# Committee on the Elimination of Racial Discrimination (CERD) Submission for the review of the United States of America on Women, Girls, Non-binary People, and Gender Minorities with Disabilities from Marginalized Races

#### I. Introduction Rights at the intersection of Gender Disability and Race

The U.S. Alliance of Women, Nonbinary Persons and Other Gender Minorities with Disabilities, <sup>1</sup> Women Enabled International (WEI), <sup>2</sup> Autistic Women & Nonbinary Network, <sup>3</sup> the Autistic People of Color Fund, <sup>4</sup> and the Autistic Self Advocacy Network <sup>5</sup> appreciate the opportunity to contribute to the CERD Committee's consideration of the U.S.'s periodic report to the Committee. This submission will provide an overview of some of the human rights violations under the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) facing women, girls, non-binary people, and other gender minorities with disabilities from racially marginalized groups in the United States of America (U.S.)

This submission will highlight the following issues as it relates to women and gender minorities who are from marginalized races: access to healthcare, institutionalization, access to services during natural disasters, and violence against women and gender minorities. This submission also provides recommendations regarding the steps the U.S. should take to address the issues highlighted.

#### II. Background and Legal Framework

Women and girls with disabilities account for approximately 16% of all women in the U.S., and although gender identity is not included in the U.S. Census, there is a significant number of non-binary people and other gender minorities with disabilities in the U.S., as well. Even though disaggregated data on race, gender, and disability is not readily available, within the U.S., approximately three in ten American Indian/Alaska natives identify as a person with a disability, and one in four Black people report being a person with a disability, compared to only one in five White people. Disaggregating this data by age, 35% of Black people aged 44-65, and almost half of Black people over 65, have some form of disability. This means that the experience of gender and disability based marginalization intersects significantly with marginalization based on race in the U.S.

When disability, race, and gender intersect, the oppression people living at this intersection experience is further heightened and qualitatively different from that experienced by people who only experience one form of marginalization. <sup>10</sup> People with disabilities consistently face ableism - attitudinal, environmental, economic, structural, and policy barriers that hinder their equal participation in society and put them at great risk of victimization and discrimination. Women and other gender minorities with disabilities, especially from marginalized races, and ethnic groups face multiple disparities in the U.S. <sup>11</sup>

Due to intersectional discrimination based on gender, disability, and race, women and gender minorities with disabilities from marginalized races are also more likely to experience poverty. One study aiming to shed light on hierarchies of disadvantage found racially marginalized women with disabilities and less education had the highest rates of poverty and the lowest total income levels compared to other respondents of the 2015 American Community Survey. 12 Another study found the prevalence of communities below the federal poverty level was 24.2% for Indigenous families, 21.2% for Black families, 17.2% for Hispanic families, 9.7% for Asian/Pacific Islander/ Native Hawaiian families, and 9% for White families. 13 Several studies have highlighted the additional disparities that occur as a result of poverty, finding that racially marginalized people are living with higher rates of food insecurity, <sup>14</sup> housing segregation, and exposure to environmental pollutants.<sup>15</sup> All of these factors can lead to poor health outcomes and higher rates of disability, and unsurprisingly, data shows that Black, Hispanic, and Indigenous people are more likely to report fair or poor health status than their White counterparts, <sup>16</sup> and Black and Indigenous people experience higher rates of disability when compared to other groups.<sup>17</sup>

The U.S. has adopted laws and policies, which create an obligation to ensure the rights of women and gender minorities, people with disabilities, and people from marginalized races. These laws and policies include, among others, the ones outlined below.

- The U.S. has codified its prohibition against discrimination on racial and ethnic grounds with its passage of the Civil Rights Act of 1964 ("CRA"). <sup>18</sup> The CRA outlaws discrimination based on "race, color, religion, or national origin" in voting registration and public accommodation. <sup>19</sup> People of diverse racial and ethnic backgrounds must have full and equal enjoyment in all aspects of public accommodation and programming, including accommodations used for education, healthcare, housing, social services, and parks and recreation. <sup>20</sup> This equal enjoyment to all aspects of life cannot be segregated—people of diverse racial and ethnic backgrounds must be fully integrated, having the same access to the same public accommodations as all others. <sup>21</sup>
- The U.S. also has a legal framework that prohibits discrimination based on disability, most notably through the Americans with Disabilities Act of 1990 ("ADA"), which codified the nation's commitment to prohibiting discrimination based on disability. The ADA prohibits discrimination against people with disabilities in "employment, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and State and local government services" and has been broadly applied to ensure accessibility and support for people with disabilities in several settings. Although implementation of the ADA has lagged and has often been inconsistent. The ADA Amendments Act was passed in 2008 as an attempt to strengthen the ADA. Amendments Act was passed in 2008 as an attempt to

The U.S. has also ratified two international human rights treaties in addition to ICERD but has not yet ratified the Convention on the Rights of Persons with Disabilities (CRPD) or the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). The non-ratification of these two treaties, which are essential to guide rights protections for women, girls, and gender minorities with disabilities, has made the U.S. a global outlier and limits opportunities for women, girls, and gender minorities with disabilities to hold the U.S. accountable for human rights violations against them.

### III. Racism, Ableism, and Gender Discrimination and the Right to Health in the U.S.

Under Article 5 of ICERD, read in conjunction with Article 2, States Parties have an obligation to "prohibit and eliminate racial discrimination in all its forms" and ensure equality in the law in exercise of a number of rights, including the right to public health.<sup>25</sup> In this regard, "racial discrimination in all its forms" should be interpreted to include multiple and intersectional discrimination against people from marginalized races, including racially marginalized women and gender minorities with disabilities.

Legislation at the national and state levels further outlines specific protections against discrimination in the context of healthcare. Most notably, Section 1557 of the Patient Protection and Affordable Care Act prohibits discrimination in health programs or activities on the basis of sex, as well as providing similar anti-discrimination protection in healthcare in regards to race, color, national origin, age, or disability. <sup>26</sup> As the points below illustrate, however, this legal obligation is not always fulfilled, especially for people at the intersection of gender, race, and disability.

