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The Lurie Institute  
*for* Disability Policy

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**Joint Submission to the United Nations Universal Periodic Review:  
United States of America  
Third Cycle**

Women Enabled International (WEI) and The Lurie Institute for Disability Policy at Brandeis University jointly submit this report for consideration during the third Universal Periodic Review of the United States of America (U.S.).

This submission is endorsed by the U.S. International Council on Disability.

**Women Enabled International (WEI)** is an organization based in the U.S. WEI works to advance human rights at the intersection of gender and disability to respond to the lived experiences of women and girls with disabilities; promote inclusion and participation; and achieve transformative equality. WEI identifies and addresses the violations, abuses, and inequalities women and girls with disabilities experience, amplifies their voices, and jointly advocates for change. We closely collaborate with women with a wide range of physical, sensory, intellectual, and psycho-social disabilities for movement and cross-movement building. WEI was established in 2012.

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**The Lurie Institute for Disability Policy at Brandeis University's Heller School** leads research that helps shape policies, programs and practices which improve the lives of people with disabilities across the lifespan. We partner with people with disabilities, community organizations, policymakers, and clinicians to generate research that addresses the critical issues that people with disabilities and their families face. This research incorporates qualitative and quantitative projects that are informed by the disability community and grounded in disability justice. It was established in 2007 at Brandeis University's Heller School for Social Policy and Management.

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**I. Introduction**

1. Globally, women and girls with disabilities<sup>1</sup> face discrimination and human rights abuses based on both their gender and disability. Despite the United States' (U.S.'s) international commitments to ensure the realization of the human rights of all persons, women and girls with disabilities face various barriers to their full exercise of fundamental 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 and services; forced reproductive health interventions including forced sterilizations; high rates of gender-based violence and substantial barriers to accessing social supports and services following violence; and violations of their right to parent and found and sustain a family.
2. During the U.S.'s previous Universal Periodic Reviews (UPRs) in 2015 and 2011, it did not receive any recommendations that specifically addressed the human rights abuses faced by women with disabilities.<sup>2</sup> However, during both reviews, states urged the U.S. to ratify the Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW).<sup>3</sup> The U.S. has not taken steps towards the ratification of either treaty since its last periodic review.
3. In addition, during its last UPR review, the U.S. accepted a number of recommendations related to ensuring equal access to health care,<sup>4</sup> including one to “[e]nsure equal access to equality maternal health and related services as an integral part of the realization of women’s rights,”<sup>5</sup> as well as a recommendation to “promote actions to eradicate sexual and domestic violence.”<sup>6</sup>
4. As this submission documents, the U.S. has not yet done enough to ensure that women with disabilities are free from violence and to guarantee their sexual and reproductive rights and their right to parent and found a family. This submission provides a brief overview of some of the violations women, girls, and nonbinary persons with disabilities face in the context of sexual and reproductive health, gender-based violence and parenting. This submission also provides suggestions for questions and recommendations to direct towards the U.S. during its third UPR.

## II. Background

5. Approximately 15% of people worldwide are persons with disabilities, and women with disabilities account for 19.2% of the total population of women around the world.<sup>7</sup> Women and girls with disabilities account for roughly 16% of all women in the U.S.,<sup>8</sup> 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.<sup>9</sup>

### *International Obligations*

6. The U.S. has ratified the International Covenant on Civil and Political Rights (ICCPR), the Convention Against Torture (CAT) and the International Convention on the Elimination of All Forms of Racial Discrimination (CERD). These legally binding commitments require the U.S. to ensure the rights of women with disabilities to equality and non-discrimination, including in the realm of parental rights and sexual and reproductive rights, and to address gender-based violence.
7. The U.S. has signed but not ratified the Convention on the Rights of Persons with Disabilities (CRPD), the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) and the International Covenant on Economic, Social and Cultural Rights (ICESCR).

