ART due to “gestational concerns”—that the person’s disability presents a threat to a future child during gestation—even when there is no evidence to support these concerns.[[46]](#endnote-46) As many persons with disabilities, like other persons, may require access to ARTs in order to have children, these provider biases pose another barrier to women and nonbinary persons with disabilities asserting their right to parent and found a family.

National law prohibits discrimination against persons with disabilities concerning the right to parent. Indeed, Title II of the ADA prohibits state and local government entities from discriminating against persons with disabilities,[[47]](#endnote-47) which include child welfare and child protective services. Title III of the ADA prohibits services and public accommodations—including doctor’s offices—from discrimination against persons with disabilities and also requires that they provide reasonable accommodations and make reasonable modifications to policies, practices, and procedures when these are necessary for ensuring access for persons with disabilities.[[48]](#endnote-48) Despite this national legal mandate, discriminatory laws and practices such as those described above persist regarding at the state level regarding the parental rights of persons with disabilities.

For example, recently in New York, a young woman with an intellectual disability had her newborn child removed from her custody by the Administration for Children’s Services (ACS) before she was discharged from the hospital. The child was removed on the basis that the woman had neglected the newborn by failing to attend parenting and treatment programs she had previously been assigned. However, ACS had failed to provide the mother with the reasonable accommodations she needed to attend these classes and further failed to accommodate her during the conference to determine the removal of her newborn, despite knowing the mother had an intellectual disability and required documented reasonable accommodations. This case was recently decided by the New York Court of Appeals, which noted that ACS has an obligation to ensure reasonable accommodations in cases like these under the ADA.[[49]](#endnote-49)

*Questions for U.S. List of Issues*

* What steps is the U.S. taking to ensure that the ADA is applied to ensure that the parental rights of persons with disabilities are maintained on an equal basis with others, and that disability itself is not a factor in the removal of children from parents or the involvement of the child welfare system in parenting?
* What is the U.S. doing to raise awareness among actors in child welfare systems about the parental rights of persons with disabilities and about biases and stereotypes that are often applied to limit those rights?
* What steps is the U.S. taking to ensure that Title III of the ADA is applied to ensure non-discrimination against and reasonable accommodations for persons with disabilities in accessing assistive reproductive health technologies?
* What steps is the U.S. taking to ensure that parents with disabilities benefit from adequate support services in fulfilling their parental role?

1. ***Gender-Based Violence:* Women, girls, and nonbinary persons with disabilities face a higher risk of gender-based violence than do others, in violation of Articles 3, 6, 7, and 26 of the ICCPR.**

Women and girls with disabilities are two to three times more likely to experience gender-based violence than are non-disabled women, and they are more likely to experience abuse over a longer period of time, and often suffer more severe injuries as a result of the violence.[[50]](#endnote-50) Multiple and intersecting forms of discrimination contribute to and exacerbate this violence, and women and girls with disabilities who are also people of color or members of minority or indigenous peoples or religious groups, who are lesbian, transgender, nonbinary, or intersex, who are older, or who live in poverty can be subject to particularized forms of violence and discrimination.[[51]](#endnote-51)

Women with disabilities are more likely to experience domestic violence and other forms of gender-based and sexual violence than are non-disabled women, are likely to experience abuse over a longer period of time, and often suffer more severe injuries as a result of the violence. Their abuser may also be their caregiver, someone that the individual is reliant on for personal care or mobility. Women with disabilities frequently do not report the violence and are not always privy to the same information available to non-disabled women, particularly where such information is not available in alternative formats.

U.S. national studies indicate that “almost 80% of people with disabilities are sexually assaulted on more than one occasion and 50% of those experienced more than 10 victimizations.”[[52]](#endnote-52) As many as 83 percent of female adults with developmental disabilities are victims of sexual assault,[[53]](#endnote-53) and women with disabilities living in institutions and nursing homes are particularly at risk.[[54]](#endnote-54) Women with disabilities living in institutions and nursing homes report a “33% prevalence” of experiencing interpersonal violence, compared to 21 percent of women without disabilities in such institutions.[[55]](#endnote-55) Additionally, Deaf persons report facing significant accessibility issues when trying to call emergency lines to report crimes or medical emergencies, due to outdated technology for accessing these services, a situation that can delay responses to interpersonal violence and put a Deaf person’s life and health at further risk.[[56]](#endnote-56)