#### a. Barriers to accessing general healthcare services

Women and gender minorities with disabilities from marginalized races in the U.S. experience unequal access to healthcare, and this section will further analyze this issue. In particular, Black women with disabilities face systemic and structural barriers in healthcare due to the legacy of slavery, as well as ongoing racism, sexism, and ableism.<sup>27</sup> Such barriers in healthcare services and settings can show up in numerous ways, including, but not limited to:

- denial of accessible communications (e.g., sign language interpreters, CART, Braille, plain language, large print);
- lack of accessible equipment (e.g., exam tables, weight scales, exam chairs, etc.);
- inaccessible facilities; and transportation options
- forced and coercive treatment;
- denial of bodily autonomy;
- denial of care;
- lack of access to a patient advocate or trusted support person;
- and lack of free and informed consent.<sup>28</sup>

A 2022 report from the Center for American Progress illustrates several of those barriers imposed on Black women with disabilities accessing healthcare in the U.S.:

- A Black woman with a disability reported a visit to the emergency room when she became unable to walk due to illness and pain. She said the hospital discharged her with a heating pad, lifted her into a cab, and sent her on her way.<sup>29</sup>
- Black women with disabilities mentioned having to "credential" themselves to get treatment. One woman said that during a hospital stay, she had to consistently mention her age and Ph.D. to receive help with a bedpan. Another woman had to constantly remind staff that they are a disability advocate and could file a complaint.
- In interviews and focus groups conducted in 2021, Black women with disabilities reported times when they did not seek treatment because they knew

they would not be believed or be treated. They said they were very mindful of their behavior—even when in pain—to avoid being perceived as angry, dangerous, or threatening. They also shared frustrations about needing to take extra steps to inform themselves about possible treatments to ensure care and avoid being labeled as difficult patients when advocating for their needs.<sup>33</sup>

Furthermore, the intersection of race, disability, and gender with other marginalized identities, such as being a migrant or part of the LGBT community, can lead to deepened discrimination in the access to healthcare.

- Even though disaggregated data on access to healthcare for LGBT people with disabilities from marginalized races is extremely sparse, the data available suggest that this population is at great risk of poor health outcomes and has less access to sexual and reproductive healthcare and screenings than non-LGBT people who are White and non-disabled.<sup>34</sup>
- A Black migrant woman with a disability living in the U.S. reported that at a young age, she noticed that healthcare providers treated her differently, particularly when her mother was with her compared with when she was alone. Her mother has darker skin, and the interviewee believed that her mother was not afforded the same level of respect and politeness because of her race. She also noted that the lack of respect and civility can be compounded when English is not the patient's first language.<sup>35</sup>

Another significant barrier to healthcare is cost, including both the costs of healthcare itself and the cost and access to insurance, as well as the lack of public funding in healthcare. While the uninsured rate has declined across the board since the passage of the Patient Protection and Affordable Care Act, studies have found significant disparities within the population that remain uninsured.

- One study found that Black people are less likely to be insured than White people.<sup>36</sup>
- Another study found that nearly one in 10 non-elderly women were uninsured,<sup>37</sup> with uninsured rates particularly high among women who are low-income and Latina, and women with poorer self-reported health status—many who likely identify as a person with a disability—were almost twice as likely as those in better health to have gone without insurance at some point in the prior year.
- While people with disabilities are less likely to lack health insurance—they are more likely to be covered by government healthcare programs like Medicare or Medicaid rather than private insurance—they are more than twice as likely as non-disabled people to have difficulty paying their medical bills.<sup>38</sup> One in three women have reported having unpaid medical bills, with 44% of Black women of all races reporting outstanding medical bills.<sup>39</sup>Additionally, Black people with and without were found to be the most likely to need, but not seek, medical care because of cost.<sup>40</sup>
- The Indian Health Services (IHS) a division of the U.S Department of Health and Human Services, which provides core healthcare services for more than 2.2 million Native Americans living in the U.S., is chronically underfunded. <sup>41</sup> For comparison, the amount of federal funding received by HIS would need to more than double to equal the amount of federal funding received by other health programs such as Medicaid. <sup>42</sup> This leaves many Native American people, including those with disabilities, without adequate healthcare and likely

contributes to a decline in life expectancy. The life expectancy of Native American women is nearly eight years less than the average life expectancy of the general population of women in the U.S., with Native women having a life expectancy of 70.4 years.<sup>43</sup>

Such barriers to accessing healthcare are due to discrimination on the grounds of racial identity, disability, and gender. They impact not only the health of women and gender minorities with disabilities who experience racism, but their overall quality of life, as poor access to healthcare may lead to the inability to work, study, and fully participate in society.<sup>44</sup>

#### b. Barriers to accessing sexual and reproductive health services

Women and gender minorities with disabilities who experience racism encounter many obstacles to exercising their sexual and reproductive health and rights (SRHR) in particular. Such barriers must be understood within the context of historical inequities.

One important factor that undermines the reproductive rights of racially marginalized women and people with disabilities who can become pregnant is the eugenics movement. Driven by racism and ableism, the eugenics movement gained traction in the U.S. in the early 1900s, deeply influencing medical practices on sexual and reproductive healthcare of the time. But such policies and practices are not just a relic of the past; as recently as 2020, women in immigrant detention centers (a population largely consisting of racially marginalized people) were being forcibly sterilized, and 31 states plus Washington, DC currently have laws that allow the forcible sterilization of people with disabilities, including those who experience racism.

Furthermore, the intersectional discrimination Black women with disabilities face in healthcare settings is often linked to biased assumptions about Black women and/or women with disabilities, such as their ability to become a parent.<sup>47</sup> In this regard:

- A Black woman with a disability in the United States shared that when she gave birth to her daughter, the doctors asked her: "Are you really sure you can do this?". At the time, she assumed the doctors asked that question because she looked young, but now, she wonders if they would have asked if she didn't identify as a person with a disability.<sup>48</sup>
- Another Black woman with a disability reported that, after having a medication abortion, the doctor declined to examine her, even though that is standard protocol. She remembered the doctor saying that the termination was "for the best" because the pregnancy had probably resulted in "some sort of mutation."<sup>49</sup>

Moreover, one study found that Black women with intellectual disabilities were less likely to receive a mammogram during a two-year period (51%) compared with White women with intellectual disabilities (76%). Another study found that Deaf Black and Hispanic or Latina women were significantly less likely (43%) than the White women in the study (69.8%) to have had a mammogram in the past two years. This lack of accessible medical equipment perpetuates healthcare disparities between people with and without disabilities, and, as this data shows, racially marginalized women with disabilities are disproportionately impacted by this access barrier.