### *United States Legal Framework related to Women with Disabilities*

8. 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. However, as the Human Rights Committee and CAT Committee have affirmed, this federal system does not limit the U.S.'s obligation to ensure the respect, protection, and fulfillment of human rights throughout its states and territories.<sup>10</sup> This submission focuses primarily on national laws and policies that impact the rights of women, girls, and nonbinary persons with disabilities and, where available, also provides information on state laws and practices.
9. The Americans with Disabilities Act (ADA) and the ADA Amendments Act are federal laws that prohibits discrimination against persons with disabilities in many aspects of their lives.<sup>11</sup> The federal Violence Against Women Act of 2013 (VAWA) was enacted to prevent and address violence against women.<sup>12</sup> Through VAWA, the U.S. Department of Justice's Office on Violence Against Women funds a limited number of programs, including programs specifically designed to address violence against, and abuse of, women with disabilities.<sup>13</sup> However, VAWA expired in December 2018; at the time of writing, it was unclear if and when it would be reauthorized.<sup>14</sup>

### III. Human Rights Abuses against Women with Disabilities in the U.S.

#### *Violations of Sexual and Reproductive Rights*

10. Women with disabilities worldwide face a wide range of unique human rights abuses in sexual and reproductive health care settings, due to both their gender and disability. Women with disabilities are disproportionately subjected to practices such as forced or coerced sterilization, contraception, and abortion.<sup>15</sup> In its General Comment No. 3 on women with disabilities, the CRPD Committee recognized that “[i]n practice, the choices of women with disabilities, especially women with psychosocial or intellectual disabilities are often ignored, [and] their decisions are often substituted by third parties, including legal representatives, service providers, guardians and family members.”<sup>16</sup> When women with disabilities are deprived of legal capacity, this can “facilitate forced interventions, such as: sterilisation, abortion, [and] contraception...”<sup>17</sup> These practices are frequently based on false and discriminatory assumptions about their sexuality and ability to parent or the desire to control their menstrual cycles<sup>18</sup> and are also considered severe human rights violations, including forms of torture or ill-treatment.<sup>19</sup>
11. Having a disability and being in good health are not mutually exclusive.<sup>20</sup> However, in the U.S., there are many challenges that 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,<sup>21</sup> including stereotypes that they are nonsexual, hypersexual, unable to make decisions for themselves, or unable to be good parents.<sup>22</sup>
12. Furthermore, providers are very often not trained to work with persons with disabilities, particularly in the sexual and reproductive health context<sup>23</sup>—one study in the U.S. found that 40–50 percent of gynecologists felt somewhat to completely unprepared to treat adolescents with disabilities<sup>24</sup>—and this lack of education and 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,<sup>25</sup> 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.
13. Compounding the lack of training is the lack of clinical guidelines for providers on the provision of reproductive and pregnancy-related health care for women with various types of disabilities. In general, there is limited clinical information on the interaction of disability and pregnancy<sup>26</sup>—a gap which stems, in part, from the U.S. government’s failure to fund and prioritize disability-specific research on women’s health. The absence of clinical practice guidelines and recommendations on preconception care,<sup>27</sup> prenatal care,<sup>28</sup> care during labor and delivery,<sup>29</sup> postpartum care,<sup>30</sup> and breastfeeding,<sup>31</sup> that are specific to women with intellectual and developmental disabilities,<sup>32</sup> women with physical disabilities,<sup>33</sup> and Deaf and hard of

hearing women,<sup>34</sup> among other disabilities, has significant adverse impacts on the quality of care they receive before, during and after pregnancy,<sup>35</sup> and on their health and pregnancy outcomes. In particular, they are at risk of receiving “inadequate, inappropriate or even damaging advice” from providers, which “can result in difficulty making informed decisions” and limit their decision-making autonomy during pregnancy and delivery.<sup>36</sup> Women with disabilities in the U.S. are at higher risk of adverse health outcomes during pregnancy, delivery and the postpartum period.<sup>37</sup>