Furthermore, sexual and domestic violence shelters are still often inaccessible, and a study of shelters and gender-based violence programs in the U.S. found that only 16 percent of programs in the study had a staff member specifically assigned for services to women with disabilities and less than 5 percent of these staff members were nurses, sign language interpreters, substance abuse specialists, or legal specialists trained to work with women with disabilities.[[57]](#endnote-57) A 2017 study of social services in the U.S. for transgender and gender non-conforming persons with disabilities also found that these individuals were more likely to experience anti-transgender discrimination when accessing domestic violence shelters and rape crisis centers.[[58]](#endnote-58)

Girls with disabilities experience sexual harassment and sexual abuse in schools at an unacceptably high rate.[[59]](#endnote-59) A 2018 report from the National Council on Disability found that one in three undergraduates with disabilities was a victim of sexual violence on campus.[[60]](#endnote-60) Furthermore, over twice as many deaf female undergraduates experienced an incident of sexual coercion from their partner compared to hearing female undergraduates (61 percent compared to 28 percent).[[61]](#endnote-61) The 2018 National Council on Disability report also found studies on campus sexual assault funded and conducted by the federal government have not included disability, that campus assault education and prevention programs, as well as information on these issues, are not inclusive of students with disabilities, and that campus staff handling sexual assault claims are not trained to provide disability accommodations.[[62]](#endnote-62) Additionally, disabled girls often are also subjected to bullying and teasing by peers in school based on disability and gender, and such bullying can negatively impact a girl’s emotional and cognitive development and can also cause low self-esteem.[[63]](#endnote-63) This harassment and abuse is compounded by lack of sexual education afforded to girls with disabilities.[[64]](#endnote-64)

Furthermore, a recent high-profile case illustrates that women with disabilities in the U.S. are also still subjected to sexual violence in long-term residential care institutions. In December 2018, in an Arizona long-term care facility for people with disabilities, a Native American woman in a vegetative state gave birth to a child after being sexually assaulted in the facility.[[65]](#endnote-65) None of the caretakers at the facility claimed to know that she was pregnant prior to her giving birth.[[66]](#endnote-66) The facility had previously come to the attention of the state for fraudulent billing, but individuals were not removed from its care at that time.[[67]](#endnote-67) At the time of writing, the case was still being investigated.[[68]](#endnote-68)

U.S. laws and programs attempt to address gender-based violence in several ways. Through the federal Violence Against Women Act of 2013 (VAWA),[[69]](#endnote-69) the U.S. Department of Justice’s Office on Violence Against Women (OVAW) funds a limited number of programs including programs specifically designed to address violence and abuse of women with disabilities.[[70]](#endnote-70) (Note, however, that VAWA expired in December 2018, and at the time of writing, it was unclear if and when it would be reauthorized.[[71]](#endnote-71)) Furthermore, the ADA, as amended in 2008, prohibits domestic and sexual violence shelters and programs from discriminating based on disability in the full and equal enjoyment of goods, services, facilities, privileges, advantages or accommodations.[[72]](#endnote-72)

The implementation of these laws falls short of protecting women, girls, and nonbinary persons with disabilities. For instance, very few programs actually receive funding from OVAW for women with disabilities-based programming, especially since funding was reduced from $10 million to $9 million in the VAWA 2013 reauthorization. In fiscal year 2016, there were only nine disability grant recipients in six out of fifty states and the total amount allocated through the Disability Grant Program was an inadequate 0.8 percent of the total allocated by OVAW.[[73]](#endnote-73)

*Questions for U.S. List of Issues*

* What steps is the U.S. taking to ensure that girls and young persons with disabilities have the information they need to protect themselves from gender-based violence, inside and outside of school, including through comprehensive sexuality education? What steps is the U.S. taking to collect disaggregated data that includes disability on the issue of campus sexual assault?
* What steps is the U.S. taking to ensure the enforcement of the ADA in ensuring that shelters and services for victims of violence are accessible to persons with disabilities?
* What steps is the U.S. taking to ensure the reauthorization of the Violence Against Women Act and to expand the Office on Violence against Women’s Disability Grant Program to ensure that shelters and gender-based violence services are accessible to and tailored towards persons with disabilities, including transgender and gender non-conforming persons with disabilities?
* What steps is the U.S. taking to monitor long-term residential care institutions to ensure freedom from gender-based violence and to comprehensively investigate allegations of violence in those institutions?