Another reproductive right was recently denied to many people with the ability to become pregnant in the U.S., including those at the intersection of race, gender, and disability. In June 2022, the U.S. Supreme Court withdrew its recognition of a nationally-protected right to abortion, creating even more significant barriers to sexual and reproductive healthcare for women and gender minorities with disabilities who can become pregnant. As a result of this decision, many U.S. states and territories have already made abortion largely illegal, and many more may do so or heavily restrict access to this procedure in the coming months.<sup>52</sup>

Abortion is essential healthcare to which women and gender minorities need safe and legal access in order to exercise control over our bodies and lives, live with dignity, and achieve full recognition of our personhood. Restrictions on access to abortion have a disproportionate impact on the lives and well-being of women and gender minorities with disabilities who experience racism for a number of reasons, such as:

- healthcare inequities;
- lack of access to information;
- lack of accessible clinics;
- poverty;
- increased barriers to travel;
- and the loss of autonomy, including bodily autonomy, among others.<sup>53</sup>

In particular, the Supreme Court's decision will require a significant portion of the population to travel out of state to exercise the right to abortion. Pregnant people with disabilities, including those who experience racism, face significant financial and logistical barriers to traveling to another jurisdiction to obtain an abortion, as travel may be too expensive, the means of travel may be inaccessible, and they may require a support person or interpreter to undertake such travel.<sup>54</sup> As a result of these significant barriers, pregnant people with disabilities—particularly those who experience multiple forms of marginalization due to race and ethnicity or other statuses—were denied their right to essential reproductive healthcare in many states. As we have seen globally, people who cannot access legal abortion may resort to unsafe and/or clandestine abortions, with attendant risks to life and health, in addition to the threats of criminal charges.<sup>55</sup>

#### c. Barriers to accessing healthcare during the COVID-19 pandemic

Of particular relevance today is how the many inequities facing racially marginalized women and gender minorities with disabilities have directly led to the disparities they have faced during the ongoing COVID-19 pandemic. In spite of the lack of data on the matter from a racial perspective, studies demonstrate that both women and people with disabilities, including those who experience racism, have been disproportionally impacted on their employment, their health, and their well-being due to the COVID-19 crisis. They faced unique and deepened barriers to exercising their rights, due to racism, ableism and sexism, even outside of times of emergency, and these barriers have been exasperated by the pandemic. <sup>56</sup>

Throughout the COVID-19 crisis, healthcare has changed in several respects in the U.S. During the first stages of the pandemic, health services were either canceled, thereby delaying needed care, or moved to virtual means like telehealth.<sup>57</sup>Telehealth can increase accessibility in some ways, but are not always accessible or adequate to meet

the specific needs of all people living at the intersection of gender, racism, and disability. As a non-binary person with multiple disabilities in Texas noted: "It has made it difficult for me to get to and from doctor's and therapist's appointments, as well as made it impossible to schedule some of the care I need. I have had a medical procedure pushed back 2 months because of COVID-19...".<sup>58</sup> Delays like this may disproportionately impact people at the intersection of disability, gender, and race, as it was often harder for them to access healthcare even before the pandemic due to discriminatory attitudes towards them or lack of accommodations to respond to their specific needs, as discussed above.

One study of the social inequities in the distribution of COVID-19 found that people with disabilities who were Black, Asian, Hispanic, or Indigenous; impoverished; young (15-17); and women were significantly more likely to reside in counties with higher COVID-19 incidence than their counterpart sociodemographic subgroups. <sup>59</sup> People with disabilities, including those from gender minorities, have faced disproportionate hospitalizations and deaths, particularly those in congregate settings such as institutions and group homes. Approximately one-third of reported COVID-19 deaths in the U.S. occurred in these settings as of March 2021. <sup>60</sup>

According to a January 2021 study by the Center for American Progress, counties in the United States with disproportionately high populations of people with intellectual or developmental disabilities also had higher rates of COVID-19. More specifically, these individuals were largely from racial or ethnic minority groups or Indigenous populations and were young, women, and living below the poverty level. As the study highlights, an intellectual disability was the strongest indicator of a COVID-19 diagnosis and, other than age, intellectual disability was the strongest independent factor for COVID-19 mortality.<sup>61</sup>

Women with disabilities who face racism have also experienced barriers to accessing COVID-19 vaccines. Those living in rural areas, where most Indigenous peoples live, <sup>62</sup> were often far from vaccination sites, and qualitative evidence shows that finding accessible transportation during the COVID-19 pandemic was very difficult. <sup>63</sup>

- A Black woman with a disability mentioned that "there was no place for me to find information about the accessibility of a vaccine location, and nobody has answers when you ask about accessibility."<sup>64</sup>
- Another Black woman with a disability reported that when the vaccine rollout began in the U.S., there were few sites accessible to residents in her city. And the few sites available were located in the suburbs—which are mostly white and wealthy neighbourhoods— areas where everyone needed a car to access. 65

Notably, however, Indigenous communities in the U.S. had the highest COVID-19 vaccination rate as of 2021,<sup>66</sup> demonstrating how targeted outreach efforts to particularly impacted groups can work to achieve equitable public health outcomes. As the United Nations Human Rights Office of the High Commissioner stated in relation to people with disabilities, "focused efforts are essential to remove barriers, pre-empt potential discrimination, and monitor distribution to ensure equality and avoid discrimination. These efforts are not only essential to protect human rights, but to ensure the effectiveness of the vaccination campaign."<sup>67</sup>

#### IV. Inequities in home and community-based services

Within Article 5 of ICERD, States Parties have an obligation to prohibit and eliminate all forms of racial discrimination in the provision of social services and in ensuring just and favorable conditions of work.<sup>68</sup> Intersectional discrimination is still present, however, in the provision of some of the services most essential to the lives of people with disabilities from marginalized races in the U.S. and is also present in conditions of work for the employment of care workers who provide those services.