14. Inaccessible gynecological and obstetric services and information present additional barriers for women with disabilities in the U.S. Studies of pregnant women with disabilities have consistently documented a lack of accessible health-care settings<sup>38</sup> and adaptive equipment<sup>39</sup>—with one study of the physical accessibility of subspecialist practices in 4 U.S. cities finding gynecology to be the subspecialty with the highest rate of inaccessible practices (44%).<sup>40</sup> The lack of accessible and relevant health information and materials<sup>41</sup> is another significant factor affecting the quality of sexual and reproductive health care provided to women with disabilities. Following its 2015 visit to the U.S., the U.N. Working Group on the Issue of Discrimination Against Women in Law and in Practice underscored “the serious inadequacies of health-care facilities to treat women with disabilities,” calling “for improvement in this regard.”<sup>42</sup>
15. 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.<sup>43</sup> 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.<sup>44</sup>
16. Additionally, because physicians frequently see women, girls, and nonbinary persons with disabilities as sexually inactive and thus not in need of reproductive health care,<sup>45</sup> and because transportation and health facilities are frequently inaccessible,<sup>46</sup> persons with disabilities are also less likely to receive needed health screenings for reproductive and breast cancers,<sup>47</sup> 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 (NCD), 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.<sup>48</sup> By law, these programs do not cover abortion,<sup>49</sup> a service that is essential to ensuring that women can make decisions about their health and lives.
17. Furthermore, women, girls, and nonbinary persons with disabilities in the U.S. are also still subjected to forced and coerced reproductive health interventions,<sup>50</sup> including forced sterilization and forced gender assignment surgeries. A 2012 report from the

NCD noted with “alarm” that “a growing trend is emerging toward sterilizing people with intellectual or psychiatric disabilities” in the U.S.<sup>51</sup> A recent study found that women with cognitive disabilities were 1.5 times more likely to be sterilized than women without disabilities in the U.S., and at a younger age.<sup>52</sup> Further, 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.<sup>53</sup>

18. 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.<sup>54</sup> 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.<sup>55</sup> 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.<sup>56</sup>
19. 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 lives.<sup>57</sup> 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,<sup>58</sup> surgeries that can also result in sterilization.
20. Erroneous stereotypes regarding the danger of procreation of persons with disabilities, particularly women with disabilities, are enshrined in U.S. state law. As of 2018, ten states retained statutory language authorizing a court to order the involuntary sterilization of, or forced contraceptive use by, a person with a disability.<sup>59</sup> 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.<sup>60</sup> 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.<sup>61</sup>
21. 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.<sup>62</sup> 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.<sup>63</sup> 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.<sup>64</sup> 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.<sup>65</sup>

22. However, the U.S. Department of Health and Human Services has recently proposed, and sought comment on, troubling revisions to the implementing regulation of the ACA's nondiscrimination provision—revisions that would roll back health protections. If enacted, these changes would substantially narrow the scope of the ACA's nondiscrimination and equal access protections for people with disabilities<sup>66</sup> and eliminate the regulation's explicit nondiscrimination protections for transgender and gender-nonconforming individuals.<sup>67</sup>

### *Gender-based Violence*

23. Gender-based violence against women with disabilities worldwide takes many unique forms. According to the former U.N. Special Rapporteur on Violence against Women, Rashida Manjoo, violence against women with disabilities can be of a “physical, psychological, sexual or financial nature and include neglect, social isolation, entrapment, degradation, detention, denial of health care, forced sterilization and psychiatric treatment.”<sup>68</sup> Violence against women with disabilities also has unique causes, including violence that is perpetuated by stereotypes “that attempt to dehumanize or infantilize, exclude or isolate them, and target them for sexual and other forms of violence.”<sup>69</sup> In its General Comment No. 3 on women with disabilities, the CRPD Committee has found that “[s]ome women with disabilities, in particular, deaf and deaf-blind women, and women with intellectual disabilities, may be further at risk of violence and abuse because of their isolation, dependency or oppression.”<sup>70</sup> Worldwide, women with disabilities are also more likely to be in unstable romantic relationships, as due to discrimination they are often considered less eligible for marriage,<sup>71</sup> and they also experience domestic violence in all of its forms—physical, sexual, emotional, psychological, and financial—at twice the rate of other women.<sup>72</sup>
24. Under its international human rights obligations, the U.S. has a duty to prevent and punish gender-based violence against all women committed by state actors and to exercise due diligence to protect women from violence committed by others. This section explores how violence against women with disabilities manifests in the U.S., and how the content and implementation of the current legal framework fails to fulfill the U.S.'s obligation to prevent and punish this violence.
25. Women and girls with disabilities in the U.S. are two to three times more likely to experience gender-based violence, including sexual and domestic 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.<sup>73</sup>