1. ***Abuses in Prisons:* The disproportionate rate of incarceration of women and nonbinary persons with disabilities in U.S. jails and prisons, gender-based violence in prisons, the use of solitary confinement, and the lack of access to needed services in prisons raise concerns under Articles 3, 7, 9, and 26 of the ICCPR.**

Although the deinstitutionalization movement in the U.S. was a largely positive development for persons with disabilities, it was not accompanied by the development of adequate community-based social services for this group. As a result, persons with disabilities now face incarceration in prisons in jails at higher rates than others. Indeed, jails actually house more persons with psychosocial disabilities than all of the country’s psychiatric hospitals combined.[[74]](#endnote-74) Furthermore, the percentage of women with disabilities who are incarcerated in the U.S. is very high compared to men with disabilities. According to the U.S. Bureau of Justice Statistics, 40 percent of women prisoners reported having a disability compared to 31 percent of men.[[75]](#endnote-75) The number in jails is even higher, as nearly half (49 percent) of the women have disabilities as compared to 39 percent of male inmates.[[76]](#endnote-76) (Note that jails are usually run by local authorities and are meant for short-term incarceration while an individual is awaiting trial or serving a short sentence, while prisons are usually run by states or the federal government and are designed for longer-term incarceration.)

Women and persons with disabilities in U.S. prisons and jails are at higher risk of sexual assault. For instance, estimates indicate that at least 13 percent of inmates have been sexually assaulted, and many have experienced repeated assaults.[[77]](#endnote-77) Prisoners with physical disabilities may be actively targeted based on their disabilities or suffer the effects of having their disability-related needs neglected.[[78]](#endnote-78) The psychological trauma of rape that occurs in prison is compounded because the victim has very limited options to escape the perpetrator and does not have access to adequate mental health services.[[79]](#endnote-79) Furthermore, most prison staff are not adequately trained to prevent or respond to inmate sexual assaults, and prison rape often goes unreported and untreated.[[80]](#endnote-80) Moreover, assaults are often perpetrated by prison staff.[[81]](#endnote-81) The lack of required data collection limits the ability of the U.S. government to address the high incidence of rape and sexual assault of women and persons with disabilities in prisons. The Prison Rape Elimination Act of 2003 (PREA) recognizes that inmates with psychosocial and other disabilities are at “increased risk of sexual victimization.”[[82]](#endnote-82) However, the Department of Justice has failed to document or collect data on violence against female prisoners with disabilities, as required by PREA.[[83]](#endnote-83)

Furthermore, both gender and disability pose risk factors related to solitary confinement or segregation in U.S. prisons and jails. For instance, a 2016 report by Amplifying Voices of Inmates with Disabilities Prison Project (AVID) documented that persons with psychosocial disabilities in the U.S. are disproportionately placed in segregation or solitary confinement due to symptoms of or behaviors related to those disabilities.[[84]](#endnote-84) A report by Disability Rights New York also found that persons with intellectual disabilities in New York prisons were still being placed in solitary confinement, despite being part of a program that identified them as persons with intellectual disabilities and was intended to prevent this form of punishment.[[85]](#endnote-85) Solitary confinement can then cause or deepen mental health crises. Indeed, solitary confinement for periods of longer than 10 days has been found to exacerbate the symptoms of psychosocial disabilities, including elevated levels of depression and anxiety, the onset of hallucinations and paranoia, and higher risks of suicide or other self-harm.[[86]](#endnote-86) Concerning women with disabilities in particular, a 2014 report from the American Civil Liberties Union (ACLU) found that women in U.S. prisons, who are frequently women with psychosocial disabilities, were placed in solitary confinement for retaliatory purposes (for instance, when a woman reported abuse by prison guards) or for behaviors related to their disability, a situation which exacerbated disabilities, increased risk of sexual abuse by prison officials, and re-traumatized women who were victims of past abuse.[[87]](#endnote-87) The report concluded that, due to these concerns, persons with psychosocial disabilities should never be held in solitary confinement.[[88]](#endnote-88)

There are also shortcomings in access to services, including mental health services, for persons with disabilities in prisons and jails, particularly women. The 2016 AVID report found that inmates with disabilities who were placed in segregation were often placed in the most restrictive types of housing, where mental health treatment and other needed services were less available than to the general prison population.[[89]](#endnote-89) AVID further found that women’s prisons offered many fewer mental health services as compared to men’s prisons in some states[[90]](#endnote-90) and documented that persons with disabilities generally faced significant accessibility barriers to accessing medications, assistive devices, services including medical services, and facilities in prisons.[[91]](#endnote-91)

*Questions for U.S. List of Issues*

* What steps has the U.S. taken in recent years to ensure access to services and mental health treatment in the community, to prevent higher rates of incarceration for persons with disabilities, particularly women with disabilities?
* What steps is the U.S. taking to collect data on violence in federal, state, and local prisons and jails that is disaggregated by disability, gender, and gender identity?
* What steps is the U.S. taking on a federal level to end the use of solitary confinement on persons with disabilities, particularly persons with psychosocial disabilities, and to ensure that states also end this practice in jails and prisons?
* What steps is the U.S. taking to expand access to needed services for persons with disabilities in prisons, including mental health services, and to address the disparity in these services between women’s and men’s prisons?