Home and community-based services (HCBS) are services used almost exclusively by people with disabilities to ensure they are able to complete their activities of daily living (ADLs)<sup>69</sup> with the assistance of another person in their own homes in the community. While a large portion of the disability community receives HCBS by unpaid caregivers, Medicaid (a state- and federally-funded health insurance program for low-income individuals) is the largest funder of these services.<sup>70</sup> Nationally, 5.5 million people receive HCBS<sup>71</sup> through either Medicaid waivers or as part of their Medicaid state plan benefit package.<sup>72</sup>Although these numbers may seem high, as of 2020, there were 665,015 people on the waiting list for HCBS nationwide,<sup>73</sup> and there are countless more people who do not receive services that go unaccounted for.

Race and gender appear to negatively influence the receipt of HCBS services. For instance, one study analyzed Medicaid claims and enrollment data for people with intellectual and developmental disabilities in the U.S. state of North Carolina, from 2017-2018.<sup>74</sup> Results revealed that women had a 12% lower likelihood of receiving HCBS. Additionally, people from marginalized races had a lower likelihood of receiving these benefits compared to non-Hispanic White people (specifically, 37% lower for Hispanic Whites and 15% lower for non-Hispanic Blacks).

When women and gender minorities who experience racism do receive services, they are not equal to that of their White counterparts. One study analyzed data related to 7,550 HCBS recipients and found that Black people, a majority of which were women, were less likely to receive case management, equipment, technology and modification services, and nursing services. This means that they are receiving less support such as assistance with daily care needs, communication devices, home modifications and mobility equipment, and less care for the healthcare concerns they have. These supports are vital to helping people live independently in the community.

Within all of the issues mentioned above, the lack of service continuity of HCBS leads to disparities that are felt the hardest by people in rural communities. These communities are often low-income and without accessible public transportation, as well as include a significant number of people from marginalized races. Within rural areas, there tends to be staff shortages often due to lack of accessible transportation and the area's population size. Furthermore, due to the location and the amount of income offered to perform the tasks associated with assisting HCBS recipients, many prospective direct service workers are unwilling to make the commute to rural areas, as these care workers are also facing rising costs of living nationwide and cannot afford additional transportation costs. To

Importantly, care workers who provide HCBS are themselves primarily women (nearly 90%) and are disproportionately from marginalized races; 50% of home care workers are people of color, as compared to 25% of the U.S. workforce.<sup>78</sup> Despite the

importance of the work these home care workers undertake, in many locations these workers receive extremely low pay and are not provided with healthcare benefits by their employers, leaving them in precarious financial and personal circumstances. Indeed, nearly 25% of these workers nationwide live below the federal poverty line. This work is undervalued in part due to racism and gender discrimination targeted at home care workers themselves, but also due to ableism, which reinforces that this work is not "valuable" because the lives of the people who receive the services (people with disabilities) are themselves not valued. Simultaneously, these poor working conditions jeopardize the provision of the care and support which people with disabilities, in particular those from marginalized races, need in order to ensure they can live with dignity. Sharing her own personal experience, Ashley, a member of the U.S. Alliance of Women, Nonbinary People and Other Gender Minorities with Disabilities, reported:

I am a White and Filipino woman who utilizes HCBS provided by my state of residence. My HCBS provider is a woman of color. She injured herself just over a year ago. Since the state does not provide her with medical insurance or paid leave, and I cannot afford to provide these benefits, she did not get medical care for her injuries. Furthermore, she continued coming to work. She knew if she did not continue working for me that I would be unable to find a replacement and get the care I need. She makes sure I can have the best quality of life possible, even though the state does not take care of her. How can we expect HCBS workers to take care of our loved ones, when we do not take care of them?

#### **IV Access to Services During Natural Disasters**

The obligation to ensure freedom from discrimination in the provision of social services extends to those provided in the event of natural disasters. However, women, girls, and other gender minorities face different and often more negative outcomes in humanitarian crisis in the United States, its territories, and elsewhere. Those who are disabled and also people of color experience further vulnerabilities in these emergency situations. <sup>80</sup> While the U.S. has agencies and processes in place for a variety of humanitarian crisis, the same populations continue to be most affected by these crisis events.

In 1979, coordinated response to emergencies was assigned to a federal agency called the Federal Emergency Management Agency (FEMA).<sup>81</sup> FEMA responds to declared disasters around the U.S. without regard for cause. As the primary federal agency responsible for humanitarian crisis, they are required to adhere to Section 308 of the Stafford Act, the non-discrimination clause. This section states:

[The] distribution of supplies, the processing of applications, and other relief and assistance activities shall be accomplished in an equitable and impartial manner, without discrimination on the grounds of race, color, religion, nationality, sex, age, disability, English proficiency, or economic status. 82

Equal access to services during natural disasters is also required by Articles 2 and 5 of the ICERD.

Despite these requirements, programmatic, systemic, and sometimes personal racist, sexist, and ableist discrimination create greater vulnerability in response for people who experience all three. These failures are compounded by the societal realities many multi-marginalized people experience that put them at greater risk in these crisis events.

Women and gender minorities with disabilities from marginalized races have long been at increased risk during natural disasters in the U.S., as they are rarely included in disaster preparedness, response, and recovery efforts.<sup>83</sup> Furthermore, women and gender minorities from marginalized races face significant barriers to evacuating or reaching safety during natural disasters or other emergencies.<sup>84</sup> As communities of Black, Indigenous, and People of Color (BIPOC) in the U.S. are often built in precarious geographic locations, this puts members of the community who also identify as people with disabilities at further risk during disasters.<sup>85</sup>

In 2017, Hurricane Maria had devastating impacts on the U.S. territory of Puerto Rico, where 22% of women are women with disabilities. REMA is the lead federal agency responsible for helping Puerto Rico recover from natural disasters. Yet, response efforts were delayed until three weeks after the hurricane had made landfall, leaving thousands without power, enduring blackouts, trapped due to closed roads, and other circumstances which exacerbate disability. Reloss of power had devastating consequences for people who rely on electricity for breathing or mobility assistance. people with disabilities on the Island also reported FEMA denied their requests for assistance replacing damaged mobility devices. For example, Keishla Rolón, who lived on the Island during Hurricane Maria, recounted in a blog post that FEMA denied her request to replace her power wheelchair and her adjustable bed, which broke due to flooding from the hurricane.