Their abuser may also be their caregiver, someone that the individual is reliant on for personal care or mobility. One population-based study in Massachusetts found that women with disabilities are three to four times more likely to experience physical abuse before and during pregnancy as compared to women without disabilities.<sup>74</sup> Further, women with disabilities in the U.S. are more likely to experience adverse psychological consequences following violence, such as severe distress, anxiety and depression, than non-disabled women.<sup>75</sup> Women with disabilities in the U.S. have also “been found to be at risk for disability-related violence, including medication manipulation, denial or destruction of assistive technology, and/or denial of personal care.”<sup>76</sup>

26. 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.<sup>77</sup> Further, 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.
27. U.S. national studies indicate, “almost 80% of people with disabilities are sexually assaulted on more than one occasion and 50% of those experienced more than 10 victimizations.”<sup>78</sup> As many as 83 percent of female adults with developmental disabilities are victims of sexual assault,<sup>79</sup> and women with disabilities living in institutions and nursing homes are at greater risk.<sup>80</sup> 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.<sup>81</sup>
28. Women with disabilities who experience violence also face significant barriers to accessing justice, due to discrimination based on gender and disability, stigma, isolation, communication barriers, dependence on caregivers who may also be their abusers, accessibility barriers to the justice system and a lack of reasonable accommodations, among other factors.<sup>82</sup> For example, 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.<sup>83</sup> In addition, where people with intellectual disabilities “do report abuse, law enforcement responders often lack knowledge of disability and specialized skills [to conduct] forensic interviewing” in a manner accessible to persons with intellectual disabilities.<sup>84</sup>
29. 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 per cent of these staff members were

nurses, sign language interpreters, substance abuse specialists, or legal specialists trained to work with women with disabilities.<sup>85</sup> 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.<sup>86</sup>

30. Girls with disabilities experience sexual harassment and sexual abuse in schools at an unacceptably high rate.<sup>87</sup> A state-wide Massachusetts study found that one in four high school girls with disabilities report dating violence—roughly 3.5 times the rate of dating violence against girls without disabilities and boys with disabilities. The study further found that they were at higher risk of negative health outcomes following violence, including drug use, feeling sad or hopeless, or seriously considering suicide.<sup>88</sup> A 2018 NCD report found that one in three undergraduates with disabilities was a victim of sexual violence on campus.<sup>89</sup> 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).<sup>90</sup> The report also found that 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.<sup>91</sup> Additionally, girls with disabilities often are subjected to bullying and teasing by peers in school based on disability and gender, which can negatively impact a girl’s emotional and cognitive development and cause low self-esteem.<sup>92</sup> This harassment and abuse is compounded by the lack of sexual education afforded to girls with disabilities.<sup>93</sup>
31. 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 by a nurse in the facility.<sup>94</sup> None of the caretakers at the facility claimed to know that she was pregnant prior to her giving birth.<sup>95</sup> A subsequent medical exam revealed that she had “suffered multiple sexual assaults” and “may have been pregnant before.”<sup>96</sup> 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.<sup>97</sup>
32. U.S. laws and programs attempt to address gender-based violence in several ways. As mentioned earlier, through the federal Violence Against Women Act of 2013 (VAWA),<sup>98</sup> 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.<sup>99</sup> (Note, however, that VAWA expired in December 2018, and at the time of writing, it was unclear if and when it would be reauthorized.<sup>100</sup>) Furthermore, the ADA Amendments Act of 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.<sup>101</sup>