1. ***Conclusions***

As outlined above, women, girls, and nonbinary persons with disabilities face severe violations of their civil and political rights in the U.S., frequently as a result of discrimination against them based on gender, gender identity, and disability, among other statuses. We hope these issues will be addressed in the LOIPR the Human Rights Committee is preparing on the U.S., which will be used to guide the upcoming review of its record under the ICCPR.

Our organizations thank you for your time in reviewing this submission. If you should have any questions or require further information, please do not hesitate to contact us: Stephanie Ortoleva, WEI President and Executive Director, at [president@womenenabled.org](mailto:president@womenenabled.org), and Amanda McRae, WEI Director of U.N. Advocacy, at [a.mcrae@womenenabled.org](mailto:a.mcrae@womenenabled.org).

1. This calculation is based on an estimate from the Centers for Disease Control that there are 27 million women with disabilities in the U.S., as well as the total population of women in the U.S. provided by the U.S. census bureau (approximately 165 million). *See* United States Census Bureau, *Quickfacts*, <https://www.census.gov/quickfacts/fact/table/US/LFE046217>; Centers for Disease and Control and Prevention, *Women with Disabilities* (2018), https://www.cdc.gov/ncbddd/disabilityandhealth/women.html. [↑](#endnote-ref-1)
2. Studies estimate that there are approximately 245,000 to 350,000 non-binary adults in the U.S., and approximately 15 percent of those adults are likely persons with disabilities. *See, e.g.*, “States are starting to recognize a third gender: Non-binary,” USA Today, June 21, 2017 https://www.usatoday.com/story/news/2017/06/21/third-gender-option-non-binary/359260001/. [↑](#endnote-ref-2)
3. *See, e.g.*, Human Rights Committee, *Concluding Observations: United States of America*, ¶ 4, U.N. Doc. CCPR/C/USA/CO/4 (2014). [↑](#endnote-ref-3)
4. J. P. Wisdom, M. G. McGee, et al, “Health Disparities Between Women With and Without Disabilities: A Review of the Research,” National Center for Biotechnology Information, U.S. National Library of Medicine, National Institutes of Health (2003), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3546827/. [↑](#endnote-ref-4)
5. *Id.* [↑](#endnote-ref-5)
6. Center for Research on Women with Disabilities, *Medical Professionals Knowledge*, https://www.bcm.edu/research/centers/research-on-women-with-disabilities/topics/health-care/medical-professionals-knowledge. [↑](#endnote-ref-6)
7. Payal Shah, et. al, *Gynecological Care for Adolescents with Disability: Physician Comfort, Perceived Barriers, and Potential Solutions*, in 18 J. of Pediatric and Adolescent Gynecology 101, 102 (2005). [↑](#endnote-ref-7)
8. Center for Research on Women with Disabilities, *Access to Reproductive Health Care*,https://www.bcm.edu/research/centers/research-on-women-with-disabilities/topics/health-care/reproductive-health-care. [↑](#endnote-ref-8)
9. “More Than One-Third of LGBTQ Adults Identify as Having a Disability.” RespectAbility, June 29, 2018, https://www.prnewswire.com/news-releases/more-than-one-third-of-lgbtq-adults-identify-as-having-a-disability-300674869.html. [↑](#endnote-ref-9)
10. S.K. Kattari, N.E. Well, & S.R. Speer, *Differences in Experiences of Discrimination in Accessing Social Services Among Transgender/Gender Nonconforming Individuals by (Dis)Ability*, 16(2) J. Soc. Work. Disabil. Rehabil. 116 (April 2017), https://www.ncbi.nlm.nih.gov/pubmed/28447917 [hereinafter S.K. Kattari, et al, *Differences in Experiences*]. [↑](#endnote-ref-10)