During natural disasters people with disabilities are often not just left without the mobility equipment they depend on; they also often lose accessible housing in the community. For example, the National Council on Disability uncovered a pattern of people with disabilities who lived in the community before Hurricane Harvey in 2017 being placed in nursing homes after the storm. 91 This was in part due to a lack of post-shelter housing options or the challenges of disaster recovery. This trend has continued because the federal government allows states to place disaster-impacted people with disabilities into institutional settings for the convenience of emergency managers and health care providers, 92 in possible violation of the ADA. As the next section explains, women and gender minorities with disabilities from marginalized races are particularly at risk for adverse outcomes when placed in a nursing home.

# V. Institutionalization of People with Disabilities and Violations in Interactions with Police and the Justice System

Under ICERD, States Parties have an obligation to prohibit and eliminate all forms of racial discrimination in the exercise of civil and political rights related to institutionalization and incarceration—including as related to freedom of movement and freedom from arbitrary detention—as well as in the right to housing. <sup>93</sup> The Supreme Court case of *Olmstead v. L.C.* held that people with disabilities cannot unjustifiably be institutionalized, as that is a violation of Title II of the ADA. <sup>94</sup> The Court based this holding on the idea that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options,

economic independence, educational advancement, and cultural enrichment."<sup>95</sup> *Olmstead* further states that public entities must provide community-based services to people with disabilities when the services are appropriate, when the person with a disability does not oppose community-based treatment, and community-based services can be reasonably accommodated, taking into account the available resources.<sup>96</sup>

However, here is a long history of involuntarily, unjustifiably institutionalizing people with disabilities in the U.S., which significantly implicates the intersection of race, gender, and disability. For instance, as medical technology advances, more people are living to older ages, and the prevalence of disability increases for older people. Furthermore, as fewer people with disabilities are housed in institutions, more face incarceration due to a lack of community-based support and housing, an issue that is compounded by race. <sup>98</sup>

#### a. Institutionalization in Nursing Homes and Long-Term Care Facilities

Women with disabilities are substantially more likely to be institutionalized than men with disabilities. <sup>99</sup> Looking further at the intersection of race, gender, and disability, women are twice as likely to be placed in nursing homes than men, <sup>100</sup> and Black women with disabilities are slightly less likely than White women to be institutionalized in a nursing home. <sup>101</sup> However, looking at the intersection with gender, Black women with disabilities are more likely than Black men with disabilities to face institutionalization. <sup>102</sup> This is specifically important to consider when Black people have a higher death, illness, and disability rate in the U.S. <sup>103</sup>

Furthermore, the quality of care that people with disabilities from marginalized races receive in these institutions is far poorer than the quality of care received by White people in nursing homes. People from marginalized races are more likely to be placed in racially segregated nursing homes with lower quality of care, <sup>104</sup> including lower cleanliness and maintenance ratings. <sup>105</sup> Black people are three times as likely to have feeding tubes placed than White people in nursing homes, leading to many complications such as aspiration, infection, and pain. <sup>106</sup> Black people in nursing homes are also up to 40% less likely to receive socialization. <sup>107</sup> Further, Black elderly cancer patients in long-term care facilities are 63% more likely to be left untreated for pain. <sup>108</sup> People of diverse racial and ethnic backgrounds in nursing homes are also twice as likely to face psychological abuse as White people in nursing homes, and five times as likely to be victims of financial exploitation. <sup>109</sup> Furthermore, women in nursing homes are more likely to be sexually abused in nursing homes than men. <sup>110</sup>

Disparities in treatment by race in nursing homes was exacerbated during the COVID-19 pandemic. Nursing homes with the fewest White residents were more than twice as likely to experience COVID-19 cases and deaths as opposed to predominantly White nursing homes.<sup>111</sup>

## b. Violations in the Context of Interactions with Police and the Criminal Justice System for People with Disabilities from Marginalized Races

Race, gender, and disability also intersect to increase the risk of incarceration for women and gender minorities with disabilities. People with disabilities are nearly 1.5 times more likely to face arrest than nondisabled people, and Black women with

disabilities are more than twice as likely to face arrest than other Black women. <sup>112</sup> Furthermore, people who experience racism and people with disabilities are substantially more likely to be murdered by the police. <sup>113</sup>

People with disabilities and racially marginalized people are overrepresented in the prison population, with 40% of women in prisons reporting having a disability, and Black and Latin people having higher incarceration rates than that of White people. While incarcerated, many people with disabilities are denied medical treatment, which impacts their health conditions. Further, people with disabilities are disproportionately segregated and given solitary confinement, exacerbating poor mental health. 116

People with disabilities from marginalized races also face an increased risk of violence in interactions with police. 117 As the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health affirmed, violence does not originate in a vacuum but in contexts of inequality and multiple forms of discrimination. 118 Therefore, analyzing violence against women and gender minorities with disabilities who experience racism requires adopting an intersectional and non-discriminatory approach. 119

There are many demonstrations of racism, sexism, and ableism in interactions with the police, which have deleterious consequences, especially for individuals living at the intersection of race, gender, and disability. In this regard:

- On one occasion, the body cam footage of police officers showed them attempting to arrest a deaf Black woman. The police officers denied her access to a qualified sign language interpreter and requested that her twin daughters provide interpretation. The officer described her use of sign language as "erratic movement" of her arms in his notes. Hollingsworth's inability to hear the officers' commands and their misinterpretation of her arm movements led officers to place her in handcuffs and forcefully push her onto the sidewalk. It was later determined she had not committed a crime.
- A Black deaf-blind woman reported that "someone might be yelling for me to do something, and I don't hear. And then they [the police] assume that I'm a threat". 121

Black women with disabilities have also been represented in the high-profile incidents of police killings in the U.S. in recent years. <sup>122</sup> Even though there is a lack of intersectional data in this regard, studies show that both Black people and people with disabilities are more likely to be killed by the police in the U.S., <sup>123</sup>