33. 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.<sup>102</sup>

#### *Violations of Parental Rights*

34. Parents with disabilities are disproportionately subject to state intervention in their parental role as a result of discrimination and stereotypes. According to the 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[.]”<sup>103</sup>

35. 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.<sup>104</sup> In the U.S., the child welfare system is generally located within state governments, rather than within the federal government. The 2012 NCD report highlighted that 37 U.S. states and the District of Columbia list some form of disability—primarily psychosocial and intellectual disability, but also physical disability—as grounds for removing a child from a disabled parent.<sup>105</sup> Although recent legislative initiatives at the state level have sought to address this discrimination, according to the National Research Center for Parents with Disabilities the majority of U.S. states (approximately 70%) still list some form of disability as grounds for removing a child from a disabled parent.<sup>106</sup>

36. The 2012 NCD 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,<sup>107</sup> 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.<sup>108</sup> 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.”<sup>109</sup>

37. For instance, a study in the U.S. state of Minnesota revealed 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.<sup>110</sup>

38. Nationally, according to the 2012 NCD report:
- a. 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.<sup>111</sup> 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.<sup>112</sup>
  - b. 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.”<sup>113</sup> This leads to removal even when there is not any evidence of neglect or abuse.<sup>114</sup> 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.<sup>115</sup>
  - c. 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.<sup>116</sup>
  - d. **Poverty and race** are exacerbating factors affecting 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 non-disabled peers,<sup>117</sup> and poverty is the most consistent factor in cases where a parent is deemed unfit or in families where child neglect is found.<sup>118</sup> 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.<sup>119</sup>
39. In addition, a 2017 U.S. study by the National Research Center for Parents with Disabilities found that parents with disabilities “experience significantly poorer health and greater numbers of chronic conditions compared with parents without disabilities,”<sup>120</sup> which may be due to the added stress associated with the unique and systematic discrimination they face as parents with disabilities, the additional barriers they face in accessing health care,<sup>121</sup> and the “lack of support and accommodations faced by parents with disabilities.”<sup>122</sup>
40. 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.<sup>123</sup> 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.<sup>124</sup>

41. 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,<sup>125</sup> which include child welfare and child protective services. Title III of the ADA prohibits services and public accommodations—including doctor’s offices—from discriminating 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.<sup>126</sup> Despite this national legal mandate, discriminatory laws and practices, such as those described above, persist at the state level regarding the parental rights of persons with disabilities.
42. 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 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.<sup>127</sup>

#### **IV. Conclusions and Recommendations**

43. As this submission demonstrates, there are many ways in which the U.S. has failed to fulfill its human rights obligations, particularly for women with disabilities. With this in mind, we recommend that states ask the following questions and give the following recommendations to the U.S. during its upcoming UPR.
44. Questions for Interactive Dialogue:
  - 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 steps is the U.S. taking to ensure the enforcement of the ADA and the reauthorization of the Violence Against Women Act to prevent violence against women with disabilities, 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 ensure that the ADA is applied to guarantee 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?

#### 45. Recommendations to the U.S.:

##### General

- Ratify the CRPD and CEDAW.
- Abolish systems of guardianship that allow guardians or others to make important decisions about the lives and health of women with disabilities, including regarding institutionalization, sterilization and contraception, without their consent. Establish regimes that provide women with disabilities with support services, when requested, to make their own decisions.<sup>128</sup>
- Undertake a public information campaign that depicts women with disabilities as contributors to society, holders of rights, and good parents. Raise awareness about and stigmatize harassment of and violence against women and girls with disabilities in homes, in public, in educational settings and in institutions.<sup>129</sup>
- Improve data collection on persons with disabilities in general, and women with disabilities in particular, including on gender-based violence and sexual and reproductive health care.