11. Erin Billups, *Women with Disabilities Have Trouble Receiving Gynecology Services in City*, N.Y. Times, Apr.15, 2014, <http://www.ny1.com/content/lifestyles/health_and_medicine/207001/women-with-disabilities-have-trouble-receiving-gynecology-services-in-city>. [↑](#endnote-ref-11)
12. Nancy Mele et al., *Access to Breast Cancer Screening Services for Women with Disabilities*, 34 J. of Obstetric, Gynecologic, & Neonatal Nursing 453-64 (July 2005). [↑](#endnote-ref-12)
13. The National Center for Health Statistics found that as of 2005, 65-71 percent of women with disabilities have had a Pap Smear test compared to 83% of women without disabilities. *See also* Elizabeth Pendo, *Reducing Disparities through Health Care Reform: Disability and Accessible Medical Equipment*, 4 Utah L. Rev. 1057, 1065 (2010); Drew Rivera et al., *Disability and Pap Smear Receipt among U.S. Women, 2000 and 2005*, 42 Persp. on Sexual and Reprod. Health, 258-66 (2010). [↑](#endnote-ref-13)
14. National Council on Disability, *The Current State of Health Care for People with Disabilities* (Sept. 2009),https://www.ncd.gov/publications/2009/Sept302009#. [↑](#endnote-ref-14)
15. For more information about these restrictions, *see* American Civil Liberties Union, *Access Denied: Origins of the Hyde Amendment and other Restrictions on Public Funding for Abortion*, https://www.aclu.org/other/access-denied-origins-hyde-amendment-and-other-restrictions-public-funding-abortion*.* [↑](#endnote-ref-15)
16. Americans with Disabilities Act (ADA) of 1990, 42 U.S.C. § 12181 et seq. (2008). [↑](#endnote-ref-16)
17. U.S. Dep’t of Health and Hum. Serv., *Section 1157 of the Patient Protection and Affordable Care Act*; *see also* U.S. Dep’t of Health and Hum. Serv., *Affordable Care Act Expands Prevention Coverage for Women’s Health and Well Being*. [↑](#endnote-ref-17)
18. *See* U.S. Access Board, *Advancing Equal Access to Diagnostic Services: Recommendations on Standards for the Design of Medical Diagnostic Equipment for Adults with Disabilities* (Dec. 6, 2013), http://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking/advisory-committee-final-report/5-recommendations. [↑](#endnote-ref-18)
19. U.S. Access Board, *About the Rulemaking on Medical Diagnostic Equipment*, https://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking; U.S. Dep’t of Justice & U.S. Dep’t of Health and Human Services, *Access To Medical Care For Individuals With Mobility Disabilities* (2010), https://www.ada.gov/medcare\_mobility\_ta/medcare\_ta.htm. [↑](#endnote-ref-19)
20. Julia A. Rivera Drew*, Hysterectomy and Disability Among U.S. Women*, 45 Persp. On Sexual and Reprod. Health 157, 161 (2013); Elizabeth Pendo, *Disability, Equipment Barriers, and Women’s Health: Using the ADA to Provide Meaningful Access*, 2 SLU J. of Health Law & Policy 44-45 (2008), http://ssrn.com/abstract=1435543. [↑](#endnote-ref-20)
21. *See* Anne Finger, *Forbidden Fruit*, 233 The New Internationalist (July 1992),

    http://www.newint.org/issue233/fruit.htm; *see also* Carolyn Frohmader, *Moving Forward and Gaining Ground: The Sterilisation of Women and Girls with Disabilities in Australia*, Women With Disabilities Australia 6-7 (2012),

    http://wwda.org.au/wp-content/uploads/2013/12/Moving\_Forward\_Gaining\_Ground.pdf. [↑](#endnote-ref-21)
22. Jesse Krohn, *Sexual Harassment, Sexual Assault, and Students with Special Needs: Crafting an Effective Response for Schools*, 17 U. Pa. J. L. & Soc. Change 29, 42 (2014), http://scholarship.law.upenn.edu/cgi/viewcontent.cgi?article=1163&context=jlasc [hereinafter *Sexual Harassment, Sexual Assault, and Students with Special Needs*]. [↑](#endnote-ref-22)
23. Lambda Legal, “Changing Birth Certificate Sex Designation: State-by-State Guidelines” (Sept. 2018),