In spite of the overrepresentation of Black people with disabilities among those who experience police violence, the media coverage and investigation of their deaths often focus on their disability, ignoring their racial identity, whereas in others, the racism involved in their death is considered relevant, but not the ableism. <sup>124</sup> As a Black activist with a disability states, the media does not focus on the overlap between the two identities of the victim, which gives the public an incomplete story. <sup>125</sup>

Furthermore, gender and disability are often not considered when cases related to police abuses and killings in the Black community are heard by the courts. In a case adjudicated by the state of California in 2017, a Black woman with a psychosocial

disability was killed by a police officer while handcuffed because that officer perceived her size and strength as a threat and thought she was "under the influence of a central nervous system stimulant..." The courts did not address gender or disability in their assessment of her case; however, the police officer who killed her was ultimately convicted of that crime. Although several police departments in the U.S. have guidelines related to interactions with people with disabilities, these rarely include consideration of gender. A set of examples and resources issued by the U.S. Department of Justice in 2017 on ensuring disability rights as part of law enforcement failed to mention women with disabilities or gender as part of this guidance.

Police violence can contribute to the fear of interacting with the police and to the underreporting of crimes, such as gender-based violence, which also impacts those living at the intersection of race, gender, and disability. This type of violence is a demonstration of patriarchal, racist, ableist, and sexist oppression, rooted in unequal power relationships within the binary approach to gender. Black women with disabilities who experience gender-based violence often face increased barriers to reporting the crime and seeking help, such as the lack of accessible information about support services; lack of accessible shelters; lack of a financial safety net; lack of knowledge of the legal system; among others.

#### VI. Recommendations

To ensure that the U.S. guarantees the rights of people living at the intersection of race, disability, and gender, we suggest the recommendations below. We hope that the CERD Committee will consider including these recommendations in its Concluding Observations to the State:

- Ratify the CRPD and CEDAW to provide an intersectional human rights framework through which to address human rights issues occurring at the intersection of gender, race, and disability.
- Adopt policies to improve data collection concerning healthcare for people with disabilities across the lifespan, disaggregated by sex, gender, age, race, Indigenous identity, language, religion, and type of disability (at a minimum).
   Further, increase the research available on Black, Latina and Indigenous women with disabilities from an intersectional perspective, analyzing data and its impact accordingly.
- Ensure universal, low-cost or free health coverage or insurance for racially marginalized women and gender minorities with disabilities, which must include coverage for, at a minimum, all the essential health services and medications and community-based long-term services and supports.
- Recognizing the disproportionate impact of abortion restrictions on marginalized populations, including women and gender minorities with disabilities from marginalized races, ensure a right to abortion is guaranteed at all levels and that abortion is accessible and available as an essential part of sexual and reproductive healthcare.
- Ensure all laws developed that guarantee the right to health include gender, race, ethnicity, Indigenous identity, and disability perspectives. Include racially marginalized women with all types of disabilities, as well as their representative organizations, in the development and implementation of all laws and policies that directly or indirectly affects their lives. Adopt laws and policies at the state

- and federal levels that prohibit reproductive health interventions (including forced sterilization) performed without the free, prior, and informed consent of the person.
- Ensure the accessibility, availability, acceptability, and quality of health information, goods, and services, including by ensuring the availability of accessible information on healthcare services, such as providing information in Indigenous local languages, Sign languages, and Easy Read formats; training healthcare staff members to work with and provide respectful care to people with disabilities; and ensuring the availability of accessible healthcare services, including SRHR, in rural and remote areas.
- Adopt policies and programs that address the Indigenous, racial, gendered, and disability impacts of the pandemic, and develop a legal framework, in line with international human rights standards, to provide legal mechanisms to monitor and respond to the inequitable health impacts of COVID-19 and future public health emergencies based on disability, gender, race, and Indigenous identity.
- Ensure that people at the intersection of race, disability, and gender, including those living in rural or remote areas, have access to quality home and community-based services.
- Eliminate all waiting lists for home and community-based services and ensure those who need it receive services as soon as possible after their eligibility for services is confirmed.
- Ensure that home and community-based services are transportable across all
  U.S. states. This will ensure those who need it maintain their services when they
  move to a different state.
- Guarantee an appropriate number of professionals working on home and community-based services. Provide payment and benefits for this work, which ensures an adequate standard of living, and that such professionals receive training on the specific needs of women and gender minorities with disabilities who experience racism.
- Ensure that plans for emergency management include multiply marginalized women with disabilities and gender minorities. Drills, and solutions aimed at serving these populations should be tested for quality and success and updated periodically to better align policy with a communities' changing needs.
- Ensure equitable evacuation practices and access to safe and accessible shelter, food, water, and basic medical equipment and power source. Prioritize all levels of safety, including increased domestic violence risk or abandonment with evidence established shelter, evacuation, and resource practices.
- Increase mitigation efforts to protect communities from additional disaster impacts. This can include increases in resiliency funding and grants, increased standards and regulations regarding flood zones and risk mapping, expansions of FEMA aid to renters, and urgency in the development and expansion of accessible affordable housing.
- Passage of legislation that prioritizes funding for disaster risk reduction and mitigation.
- Focus on climate resilience in future infrastructure development and work to undue and mitigate the negative environmental impacts of racism in neighborhoods. Including the increased health hazards due to lack of water

- cleanup and chemicals, waste plant zoning, and heat island effects that disproportionally impact multiply marginalized populations.
- Implement policy requiring police officers to be trained in issues specifically related to the intersection of race, gender, and disability. This policy should include training on de-escalation; racial bias in policing and imprisonment, specifically in regards to the over policing in predominantly Black and Latin communities; and interacting with people with disabilities, including people with intellectual, developmental, and psychosocial disabilities.
- Require all U.S. states to have criminal justice diversion programming in place and actively utilized. This diversion programming would include re-education programming, substance abuse counseling and education, psychoeducation, and community restoration efforts as a manner in which to minimize imprisonment.

https://www.census.gov/quickfacts/fact/table/US/LFE046217; Women with Disabilities, CTRS. FOR DISEASE CONTROL AND PREVENTION (Sept. 16, 2020), https://www.cdc.gov/ncbddd/disabilityandhealth/women.html .

https://www.usatoday.com/story/news/2017/06/21/third-gender-option-non-binary/359260001/.