##### Sexual and Reproductive Rights

- 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.
- Require disability-related clinical education and training for all health care providers, including sexual and reproductive health care providers. Train medical professionals to shift their attitudes about the contributions women with disabilities make to society, overcome stereotypes about their sexuality and roles as parents, and provide necessary reasonable accommodations enabling women and girls with disabilities to access sexual and reproductive health information, facilities and services.
- Ensure the development of clinical practice guidelines for providers on the provision of care for women with disabilities, in collaboration with women with disabilities.
- Ensure that health-related information is in accessible language or alternative formats.
- Ensure that states eliminate laws and practices that force or coerce sterilization and that limit the legal capacity of persons with disabilities concerning their reproductive lives.

##### Gender-Based Violence

- Take immediate steps to prevent and address the disproportionate rates of violence

experienced by women and girls with disabilities, including in schools and institutions.

- Reauthorize the Violence Against Women Act and expand the Office on Violence against Women’s Disability Grant Program.
- Ensure monitoring and oversight of long-term residential care institutions to ensure freedom from gender-based violence and comprehensively investigate allegations of violence in those institutions.
- Ensure that shelters and services for victims of violence are accessible to, and tailored towards, persons with disabilities, including transgender and gender non-conforming persons with disabilities.

### Parental Rights

- Ensure that the ADA is applied to guarantee 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.
- 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 them. Ensure that parents with disabilities benefit from adequate support services in fulfilling their parental role.

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<sup>1</sup> This report will address the situation of women with disabilities throughout the life cycle. Any reference to “women with disabilities” should be interpreted to include girls with disabilities unless otherwise indicated.

<sup>2</sup> Morocco urged the U.S. to reinforce the broad range of safeguards in favour of the most vulnerable groups such as persons with disabilities and the homeless to allow them the full enjoyment of their rights and dignity. Human Rights Council, *Report of the Working Group on the Universal Periodic Review: United States of America*, Rec. 92.198, U.N. Doc. A/HRC/16/11 (2011).

<sup>3</sup> Human Rights Council, *Report of the Working Group on the Universal Periodic Review: United States of America*, Recs. 176.19-22, 176.25, 176.33, 176.35-36, 176.39, 176.49, 176.54, 176.56, 176.58, 176.61, 176.196, U.N. Doc. A/HRC/30/12 (2015) and Human Rights Council, *Report of the Working Group on the Universal Periodic Review: United States of America*, Recs. 92.1, 92.4-6, 92.13, 92.17-21, 92.24-25, 92.35, 92.114, 92.133, U.N. Doc. A/HRC/16/11 (2011).

<sup>4</sup> Human Rights Council, *Report of the Working Group on the Universal Periodic Review: United States of America*, ¶¶ 176.313, 176.314, 176.317, U.N. Doc. A/HRC/30/12 (2015).

<sup>5</sup> *Id.* at ¶ 176.316.

<sup>6</sup> *Id.* at ¶ 176.255.

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<sup>8</sup> 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>.

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- <sup>11</sup> Americans with Disabilities Act, 42 U.S.C. § 12101 (1194); Americans with Disabilities Act (ADA) of 1990, 42 U.S.C. § 12181 et seq. (2008).
- <sup>12</sup> Violence Against Women Reauthorization Act of 2013, Pub. L. No. 113:4, Overview (Mar. 7, 2013).
- <sup>13</sup> 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.
- <sup>14</sup> 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>.
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- <sup>16</sup> CRPD Committee, *General Comment No. 3: Article 6: Women and Girls with Disabilities*, U.N. Doc. CRPD/C/GC/3, ¶ 44 (2016).
- <sup>17</sup> *Id.*
- <sup>18</sup> SRVAW, *Report on women with disabilities*, supra note 15, ¶¶ 28 & 36.
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