    https://www.lambdalegal.org/know-your-rights/article/trans-changing-birth-certificate-sex-designations. [↑](#endnote-ref-23)
24. Arkansas (Ark Code Ann. §20-49-101 (2010)); Colorado (Colo. Rev. Stat. §27-10.5-130 (2012)); Delaware (Del. Code Ann. 16 §5712 (2013)); Georgia (Ga. Code Ann. §31-20-3 (2010)); Maine (Me. Rev. Stat. 34-B §7010 (2011)); North Carolina (N.C. Gen. Stat. §35A-1245 (2010)); Oregon (Or. Rev. Stat. §436.205 (2011)); Utah (Utah Code Ann. §62A-6-102 (2011)); Vermont (Vt. Stat. Ann. 18 §8705 et seq. (2009)); Virginia (Va. Code Ann. §54.1-2975 et seq. (1988)); West Virginia (W. Va. Code R. §27-16-1 et seq. (2013)). [↑](#endnote-ref-24)
25. Americans with Disabilities Act of 1990, 42 U.S.C., §§12101-12213 (2000). [↑](#endnote-ref-25)
26. Courts granting nonconsensual sterilization of females with disabilities are the following: Conservatorship of Person and Estate of Maria B., 160 Cal. Rptr. 3d 269 (Cal. Ct. App. 2013); Matter of A.W., 637 P.2d 366 (Colo. 1981); Estate of C.W., 640 A.2d 427 (Pa. Super. 1994); Matter of Mildred J. Terwilliger, 304 A.2d 1376 (Pa. Super. 1982). Courts denying nonconsensual sterilization of females with disabilities are the following: Conservatorship of Valerie N., 40 Cal. 3d 143 (Cal. 1985); Matter of Romero, 790 P.2d 819 (Colo. 1990); Wentzel v. Montgomery General Hosp., 447 A.2d 1244 (Md. 1982); Matter of Truesdell, 329 S.E.2d 630, 636 (N.C. 1985). [↑](#endnote-ref-26)
27. CRPD Committee, *General Comment No. 3: Article 6: Women and Girls with Disabilities*, U.N. Doc. CRPD/C/GC/3, ¶ 46 (2016). [↑](#endnote-ref-27)
28. Nat’l Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children* 94 (Sept. 27, 2012) [hereinafter NCD, *Rocking the Cradle*]. [↑](#endnote-ref-28)
29. *Id.* at Appendix B. [↑](#endnote-ref-29)
30. *Id.* at 72. [↑](#endnote-ref-30)
31. *Id.* at 156. [↑](#endnote-ref-31)
32. *Id.* at 18. [↑](#endnote-ref-32)
33. S. Singh, et al., “Parental Disability and Termination of Parental Rights in Child Welfare,” Minn-LInK Brief No. 12 (2012), https://www.lcc.leg.mn/tfcp/meetings/02252016/Brief\_12\_ParentalDisability&TPR.pdf. [↑](#endnote-ref-33)
34. NCD, *Rocking the Cradle*, *supra* note 28, at 79. [↑](#endnote-ref-34)
35. *Id.* [↑](#endnote-ref-35)
36. *Id.* at 80. [↑](#endnote-ref-36)
37. *Id.* [↑](#endnote-ref-37)
38. *Id.* [↑](#endnote-ref-38)
39. *Id.* at 77. [↑](#endnote-ref-39)
40. Center for Poverty Research, Univ. of California at Davis, “How is poverty status related to disability?” (2014), https://poverty.ucdavis.edu/faq/how-poverty-status-related-disability. [↑](#endnote-ref-40)
41. NCD, *Rocking the Cradle*, *supra* note 28, at 95. [↑](#endnote-ref-41)
42. *Id.* at 78-79. [↑](#endnote-ref-42)
43. *Id.* at 94. [↑](#endnote-ref-43)
44. Margaret A Nosek, et al., *Vulnerabilities for Abuse Among Women with Disabilities*, 19 Sexuality and Disability 177, 177-189 (2001). [↑](#endnote-ref-44)
45. NCD, *Rocking the Cradle*, *supra* note 28, at 209-222. [↑](#endnote-ref-45)
46. *Id.* [↑](#endnote-ref-46)
47. Americans with Disabilities Act of 1990 (ADA), 42 U.S.C., §§12101-12213 (2000). [↑](#endnote-ref-47)
48. *Id.*, §§36101-36607. [↑](#endnote-ref-48)
49. *Lacee L*., 2018 N.Y. 06966 (slip op.) [↑](#endnote-ref-49)
50. U.N. General Assembly, *Report of the Special Rapporteur on violence against women, its causes and consequences*, **¶** 31, U.N. Doc. A/67/227 (2012), http://www.ohchr.org/Documents/Issues/Women/A.67.227.pdf. [↑](#endnote-ref-50)