<sup>&</sup>lt;sup>1</sup> The U.S. Alliance of Women, Nonbinary Persons and Other Gender Minorities with Disabilities is a new disability justice oriented collective convening women, nonbinary persons, and other gender minorities with disabilities from across the United States together to take action on issues important to our community. This includes addressing ableism along with other relevant intersections of discrimination and prejudice.

<sup>&</sup>lt;sup>2</sup> Women Enabled International (WEI) is a U.S. based organization with the mission to advance human rights at the intersection of gender and disability to respond to the lived experiences of women, girls, and other gender minorities with disabilities; promote inclusion and participation; and achieve transformative equality.

<sup>&</sup>lt;sup>3</sup> The Autistic Women & Nonbinary Network (AWN) provides community support and resources for Autistic women, girls, transfeminine and transmasculine nonbinary and genderqueer people, trans people of all genders, Two Spirit people, and all others of genders minorities.

<sup>&</sup>lt;sup>4</sup> The Autistic People of Color Fund provides direct support, mutual aid, and reparations by and for autistic people of color.

<sup>&</sup>lt;sup>5</sup> The Autistic Self Advocacy Network (ASAN) is a nonprofit organization run by and for autistic people. ASAN work supports all forms of self-advocacy and helps change policy as well as the way people think about autism.

<sup>&</sup>lt;sup>6</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 Quickfacts*, UNITED STATES CENSUS BUREAU (July 1, 2021)

<sup>&</sup>lt;sup>7</sup> 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.*, William Cummings, *When asked their sex, some are going with option 'X'*, USA TODAY (June 21, 2017),

<sup>&</sup>lt;sup>8</sup> Elizabeth Court-Long at al., *Socioeconomic Factors at the Intersection of Race and Ethnicity Influencing Health Risks for People with Disabilities*, J. RACIAL AND ETHNIC HEALTH DISPARITIES, 2017, at 213-22.

<sup>&</sup>lt;sup>9</sup> THE MOVEMENT FOR BLACK LIVES, A Vision for Black Lives: Policy demands for Black Power, Freedom, & Justice (2020), <a href="https://m4bl.org/wp-content/uploads/2020/06/05-End-the-War-on-Black-Health-and-Black-Disabled-People.pdf">https://m4bl.org/wp-content/uploads/2020/06/05-End-the-War-on-Black-Health-and-Black-Disabled-People.pdf</a> at 2.

<sup>&</sup>lt;sup>10</sup> Moya Bailey & Izetta Autumn Mobley, *Work in the Intersections: A Black Feminist Disability Framework*, 33 GENDER & SOCIETY 19 (Oct. 12, 2018).

<sup>&</sup>lt;sup>11</sup> *Id*.

<sup>&</sup>lt;sup>12</sup> Michelle Maroto et al., *Hierarchies of Categorical Disadvantage: Economic Insecurity at the Intersection of Disability, Gender, and Race*, 33 GENDER & SOCIETY 64 (Sept. 11, 2018).

<sup>&</sup>lt;sup>13</sup> Bettina M. Beech et al., *Poverty, Racism, and the Public Health Crisis in America*, 9 FRONTIERS IN PUBLIC HEALTH 1 at 2 (Sept. 6, 2021).

<sup>&</sup>lt;sup>14</sup> Kelly Brooks, *Research shows food deserts more abundant in minority neighborhoods*, The Hub (2014), <a href="https://hub.jhu.edu/magazine/2014/spring/racial-food-deserts/">https://hub.jhu.edu/magazine/2014/spring/racial-food-deserts/</a>

<sup>&</sup>lt;sup>15</sup> Princeton University, *Study Links Unhealthy Segregated Neighborhoods to Childhood Asthma*, SCIENCE DAILY (Aug. 7, 2017), <a href="https://www.sciencedaily.com/releases/2017/08/170807111454.htm">https://www.sciencedaily.com/releases/2017/08/170807111454.htm</a>

<sup>&</sup>lt;sup>16</sup> Latoya Hell et al., *Key Facts on Health and Health Care by Race and Ethnicity*, KAISER FAMILY FOUND. (JAN. 26, 2022), https://www.kff.org/report-section/key-facts-on-health-and-health-care-by-race-and-ethnicity-health-status-outcomes-and-behaviors/

<sup>&</sup>lt;sup>17</sup> Elizabeth Court-Long at al., *supra* note 8.

<sup>&</sup>lt;sup>18</sup> Civil Rights Act of 1964, 42 U.S.C. § 2000e et seq (1964) (hereinafter CRA).

<sup>19</sup> CRA §§ 101, 201

<sup>&</sup>lt;sup>20</sup> CRA § 606(3)(A)(ii)

<sup>&</sup>lt;sup>21</sup> See generally CRA. See also Brown v. Board of Education, 347 U.S. 483 (1954) (prohibiting the segregation of schools); City Council of Baltimore City v. Dawson, 350 U.S. 877 (1955) (prohibiting the segregation of beaches and bathhouses), Holmes v. City of Atlanta, 350 U.S. 879 (1955) (prohibiting the segregation of golf courses), Turner v. City of Memphis, 369 U.S. 350 (1962) (prohibiting the segregation of restaurants), Johnson v. California 545 U.S. 162 (2005) (prohibiting the segregation of prisons). All decisions given by The U.S. Supreme Court must

be protected and upheld by every state, per the Supremacy Clause of the Sixth Amendment of the U.S. Constitution. U.S. Const. art. VI.

- <sup>22</sup> Americans with Disabilities Act of 1990, 43 U.S.C. § 12101 (1990) (hereinafter ADA).
- <sup>23</sup> ADA § 12101(a)(3)
- <sup>24</sup> ADA, 42 U.S.C. § 12181 et seq. (2008).
- <sup>25</sup> International Convention on the Elimination of All Forms of Racial Discrimination, Jan. 4, 1965, 660 U.N.T.S. 195, art. 5(e)(iv) (hereinafter ICERD)
- <sup>26</sup> Patient Protection and Affordable Care Act, 42 U.S.C. § 18116(a) (2010) (hereinafter ACA)
- <sup>27</sup> Megan Buckles & Mia Ives-Rublee, *Improving Health Outcomes for Black Women and Girls With Disabilities*, Am. PROGRESS (Feb. 15, 2022), <a href="https://www.americanprogress.org/article/improving-health-outcomes-for-black-women-and-girls-with-disabilities/">https://www.americanprogress.org/article/improving-health-outcomes-for-black-women-and-girls-with-disabilities/</a>.
- <sup>28</sup> See Committee on the Rights of Persons with Disabilities, General Comment No. 3: Article 6 (Women and Girls with Disabilities), U.N. Doc. CRPD/C/GC/3 (Sept. 2, 2016).
- <sup>29</sup> Megan Buckles & Mia Ives-Rublee, *supra* note 27.
- <sup>30</sup> *Id.* The report draws from interviews and three roundtable conversations that the Center for American Progress hosted with Black disabled women and girls in 2021.
- <sup>31</sup> *Id*.
- <sup>32</sup> *Id*.
- <sup>33</sup> *Id*.
- <sup>34</sup> See Judy Y. Tan, et al., *High Stakes for the Health of Sexual and Gender Minority Patients of Color*, 32 J. OF GEN. INTERNAL MEDICINE (2017). See also Health Disparities at the Intersection of Disability and Gender Identity, DREDF (July, 2018), https://dredf.org/health-disparities-at-the-intersection-of-disability-and-gender-identity/.
- <sup>35</sup> Megan Buckles & Mia Ives-Rublee, *supra* note 27.
- <sup>36</sup> Nanette Goodnan et al., *Financial Equity: Disability, Race and Poverty in America*, NAT'L DISABLITY INST. (2019), https://www.nationaldisabilityinstitute.org/wp-content/uploads/2019/02/disability-race-poverty-in-america.pdf.
- <sup>37</sup> Women's Coverage, Access, and Affordability: Key Findings from the 2017 Kaiser Women's Health Survey, KAISER FAMILY FOUND. (Mar. 13, 2018),
- <sup>38</sup> Nanette Goodnan et al., *supra* note 36.
- <sup>39</sup> Women's Coverage, Access, and Affordability, supra note 37.
- <sup>40</sup> *Id*.
- <sup>43</sup> Cindy Edgar, *US life expectancy still falling, Native Americans hardest hit*, INST. OF BEHAVIORAL SCIENCE (June 24, 2022), https://ibs.colorado.edu/us-life-expectancy-still-falling-native-americans-hardest-hit/
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- <sup>45</sup> Maya Manian, *Immigration Detention and Coerced Sterilization: History Tragically Repeats Itself*, ACLU (Sept. 29, 2020), <a href="https://www.aclu.org/news/immigrants-rights/immigration-detention-and-coerced-sterilization-history-tragically-repeats-itself">https://www.aclu.org/news/immigrants-rights/immigration-detention-and-coerced-sterilization-history-tragically-repeats-itself</a>
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- <sup>49</sup> Shruti Rajkumar, *With Roe v. Wade overturned, disabled people reflect on how it will impact them*, NPR (June 25, 2022), <a href="https://www.npr.org/2022/06/25/1107151162/abortion-roe-v-wade-overturned-disabled-people-reflect-how-it-will-impact-them">https://www.npr.org/2022/06/25/1107151162/abortion-roe-v-wade-overturned-disabled-people-reflect-how-it-will-impact-them</a>
- <sup>50</sup> G.L lbrecht & P.J Devlieger PJ., *The disability paradox: high quality of life against all odds.*, Soc. Science & Medicine (April, 1999).
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<sup>&</sup>lt;sup>80</sup> During Hurricane Harvey, a Category 4 hurricane that hit the U.S. states of Texas and Louisiana in August 2017, Black, indigenous, People of Color (BIPOC) were particularly vulnerable. Many communities of color in Texas and Louisiana are built on low lying areas of the city without proper drainage for waste water.<sup>[10]</sup> Given this, it is not surprising that a survey of Hurricane Harvey victims conducted by the Kaiser Family Foundation found that Hispanic and Black residents disproportionately reported property damage and loss of income. The survey also found that White residents were twice as likely to report having their claim for assistance approved by the Federal Emergency Management agency. *See* Ayana Byrd, *Why Texan Communities of Color Are Particularly Vulnerable to Hurricane Harvey*, COLORLINES (Aug. 28, 2017), https://www.colorlines.com/articles/why-texan-communities-color-are-particularly-vulnerable-hurricane-harvey.

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For example, when the category five Hurricane Katrina hit the U.S. city of New Orleans in 2005, 80% of the people left in New Orleans after the mandatory evacuation was issued were women; a majority of these women were Black and disabled. Laura Butterbaugh, *Why Did Hurricane Katrina Hit Women So Hard?*, 35 OFF OUR BACKS 17 (2005). Reasons for not evacuating included not being physically able to do so or being responsible for caring for someone with a disability. Many of the evacuation buses were not accessible to people with physical disabilities and some shelters were not accessible to people with disabilities. Furthermore, pertinent information about the evacuation was not communicated in sign language or other accessible means for people who are deaf. These access issues are in violation of the ADA which prohibits discrimination on the basis of disability by state and local government entities, as well as places of public accommodation. ADA, 42 U.S.C. § 12181 et seq. (2008)). Although the U.S. has taken some steps towards reducing the barriers victims with disabilities faced during Hurricane Katrina, many of these barriers existed during recent natural disasters in the U.S. *See Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters*, NAT'L COUNCIL ON DISABILITY (May 24, 2019), https://ncd.gov/sites/default/files/NCD\_Preserving\_Our\_Freedom\_508.pdf. *See also NCD Statement for the Record House Sub-committee on Emergency Preparedness, Response, & Recovery*, NAT'L COUNCIL ON DISABILITY (Oct. 7, 2021), https://ncd.gov/publications/2021/ncd-statement-house-subcomitte-emergency-preparedness-response-recovery.

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