51. Stephanie Ortoleva & Hope Lewis, *Forgotten Sisters - A Report on Violence Against Women with Disabilities: An Overview of its Nature, Scope, Causes and Consequences*, Northeastern University School of Law, Research Paper No. 104-2012 (Aug. 21, 2012), *available at* http://ssrn.com/abstract=2133332. [↑](#endnote-ref-51)
52. *Sexual Violence Against Individuals with Disabilities*, Maine Coalition Against Sexual Assault,http://www.mecasa.org/index.php/special-projects/individuals-with-disabilities. [↑](#endnote-ref-52)
53. *Id.* [↑](#endnote-ref-53)
54. Margaret Nosek, et al., *Vulnerabilities for Abuse Among Women with Disabilities*, 19 Sexuality & Disability 177 (2001). [↑](#endnote-ref-54)
55. K.A. Barrett, et al., *Intimate Partner Violence, Health Status, and Health Care Access Among Women with Disabilities*, 19 Women’s Health Issues 94 (2009). [↑](#endnote-ref-55)
56. Ashley DeJean, “911 Is Practically Useless for Millions of People. Here’s Why,” Mother Jones, Mar. 16, 2017, https://www.motherjones.com/politics/2017/03/text-911-deaf-accessibility-ada-lawsuits-1/. [↑](#endnote-ref-56)
57. Baylor College of Medicine. *Domestic Violence Programs*. Information based on excerpts from M.A. Nosek, C.A. Howland, and M.E. Young, “Abuse of Women with Disabilities: Policy Implications,” https://www.bcm.edu/research/centers/research-on-women-with-disabilities/topics/violence/access-to-domestic-violence-programs. [↑](#endnote-ref-57)
58. S.K. Kattari, et al, *Differences in Experiences*, *supra* note 10. [↑](#endnote-ref-58)
59. *Sexual Harassment, Sexual Assault, and Students with Special Needs*, *supra* note 22. [↑](#endnote-ref-59)
60. National Council on Disability, *Not on the Radar: Sexual Assault of College Students with Disabilities* 10 (Jan. 2018), https://ncd.gov/sites/default/files/NCD\_Not\_on\_the\_Radar\_Accessible.pdf. [↑](#endnote-ref-60)
61. Melissa Anderson et al., *Interpersonal Violence Against Deaf Women*, 16 Aggression & Violent Behavior 200, 203 (2011). [↑](#endnote-ref-61)
62. National Council on Disability, *Not on the Radar: Sexual Assault of College Students with Disabilities* 11 (Jan. 2018), https://ncd.gov/sites/default/files/NCD\_Not\_on\_the\_Radar\_Accessible.pdf. [↑](#endnote-ref-62)
63. Jonathan Young et al., *Briefing Paper: Bullying and Students with Disabilities*, Nat’l Council on Disability, (2011) (discussing bullying in the United States); *see also* Laetitia Antonowicz, *Too Often in Silence: A Report on School-Based Violence in West and Central Africa*, UNICEF 35 (Mar. 2010). [↑](#endnote-ref-63)
64. *Sexual Harassment, Sexual Assault, and Students with Special Needs*, *supra* note 22, at 42. [↑](#endnote-ref-64)
65. “Phoenix facility where woman in coma gave birth faced criminal inquiry,” Associated Press, Jan. 13, 2019, https://www.theguardian.com/us-news/2019/jan/13/woman-coma-birth-phoenix-facility-2016-investigation. [↑](#endnote-ref-65)
66. Robyn Powell, “The Rape of an Arizona Woman in a Coma is Not an Isolated Incident,” Rewire, Jan. 10, 2019, https://rewire.news/article/2019/01/10/the-rape-of-arizona-woman-in-coma-is-not-an-isolated-incident/. [↑](#endnote-ref-66)
67. “Phoenix facility where woman in coma gave birth faced criminal inquiry,” Associated Press, Jan. 13, 2019, https://www.theguardian.com/us-news/2019/jan/13/woman-coma-birth-phoenix-facility-2016-investigation. [↑](#endnote-ref-67)
68. *Id.* [↑](#endnote-ref-68)
69. Violence Against Women Reauthorization Act of 2013, Pub. L. No. 113:4, Overview (Mar. 7, 2013). [↑](#endnote-ref-69)
70. U.S. Dep’t of Justice, *Education, Training and Enhanced Services to End Violence Against and Abuse of Women with Disabilities*, Grant Programs, Office of Violence Against Women. [↑](#endnote-ref-70)
71. Jenny Gathright, “Violence Against Women Act Expires Because of Government Shutdown,” National Public Radio, December 24, 2018, https://www.npr.org/2018/12/24/679838115/violence-against-women-act-expires-because-of-government-shutdown. [↑](#endnote-ref-71)
72. Americans with Disabilities Act (ADA) of 1990, 42 U.S.C. § 12181 et seq. (2008). [↑](#endnote-ref-72)
73. U.S. Dep’t of Justice, *FY 2016 OVW Grant Awards By Program*, Awards, Grant Programs, Office of Violence Against Women (OVW) (reporting that the nine states that received funds were: CA, MA, MI, MN, NY, OH, and WA with MA and MN receiving two grants). OVW disability-related grants totaled $3,775,000, a mere 0.8% of the overall total allocated by OVW Grant Program of $452,886,693. [↑](#endnote-ref-73)
74. Prison Rape Elimination Act of 2003, Pub. L. No, 108-79, 117 Stat. 972, 42 U.S.C. §§ 15601-609 (Sept. 4, 2003). [↑](#endnote-ref-74)
75. U.S. Department of Justice Bureau of Justice Statistics, *Disabilities Among Prison and Jail Inmates*, 2011–12, 2015, Figure 1, (Dec 2015), *available at* <https://www.bjs.gov/content/pub/pdf/dpji1112.pdf>. [↑](#endnote-ref-75)
76. *Id.* [↑](#endnote-ref-76)
77. Prison Rape Elimination Act of 2003, Pub. L. No, 108-79, 117 Stat. 972, 42 U.S.C. §§ 15601-609 (Sept. 4, 2003). [↑](#endnote-ref-77)
78. UNODC, *Handbook for Prison Managers and Policymakers on Women and Imprisonment* (2009). [↑](#endnote-ref-78)
79. *Id.* at 288. [↑](#endnote-ref-79)
80. Prison Rape Elimination Act of 2003, Pub. L. No, 108-79, 117 Stat. 972, 42 U.S.C. §§ 15601-609 (Sept. 4, 2003). [↑](#endnote-ref-80)
81. Joaquin Sapien, “Guards May Be Responsible for Half of Prison Sexual Assaults,” ProPublica, Jan. 23, 2014, https://www.propublica.org/article/guards-may-be-responsible-for-half-of-prison-sexual-assaults. [↑](#endnote-ref-81)
82. Prison Rape Elimination Act of 2003, Pub. L. No, 108-79, 117 Stat. 972, 42 U.S.C. §§ 15601-609 (Sept. 4, 2003). [↑](#endnote-ref-82)
83. Joye Whatley, *Violence Against Women with Disabilities: Policy Implications of What We Don’t Know*, 13 Impact 3 (2000), *available at* http://ici.umn.edu/products/impact/133/over3.html. [↑](#endnote-ref-83)
84. AVID Prison Project, *Locked Up and Locked Down: Segregation of Inmates with Mental Illness* 5-7 (Sept. 2016), http://avidprisonproject.org/ [hereinafter AVID, *Locked Up and Locked Down*]. [↑](#endnote-ref-84)
85. Disability Rights New York, *Report and Recommendations on the Treatment of Individuals with Intellectual, Developmental, and Mental Health Disabilities at Sullivan Correctional Facility* 15-16 (2016), http://www.new.drny.org/docs/2016\_07\_28\_CAR\_Report\_and\_Addenda\_MERGED.pdf. [↑](#endnote-ref-85)
86. American Civil Liberties Union, *Worse than Second-Class: Solitary Confinement of Women in the United States* 5 (Apr. 2014), https://www.aclu.org/report/worse-second-class-solitary-confinement-women-united-states, [↑](#endnote-ref-86)
87. *Id.* at 5-9. [↑](#endnote-ref-87)
88. *Id.* at 10. [↑](#endnote-ref-88)
89. AVID, *Locked Up and Locked Down*, *supra* note 84, at 15. [↑](#endnote-ref-89)
90. *Id.* at 30-31. [↑](#endnote-ref-90)
91. Rebecca Vallas, “Nearly Half of All Women in Jail are Disabled,” The Nation, July 19, 2016, https://www.thenation.com/article/nearly-half-of-all-women-in-jail-are-disabled/. [↑](#endnote-ref-91)